CHAPTER 1

INTRODUCTION

NOTE:

The resources used in my research have been drawn primarily from Australia, England, America and South Africa. Attitudes toward disabilities and the opportunities available differ markedly in other countries, such as India.

1.1 Motivation for this Research

This thesis is self-reflective and autobiographical in character. It is my narrative. Sacks (1986, p105) states each one of us constructs and lives a narrative. My focus is on re-educating myself and others on the impact of visual loss and how people with visual loss adapt and interact. As a person legally classified as blind, and yet with sufficient sight to be an independently mobile pedestrian (not needing a white cane) I have lived with a sense of being in a limbo state between the perceived ‘normal’ and the perceived ‘blind’. This sense of limbo state has been further exacerbated by my having clear blue eyes, able to, in most cases, appear focussed, and able to maintain eye contact.

This thesis tells of my own ongoing journey to self-acceptance and embracing my limbo status. It also advocates strategies for promoting ‘interactive ease’, as opposed to the more usual expectation of interactive unease, between those labelled as ‘normal’ and those labelled as ‘disabled’ in our society.

Often blindness and visual impairment are portrayed as melodramas of personal losses and overwhelming life problems. I question whether every person with visual loss experiences multiple losses and problems. If so, how are the losses perceived and dealt with? I question whether many of the life problems should be attributed to the condition of visual loss. Does this causal explanation ignore the adaptive skills and personal qualities of the individual? Does it reinforce the image of people with visual loss as the victims? I
challenge this association and offer more realistic portrayals on the impact that visual loss has on people's lives.

I argue that most of the theories to explain varied adjustment of visual loss have a percentage of truth. Misconceptions arise when one theory is accepted as doctrine. Theories such as the loss or disaster model, (Carroll 1961), perpetuates the stereotype of the helpless blind, who must die to sight and be reborn to a life of blindness. Equally misleading is the stigma theory (Goffman 1968) that characterises societal attitudes as bigoted and discriminatory. This perception recycles the image of people with visual loss as the victims or the aggressors, discriminatory attitudes as fixed and persistent. My optimism argues that people need to be equally persistent to erode stigmatised attitudes. There is no one right strategy but a combination of education, positive interaction, appropriate humour, appropriate media portrayals etc.

I consider it imperative to develop a holistic perspective that accepts no one theory as a complete explanation. It is disturbing to observe that many recent articles and research reports still refer to the Loss and Disaster models as established fact. The theorotyping (Rowland 1985) can be as misleading as stereotyping. Theories are speculative and are influenced by the theorists' values. What value do they place on full sight? Do the theorists claim to be experts offering facts. In this thesis I explore a kaleidoscope of views.

In modern life, sight is usually the most utilised of the five human senses1 and the "loss of sight is feared" (Schultz 1975). I believe that if theorists were aware of the value they placed on full sight this could prevent theories that over dramatise or trivialise the impact of visual loss.

While discriminatory attitudes still pervade in Australia, the objects of the Federal Disabilities Discrimination Act 1992 are, a) to eliminate discrimination for example in work or provision of goods, b) ensure that people with disabilities have the same rights and equality before the law as the wider community, c) promote recognition and acceptance within the community as in (b) above. The act aims to be broad and fill in the gaps of State legislation and provide uniform protection. People with visual loss can now take action against discrimination. Australian society is gradually providing more equal opportunities with affirmative employment strategies, access to technology, legislation and new building codes that allow access for people with disabilities.

My research has revealed a focus on two extreme views on the impact of visual loss. A blindness phobia connects blindness with loss, death, dementia and helplessness (Carroll 1961; Cuttsforth 1951; Monbec 1973). The opposing view trivialises the impact of blindness as a minor inconvenience or nuisance value (Jemigan 1970). I offer a middle view that places the negative and positive impact of blindness in proportion:

---

1 I refer to the five senses of: touch, hearing, sight, taste and smell, as classified by Aristotle.
that acknowledges more daily stresses and more challenges to overcome;
- that optimises what people with visual loss can do, not what they can’t do;
- that accepts certain physical limitations but argues that personal proclivities are probably the primary deciding factor for how people deal with daily stresses, and so adapt;
- that we cannot classify and measure the impact of blindness in a positivist tradition, as this ignores the uniqueness and individuality of each person experiencing a visual loss;
- that the only attribute we can assume that people with visual loss share in common is the physically disabling limitations.

Adaptation must take into account a plethora of considerations: cultural, socioeconomic, gender roles, physical and psychological health, age of onset and importantly, personal proclivities. By emphasising specific attributes, the narrow and extreme views of impact-disaster and loss or minor inconvenience, are created.

In contrast to the extreme views, I propose that the impact of visual loss depends on a variety of factors, and emphasise that:-

1. People adapt to visual loss in diverse ways.
2. The impact that visual loss has on the individual’s life varies accordingly.

I am not looking for generalisations but diversity. Adaptation is a complex issue in a world that is primarily constructed for people with full vision. I recognised my own need to change and accommodate, as a person with a visual loss. I had to work through my own fears and discrimination before suggesting social change.

In 1992 I changed from the topic of: “Cooperative Lifestyles On Rural Communities” to “Exploring the Social Effects of Visual Loss on Human Interaction.” Colleagues had urged me to explore the impact of visual loss on my research process. I had resisted. What impact I asked myself? How is my research process different? This was the impetus for my current research.

It was risky to explore the impact of visual loss on my research process. Discoveries mean changes. I would have to confront my fears and prejudices. By recognising my resistance I discovered my true research passion: to re-educate myself and hence others on the impact of visual loss and how people with visual loss adapt and interact. Consequently there is an autobiographical focus in my research. By beginning with the impact of visual loss on my own life, my adaptation and attitudes, I respected the uniqueness of the individual. I began with an issue that bothered me – A perceived sense of limbo status.
1.2 A Perception of Limbo Status.

My sense of limbo status was experiencing an undefinable vacuum between having no functional sight and full sight. There is much confusion about the definitions of blindness and visual impairment. The official definition of blindness in Australia is “less than ten percent sight”. The commonly accepted meaning is no ‘functional’ sight. For example, the person may have light perception but that is all. Most of the time I have used visual loss to refer to both visual impairment and blindness.

People with no sight often have different needs from people with less than ten percent sight. A simple example is pedestrian crossings. Studs in the bitumen, at the centre of the road assist a person with no sight to detect the centre of the road. The white cane feels the studs and indicates their position. These provide a landmark detectable with a white cane. A visually impaired person may benefit more from the contrast of bright yellow lines painted on the road surface.

There is a diversity of visual distortions among people with visual loss. It is difficult to give a coherent answer to the question, ‘how much can you see?’ Shadows distort my vision, so it is easier for me to focus on a cloudy day. The ability to focus decreases when I am tired. I sometimes mistake colours, but if the colour is described and contrasted my perception changes. I usually perceive the true colour.

I lost ninety percent of my sight between the ages of eight and eleven, due to a glioma of the optic chiasm. Eye tests have classified how much sight I have but in reality it is more complicated, and varies from day to day.

I now have less than ten percent sight, but what accentuated my sense of limbo status was that there was nothing technically wrong with my eyes. They are blue, focussed, and in most cases I maintain eye contact. My disability is inconspicuous, and so I can choose when to tell people. This does lead to confusion.

My research plan began with two assumptions:

1. To get rid of the sense of limbo status would lead to improved self acceptance.
2. Self-acceptance would increase my assertiveness and develop clearer communication, and so improve my interaction with people with full sight.

1 Acceptance of my Perceived Limbo Status

It was reconciling to recognise that rather than getting rid of the limbo status, I needed to accept it. There were advantages in being undefinable. My residual sight offered more choices and so more independence. I could
choose more when to ask for help and when to inform people of my visual limitations. Therefore I could maintain my anonymity.

Shopping is an example of this choice. If I want to know a label or price I use the convenient excuse, "I left my glasses behind." The main disadvantage is my credibility. There are still stereotyped expectations of how a person with visual loss should look and act. I do not wear glasses, carry a white cane nor have any visual eye abnormality, hence I am sometimes considered a fraud. Even when succinct and direct about my lack of sight and need for assistance, there can still be confusion. The shop worker will not connect my physical appearance and actions with the stereotyped image. I am too different. This is the limbo status. Being different is the limbo status. Being able to choose when to reveal my visual loss is also the limbo status.

By analysing the advantages and disadvantages of the limbo status I was able to accept this concept. To get rid of it would be escaping reality.

2. An Improved Self Acceptance

Accepting the limbo status was itself a transformation. I abandoned the dualist model – them/us, either/or, blind or sighted. I asked whether the limbo status reflected the pressure of a conformist society? Are people with visual loss compelled to fit neat categories, emulating the fully-sighted person or fulfilling the stereotyped dependent image of people who are blind?

I had created so much stress in trying to act as a fully-sighted person. I strived for the image of superwoman, overcoming all limitations.

Accepting the limbo status meant I felt more comfortable asking for help. I dropped the guilt and confusion about being labelled as a fraud (See the story 'The Impersonator' p.109). Self-acceptance led to specific, practical changes such as:

- Being more honest about how much help I required.
- Being assertive about asking for help.
- Buying a talking computer.
- Colour coding my clothes.\(^2\)
- Joining the National Federation of Blind Citizens of Australia Association.\(^3\)

I experimented with verbal communication and asked myself, does the public understand my terms and requests?

\(^2\) Colour coding clothes: My clothes are now divided in my wardrobe and shelves according to colour. It is now much easier to choose what outfit I will wear and match colours accordingly.

\(^3\) The N.F.B.C.A. is a national body that provides a political voice for people with visual loss. It deals with consumer complaints, legal enquiries and monitors service agencies.
For example: "I am visually impaired."

"I have less than ten percent sight."

"My eyes do not work well."

"I cannot see the print on that form and glasses do not help."

But I still use the convenience of "I left my glasses behind," when appropriate. My aims are to be clear, appropriately assertive and to obtain the assistance I require.

After twenty-six years, with a visual loss, I realised I had not accepted any limits caused by my visual loss. While this appeared to be positive, in reality it caused tensions because I was striving for absolute independence. I developed a sense of alienation, in contrast to my philosophy of interdependence and living cooperatively. I asked: What is the balance between dependence, independence and interdependence? Can I choose or alter how others react to my disability? Can I improve the interaction between myself and people with full sight? Can this improved interaction have significance. How can my changes be utilised in the wider community?

I identified the double perspective of being visually impaired and yet acting fully-sighted. Goffman (1968 p15) describes the "deviants" on one side and the "normals" on the other, and emphasises a constant interaction unease. This discrimination and stereotyping still exists, but I question whether it has changed in Australia over the last three decades.

Government legislation has moved from institutionalisation, to normalisation, to integration and equality of opportunity, for people with disabilities. Myths and misconceptions still exist, but legislation, education and social acceptance has improved interaction between people with and without physical disabilities. I believe it is everyone's responsibility to continue to improve this ease of interaction.

My personal task was to consciously accept the physical limitations of my visual loss. I had always considered myself well adjusted, but in retrospect I developed the image of superwoman. I fitted the stereotyped image of the inspirer and heroine. I could overcome all odds with no assistance. My research required as much unlearning and de-conditioning as learning. An assumption behind my research is that we can alter our conditioning and improve social interaction by strengthening our self-acceptance and learning about personal identity.

1.3 Definitions of Terms

Access: For a person with low or no vision, access relates to how safe and easily negotiated is the environment (Taken from N.FB.C.A.A. Street Wise pamphlet).
**Adaptive Technology:** refers to the design and use of specialised equipment, suited or modified for use by people with physical disabilities.

**Deviant:** A person who deviates from prevalent or valued norms. Society reacts negatively or punitively to this deviation. The deviant tends to define his or her situation, largely in terms of this reaction. All three conditions must be fulfilled for it to be said that deviance exists. Modified from Lemert (1975).

**Impairment:** is a condition, either physical, mental or sensory, which results in a functional limitation for the individual (from Disabled Peoples’ International).

**Disabilities:** reflect the consequences of impairment in terms of functional performance and activity by the individual. Some disabilities are hidden or invisible, while others are visible. These disabilities have different implications (from World Health Organisation). Disabilities can be defined and described in specific medical terms, in contrast to handicap.

**Handicap:** is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers (from Disabled Peoples’ International). Limited ability to perform tasks in areas relating to health care, mobility, verbal communication, schooling and employment. Handicap reflects interaction with, and adaptation to surroundings. The distinction between disability and handicap is important, (Australian Bureau of Statistics). Handicap was originally used to describe a disadvantage in sports. The concept is open to change and interpretation for example a handicap can be minimised or eliminated. A teacher working in a large, rambling school will be very handicapped with sudden severe sight loss. Learning braille or to use tape recorders and aids, and having her classes in one section, she is less handicapped as the disability does not prevent her from functioning as a teacher.

**She/her:** I will use the female pronoun instead of he/she or they, as I find this non sexist style cumbersome. He/she becomes tedious when you are using audio materials.

**Normal Vision:** Normal visual acuity ranges from 6/3.8 – 6/7.5 (Snellen). The top number of the fraction indicates the distance from the chart (6 meters). The bottom number indicates the line read (This includes people who have corrected vision with glasses).

**Blindness:** Less than ten percent of normal vision.

Definition used by the Department of Social Security:- A visual acuity of 6/60, in the better eye with best correction. A visual field of 10 degrees or less, or a combination of both.

**Adventitious blindness:** Blindness that occurs after birth – compared with congenital blindness where the person is born blind (Congenital does not necessarily mean an inherited condition).

**Low vision:** People with low vision are not necessarily categorised as blind.
**Self acceptance:** This is a broad term as humans are always changing. It refers to an evolution of the self identity with an assumed improvement in the quality of life. For example, with a clarification of values one's decision-making and action-taking can become more authentic (My personal perception of self acceptance).

**Normalisation:** Denotes a process where a person modifies views to see someone as normal or morally acceptable; where they were initially seen as unnatural, deviant, unusual etc, irrespective of whether the perception was initially accurate or justifiable (Modified from Gowman A G, 1956).

**Acronyms**

R.B.S. – Royal Blind Society of N.S.W.

1.4 **A Question of Semantics**

While I currently use the term 'person with visual loss', or 'people with visual loss', I am still dissatisfied with this nomenclature for a number of reasons. Firstly a congenitally blind person has not experienced a loss. Secondly the word loss has its own semantic problems. The early theorists such as Carroll (1961), Cuttsforth (1951) and Choldon (1958) emphasised the losses caused by blindness, and the losses are still viewed disproportionately by many people.

I have had to consider what the receiver's understanding of words are. Therefore I aim to use words that have the least chance of being misconstrued. My guiding principle will be:

- Which words will minimise damage and negative associations?
- Which words place the person first and not the disability?
- Is this language respecting human uniqueness and commonality?

I have sometimes used the label blind, to differentiate between people with less than 10% sight and people with no residual vision.

The dialogue below is an amalgamation of many discussions I have had on the semantics of labelling and stereotyping.

"Sightless departs from the negative connotations of the word blind."

"No, that’s no good because the majority of people have some sight."

"Then why not call people blind. It is easy, short and understandable. Let’s quit the euphemisms."
“We can’t use expediency as a deciding factor. And I would challenge whether people do understand what blind means.”

“Well you should know, you’ve had ten percent sight for twenty years.”

“Experience alone does not ensure understanding. If you ask twenty people what blind means they will give a dramatic diversity of perceptions. Blindness abounds in myths, misconceptions and stereotyping.”

“Then what about partially blind or partially sighted. It’s lessening the impact!”

“Do those terms perpetuate the stigma about sight loss, that the people are not quite whole?”

“Then what about visually impaired. It is used on government documents, like the travel pass. It seems to cover you from all sides.”

“That could create its own confusion. When I tell people I am visually impaired they do not know what I mean because I do not appear to have any sight loss. This year I have asked many people what they think of when I say visually impaired. The most common response has been – “glasses.” The confusion occurs because glasses can correct a visual impairment. Hence, if I have a visual impairment, I should wear glasses. So why am I asking the bank teller to help me fill out a withdrawal form.

The word impairment is also questionable. Impairment is too often contrasted with the able body. The words disabled, handicapped, impaired and afflicted have become distorted and confused.

“This is like trying to find a name for the local choir. No one can ever agree. Why don’t we just stick with blindness. It has been around the longest. We just need to re-educate people so that they have the right understanding of blind!”

“Maybe we’ve reached the bottom line. We can aim to re-educate people toward a correct perception of blindness and its effects on people.”

1.5 Social Myths About Visual Loss

In the book, “Blindness, What it is, What it Does and How to Live with it.”, Carroll (1961) discussed three myths, that help to reinforce the blind archetype, and I have added a fourth common myth.

1. That blind people have magic, divine or special gifts
2. The other senses, such as hearing, become more acute with sight loss.
3. Blindness is associated with black, dark and negative images.
4. Visual loss is associated with Dementia.
**Myth 1 – Special Gifts**

At age eleven, a glioma was discovered on my optic chiasm. This explained my rapidly deteriorating sight. I was told I was a special person. God had chosen me because I was brave and clever. This explanation was to help me and the family to cope with the loss. I was made to feel important and special, and appreciated the role.

Being special and different I received a lot of attention, in contrast it meant responsibilities and a denial of some of the teenage whims and rebellion. I always fulfilled the image of “I’m tough”. “I’m coping”. “Special people are always good.”

During my high-school years I felt a sense of superiority. I was dealing with adjustment to visual loss and often did not empathise with my peers’ problems. I was teased by the class clown, so my sense of being special helped me work extra hard to prove myself to my peers.

By striving to fulfil roles I perpetuated the myth that people with visual loss have divine or special gifts. It is a complex issue because many people with visual loss develop in self knowledge and inner strength, overcoming challenges in a world set up for people with full sight. Many friends who have critiqued this section said, “Visual loss or not Claire, you’re special.”

Many of the autobiographies written by people with visual loss (used in this research) share similar mythical beliefs. People assume an association between visual loss and a sixth sense or special powers.
ENIGMA

She stands on a book,
Creasing pages, bends binding,
And is smacked by her teacher,
Mr. J.

Mr. J. does not see,
And she does not see,
But the smack makes her see a portent,
That only nine year old intuitions
can see.

She stood on that invisible book,
A thing of joy and reverence.
Substituted by a tape recorder,
A book talker,
For bookworms going blind.

Her eyes stay blue,
But the paper fades, words jump
And lenses do not help.
Optician, doctor, eye specialist to neurosurgeon,
She turns eleven.

Her pubescent eyes are still blue,
Straining at empty blackboards
Filled with writing.

They saw her skull,
And lift her brain,
And find the tumour - snug
On the optic nerve.

At sixteen she is classified blind,
But she feels sighted,
Pensioned in her enigma
Of clear, blue eyes, impaired.

She is fed the accolades
Of her determination.— An inspiration!
Who sometimes wants to be a wimp.
Myth 2 – Other Senses Become More Acute

At age 22, I visited an ear specialist, convinced that my hearing was deteriorating. Tests showed my hearing was normal, so I monitored the times when my hearing seemed less efficient. It was situations where noises become distorted, for example a crowded room with people talking, on a busy road or in the late afternoon and evening.

My fears were assuaged when I realised that the eyes are the main tester for information sent to the brain from all the senses. We are visually oriented creatures, and a large part of our verbal communication is made understandable by non-verbal behaviour. Involuntarily we use the eyes to lip read, particularly in a crowded party room where everyone is talking at once. Lacking the non-verbal aids, a person with visual loss often misinterprets the communication.

Years later I had mobility training for a day as I considered it a neurotic fear to be terrified every time I crossed the road. The mobility trainer said I had to remain frightened to survive. He pointed out that I used ninety percent hearing when I crossed the road because I have less than ten percent sight. If I started to use a white stick I would not use my hearing as efficiently and so would rely unrealistically on the white stick. I have too much sight to use a white stick and so it is dangerous. Instead I had to make my hearing more efficient, rather than it becoming more acute. I have learnt to shut out all distractions except the noises on the traffic lane in front of me and what I can see. I use the same concentration powers when walking anywhere and if on difficult terrain I remove my shoes so that my feet feel the ground surface.

People with visual loss are often asked whether they rely more on hearing and whether their hearing improves. The aging population often experience a simultaneous decrease in sight and hearing.

The intermittent nature of the acoustic world is one of its most striking features. In contrast the perceived world is stable and continuous. The seeing world cannot escape from your eyes. Even in the darkness, you can use a torch, and force things into visibility, but I have only very limited power over the acoustic world.

... Here is another feature of the acoustic world. It stays the same whichever way I turn my head (Hull 1990).

This is one of several incidents that fray my nerves. The slam of a car door, the sudden shout of a school boy near at hand, the slam of brakes as a car pulls up in a hurry. Each is a new assault. I'm not a nervous person but I am affected by these things now, simply because I can't appreciate visual warnings of imminent sound. Every sudden and unexpected noise jars my whole being and adds another drop to my accumulated tensions. I am beginning to measure the strain that blindness places on me; by the frequency of which I am surprised by the sounds of everyday occurrences (Garland 1974).
Dahl grew up with visual loss but lost residual vision later in life. She practised locating things in her flat, using sound, and tried to make her movements more natural.

I had been told that if one faculty had been denied a person, the others would naturally be much keener. This I think was a fallacy, but there was nothing to stop me from putting my faculties to much better use than I had in the past, and I used both attention and imagination to bring this about (Dahl 1962).

There are many false assumptions about hearing acuteness in people with visual loss. By the end of the day I am often tired and my hearing is much less efficient. I do start more at sudden noises and my tolerance to noises such as radios, traffic and machines has deteriorated. What is common among people with visual loss is that senses other than sight can become more efficient, but not more acute.

**Myth 3 – Associations with Dark and Black**

The western definition for blindness is less than 10% sight. This covers a broad range of sight distortions as shown in the Royal Blind Society pamphlet, (Figure 2). The term blindness does not denote black. In the book “Blindness” Carroll (1961) explained that even if both eyes are removed, there can still be strong colour perception from the optic nerves. Hence the saying, “I’ve seen stars,” when you hit your head. Some people experience too much light. Carroll claims the important factor is the amount of sight loss and whether the loss is adventitious or congenital rather than the age of the person or the length of time. Blackness is an erroneous concept and steeped in superstitious and negative notions such as evil and death.

**Myth 4 – Another common myth. Visual Loss is associated with Dementia.**

Maddy, a resident of the Macksville Autumn Lodge Retirement Village told a story of volunteers helping at a Christmas sing-a-long. Her failing sight meant she could not read the words, and she concentrated on the print, trying to focus. A volunteer grabbed the sheet, patted her on the head, and yelled, “Give it to me dear, I’ll sing for you.” In one action Maddy felt denigrated to demented, blind and deaf.

We need to learn more about coping with adventitious visual loss and other sensory loss, because it is predicted, that by the year 2,000, the number of people over the age of sixty, in Australia, will have reached 3,000,000. There is a much higher chance of sensory loss in this age group, but nothing should be assumed. Aging people tend to be viewed in a block, rather than being given the respect of individuality.

A video called “A Feeling for Life” (Association for the Blind in Victoria 1990) highlights the problems of sight and hearing loss in the aging, and
Normal vision
A person with normal or 20/20 vision sees this street scene.

Cataract
An overall haziness of the view caused by opacity of the lens.

Macular Degeneration
A very common eye disease, resulting in decreased central vision.

Glaucoma
Advanced glaucoma involves loss of peripheral vision but the individual still retains most of his central vision.

Tunnel vision
Only a small area of central vision remains.
suggests how to support an aging person. Aging people share their common problems and needs for example:

- Introduce yourself on meeting so that they know to whom they are speaking.
- Alert the person when you're leaving the room to prevent the embarrassment of the person talking to herself.
- Begin promoting positive attitudes, looking at the person, not the disability.
- Concentrate on what the person can do, not the disability.

It was emphasised throughout the video that no strategy works for everyone, so individual factors such as age, lifestyle, the amount of loss should be taken into account, to encourage self help and independence and a feeling of self worth. Helping the aging to adapt is as complicated, as with the young, by the resistance to acknowledge and accept disabilities and our fears and ignorance. People with disabilities and their supporters all need to adapt, express their needs, have realistic expectations and find out about resources, skills and aids available.

Between 1985 and 1990 I worked with residents at nursing homes. We designed and ran courses called "New Opportunities for the Aging." The aim of the course was for the participants to have complete autonomy and control of the course. The participants chose the course, the themes and input needed. As coordinator I organised tutors and resources.

At two nursing homes the participants elected to have public relations sessions where they would have photographs in the local paper and involve high school students. The public relations aimed to debunk the common perceived connection between physical disabilities and senility. The residents challenged the patronising attitude of "the poor things".

Most of the autobiographies used for this thesis related anecdotes of being treated as senile, and most were not elderly people. The physical disability appears to be the main association, old age just adds an extra stereotype. This connection will not be easily overcome because some people like helping for egotistical reasons. This trait can ignore a person's capacity to help oneself. Do those helping need to feel superior due to fear or lack of self confidence? Have they been socialised to believe that only strong, healthy, physically able people can be successful and what is successful? Are they the "do gooders" who want to "help" the disabled people?

To debunk the association between dementia and any physical disabilities, there must be a diversity of methods. The combination of government legislation, education programs, art and humour and people with disabilities integrated in the community is slowly making changes. However there are some people who will not change patronising attitudes because it requires intent and motivation and some degree of self awareness.
I would argue that it is more important for people with disabilities to work with their self-confidence and self-acceptance. People with disabilities can then deal positively with the attitudes of discrimination or condescension and not let them affect self-confidence.

*Does she take sugar?* they ask my friend as if I cannot hear. *“How does she manage?”* they say, as if I cannot move. *“Do you dress yourself?”* *“Who buys your clothes?”* *“Who’ll look after you in your old age?”* *“Your husband must be a marvellous man.”* *“Surely you didn’t make that crochet jacket, someone must have helped you.”* (Hewett 1987).

Young people, such as Hewett, are not free from the patronising attitude. It is the direct connection between physical and mental deterioration. Noted theorists such as Carroll assert that people with visual loss return to the dependence of childhood. This helps to perpetuate the erroneous connection.

Humour can directly satirise the ignorance that connects physical disabilities with dementia. The “Talking Wheelchair Blues” song, by Fred Small, targets the patronising attitude, with the person in the wheelchair as the satirist. The song contains with a smorgasbord of patronising lines, from the table attendant, another diner and the restaurant manager. It provides insight in an enjoyable, compact song. The last verse provides the punch line of the song –

In fifty years you’ll be in worse shape than I am now,
See we’re all the same, this human race,
Some of us are called disabled, and the rest!
Well the rest of you are just temporarily able bodied

This is a generalisation about old age but provokes debate and question.

The first two verses below, challenge the concept of who is handicapped. The song is saying that the physical handicap of not being able to walk is overcome by a wheelchair. The notion of handicap remains in the stereotype image of the observer. Hence it can be simple to remove a physical handicap but a continual challenge to remove the social handicap of prejudice or discrimination. The song portrays the woman in the wheelchair as the only person with no social handicap.
Talking Wheelchair Blues by Fred Small

I went for a jog in the city air,
I met a woman in a wheelchair,
I said, "I'm sorry to hear you're handicapped."
She says "What makes you think a thing like that?"
And she looks at me real steady,
And she says -- "Want a drag?"

So she starts to roll and I start to run,
And she beat the pants off my aching bum,
You know going up hill I hit my stride,
But coming on down, she sails on by.
When I finally caught up with her she says,
"Not bad, for somebody able bodied.
You know with adequate care and supervision,
You could be taught simple tasks,
So how about something to eat ..."

1.6 Action Research on Two Levels

I considered action research as being particularly appropriate to my research, with its emphasis on:

1. involving participants as co-researchers;
2. facilitating the learning and development of all participants;
3. 'real world' settings;
4. bringing about positive change that considers values and ethical issues as central.

The changes action research may be concerned with are oriented both socially and individually (Lather 1988). Indeed change in the initiating researcher is an expected outcome of action-research projects (Lather 1988, Cancien 1989).

I planned my research on two levels –

1. Personal
2. Collaborative

1. My Personal Journey

First I had to understand how visual loss impacted on my daily life to know how I had adapted. I had not aspired toward normality, but the image of superwoman. I was continually testing my limits. My motto had been, "I'm tough. I can cope. I do not need anyone's help."
I now accept that in many cases I do experience more daily stresses than a person with full sight. I need to concentrate more and perform daily tasks with more deliberation. The research process is more tedious because I use audio material. It is harder to skim through notes with a talking computer and cassettes. Editing relies on a staggering amount of memory. I have learnt to ignore the monotone voice of my talking computer. It makes even the most dynamic writing sound boring.

I used story telling, song writing and cartoon designing to express my shortcomings and positive qualities, and obtain feedback about my changing interaction. I had to unlearn my tenacious independence and balance it with interdependence, particularly asking for, and receiving help, with dignity. I had to be clear of my own values before I could empathise with collaborators or argue for social change.

It was imperative for me to avoid the generalising and categorising that is common to positivist research methods. I have not used any collective terms such as *We* (Jernigan 1970) or *The blind* (Lukhoff 1973). I was constantly urged to problematise my research, but I have aimed to de-problematisate. I felt hypocritical, searching for problems. My own life was not confounded with problems. By problematising the issues was I perpetuating the image of people with visual loss as experiencing multiple problems?

Many of the theorists in my literary review (Chapter 3) assume that people with visual loss act in a certain way because of their visual loss. Theories are made and large groups of people are labelled on this basis. I argue that it is usually personal proclivities. Many of my close friends and my husband and family often forget that I have a visual impairment. I am viewed as an eccentric because of who I am, not because of my physical disability. I use the term *stresses* (Loenfeldt 1974)) rather than problems experienced by people with visual loss. This acknowledges that we all experience stresses but accepts that a physical disability may create more.

2. **Collaborative Research**

My personal research kept influencing the action plans for my collaborative research. Initially I planned to work with local retailers, to provide information about people with visual loss and clarify my own requirements. On accepting the benefits of my limbo status I decided against working with retailers. Those I visit regularly already know about my physical limitations. I appreciate my anonymity in a small town and choose not to share with other retailers.

After producing a radio program, on the theme of limbo status, with two women I dropped the topic of gender roles. I was interested in whether women faced different stresses from men with visual loss, particularly at different age groups. The issue proved to be too broad. It was developing into another thesis.
I then immersed myself in autobiographies written by people with disabilities. In my initial action plan I justified why I was not collaborating with people with visual loss.

- It was difficult for us to meet.
- It was hard to find a group in a small town.
- Adaptation and the impact of visual loss are individual experiences that were covered in the autobiographies.

Two colleagues asked me what the REAL reasons were that I was not collaborating with people with visual loss. What was I avoiding? I acknowledged my fear and prevarication and asked two people with visual loss to share in my action research. Amanda and Kelvin agreed to share. In Amanda’s case we discussed two issues with the aim of writing articles or reports – “What is the worst thing about being visually impaired?” and “Technology. Liberation or Frustration?”

Amanda and I lost sight adventitiously. Kelvin had less than fifteen percent sight at birth. We shared narratives and equal power in the decision making, writing and editing of our research. We did not use a formalised structure such as co-counselling or cooperative enquiry. I met separately with Kelvin and Amanda each week, we planned our approach and we decided to tape our last meeting in the form of an oral history. I was the active listener (Thompson 1978), where the narrative developed like a biography, except we shared equal power in the questions asked, the form of the narrative and the editing. Kelvin did not want a commentary nor interpretation of his story.

**Limbo Status and Self Acceptance**

I shared with two women who are not visually impaired, but have experienced a sense of limbo status and the need to develop self acceptance. Many of the challenges associated with visual loss are experienced by other people. Maureen shared the challenges of being a koori, with white skin, and Mary shared the impact of having a below knee prosthesis, after a motorbike accident, at age seventeen.

**Ethics and Appropriateness**

I always asked: “How much can I interpret our collaborative research findings?” This had to be continually negotiated and clarified to respect the confidentiality and values of my collaborators. I reflected on whether my process was holistic and working dialectically on the spiritual, creative, physical and intellectual levels.

Lukhoff and Whiteman (1973) said that blindness was not a well defined role. I question any “well defined role” as a generalisation. I believe visual loss is a complex matrix of personal and societal values. Many of the theorists in my literary review, concentrated on a select number of variables, and using a cause and effect analysis often reached a simplistic or narrow explanation. My
emphasis has not been on seeking explanatory causes, for why people with visual loss adapt in diverse ways. I have shown HOW different people adapt.

**Interaction Ease**

*Interaction unease* is the term used by Erving Goffman (1968). It describes the confusion of protocol when a person interacts with someone with a perceived stigma. The person may feel anxious, confused, repelled or indifferent. There are so many factors that can negatively or positively affect interaction. Part of my action is to develop interaction ease by using appropriate assertiveness and becoming aware of my own prejudices and fears. My increasing interaction ease has improved my self acceptance, primarily accepting the physical limitations caused by visual loss. I am being more honest and so interaction is growing more comfortable.

A personal change that occurred early in the research process was my acceptance of a limbo status. Beginning the research I viewed it as a negative feature. I immediately recognised the advantages, for example, being able to choose whom I tell about my visual loss and when. It is now less of a personal issue.

My personal transformations directly affected my action plan spiral. When I openly admitted my tendency to be totally independent I had to change my interaction. Learning the balance between independence and interdependence was dynamic and enriching. It had been occurring on a less deliberate level with my maturing. In the research process the changes were positive but overwhelming at times.

The conspicuous changes in interaction were:

- Asking people to greet me by name. For example, “Hello Claire it’s Wendy speaking” I now do not have to guess who is speaking.

- Asking for appropriate help more often and clearly, instead of wasting energy. For example, carrying heavy backpacks of shopping on the school buses, walking long distances and hitch hiking.

- Explaining my requirements more clearly to shop assistants, friends and associates. This research has helped me to be more empathetic. I realised that I could not even work out how much I could see, so how could I expect others to understand.

- I questioned independence for independence sake (Hale1975).

I became involved with a support group and research network to discuss the issues of qualitative research. How was I to measure the positive social change. How could the growing clarity and honesty of my interaction and the implications of these changes be utilised? The people I interact with experience less confusion. They trust I will ask for assistance to cross the road or read a label. We both have less fears and doubt about correct protocol – the limits to the help I require and exactly how I like to be assisted. There are many videos, pamphlets and training kits on how to assist people with visual
loss, but they can only be a guide. Individual's requirements differ. The
closest challenge remained, of how to record and measure these interaction
improvements.

**Humour in the Research Process.**

Humour is essential in my research process to confront the negative
associations with visual loss; the myths, stereotypes, prejudices and fears.
Humour can help to dissipate these negative associations. Humour also helps
to place the impact of visual loss in perspective: that it varies with daily
stresses, adaptation and personal well being.

*Anyone who does any speaking at all has a statement to make, and
that statement should not be overpowered, even by humour. Your
message must be important to you for you to work as hard as you do,
to communicate it to others. The purpose of humour is to enhance your
message and to get people to listen to it more attentively, and
remember it much longer. Humour has that power. It is so popular that
when people hear it they want to listen. It is so graphic that it sets your
message firmly in the minds of the listeners* (Perret 1984 preface).

I wrote humorous stories, but found that songs, humorous skits and
anecdotes and cartoons communicated a more succinct message, to a wider
audience. I aim to balance the desire to obtain laughter and to convey a
message. Feedback has been satisfying. People often discuss important issues
days after I have sung a song or told a humorous anecdote related to my
visual loss. I published a story – “Blind Woman's Bluff”, in Earth Garden

### 1.7 Outline of Thesis

In Chapter Two, I stressed that the impact of visual loss has no singular,
right answer, but is a complex issue and cannot be generalised. I described the
various research approaches I experimented with: Action research, Feminist
research, Social research with an autobiographical and collaborative focus and
the use of narrative, as a rich and alive way to share understanding.

I clarified my own world views on discrimination, interaction between
people with vision loss and people with full sight, my sense of limbo status
and resistance to asking for help.

What I aimed for and did not aim for were equally detailed. For example, I
aimed for appropriateness and authenticity. I did not aim to speak on behalf
of, nor represent, people with visual loss. Important questions such as “What
value do people place on full sight?” directed my enquiry. To avoid a possible
elitism in Action Research I was flexible and chose a particular form to suit
the situation. I also avoided the dualism of blind/sighted, either/or,
right/wrong.
Chapter Three shares two stories from Kelvin, who has a visual loss, and Mary, who has a below-knee prosthesis. We elaborated on the theme: "That to improve self-acceptance can improve interaction." I was asked by Kelvin and Mary to remove the commentary and respect the stories for their intrinsic value.

The sub themes in Mary's story are:
- Peoples' curiosity about Mary's prosthesis and how she deals with it.
- Mary's avoidance of asking for help.
- Her growth in self confidence and self esteem.

Initially I resisted sharing with a person with visual loss, then collaborated with Kelvin. His story shares a journey and exploration with the following themes:
- Visual loss means that activities take more time.
- The challenges of experiencing a limbo status.
- The effects of denying the impact of visual loss.
- The reconciliation of self acceptance, Kelvin's spirituality and creativity.

The stories highlight the unique and diverse ways that people deal with daily stresses, and this adaptation is an ongoing process.

In Chapter Four I challenge the categorisation and classification of visual loss. I question whether humans have a universal obsession with sight and over-value its importance, hence increase the fear of blindness. I critique a range of theories on the impact of visual loss and indicate what changes have occurred in the last decade.

I critique several theories under the theme of Victim Theories. Carroll (1961) Scott (1969) Hough Kim (1970) and Monbèc (1973) portray people with visual loss as victims, experiencing problems, and being stigmatised. I argue that they underestimate the capacity for self reliance.

Jernigan (1970) is interesting for his revolutionary style but speaks on behalf of all people with visual loss. Roper and Vader (1990) are critiqued for the high value they place on sight. I argue that this affects their interpretation.

The final group of theories I critique have more positive and empathetic research interpretations. Allen (1991) and Loenfeldt (1974) see the stresses experienced from the participants' frame of reference. Blaylock and Rickelman (1983) Rowland (1985) and English (1971) like the above two researchers give ideas for positive social change.

Wright (1983) covers many themes in her book. I discuss the major points:
- That we all have disabilities of some sort at some stage.
- That we must concentrate on what people can, not what they cannot do.
- Wright warns about an aspiration toward the 'normal'.
I summarise by again stressing the need to respect the unique individual and to question the value theorists place on sight.

Both chapters five and six are dealing with the complex subject of human interaction. Using biographical excerpts, I aimed to have the writers produce their own narrative. My commentary asked questions, clarified issues and highlighted differences between people who have no functional sight and those who have a visual impairment and have less than ten percent sight. Most of the excerpts are from writers who have no functional sight. This served as a contrast with my own stories and the two stories in Chapter Two.

The two chapters are not generalising on interaction. They respect the diverse and unique ways that individuals adapt and interact. The sub-themes explored are:

- The challenges of conversation.
- Does it take longer for people with visual loss to perform daily activities?
- Bureaucracies – how they have changed.
- Respecting the unique individual.
- Loss of personal identity.

Chapter seven reflects the stages I went through while experimenting with humour. I explored the multiple roles of humour such as improving interaction and catharsis. I described humour as a balancing mechanism, firstly, because the impact of visual loss is often overdramatised and problematised. Secondly, many theorists took much effort to justify why they were researching humour. I paralleled the experiences of people who were researching humour with people with visual loss. Both can be marginalised and have to justify and validate.

The importance of appropriate humour was stressed and I tested this notion. Cartoons elaborated on some dominant themes such as the concept of 'normal.' It was found that the clearest and least threatening images obtained the most positive feedback.

I expanded on the 'normal' concept and asked: Does normality mean conformity and a means of social stability?

Primarily autobiographical, Chapter eight unravels the theme that interaction unease can be changed to interaction ease. My stories and songs concentrate on the particular and I argue that this encourages the reader to more easily identify and learn.

The stories show how I deal with daily stresses and anecdotal examples are given. Neighbours read my story, "Blind Woman's Bluff". This altered an interaction, making it much easier. People know now when to offer me a lift. Each of the previous themes, such as the concept of normal and changing problems to stresses, was developed in story form.
PLEASE NOTE

The greatest amount of care has been taken while scanning the following pages. The best possible results have been obtained.
CHAPTER 2

Research Process: A Patchwork Quilt of Approaches

In my choice of a research process, I wanted to acknowledge the view that humans can usually choose how to act, and so can choose what meanings and values to ascribe to experience.

Some of the theorists I reviewed sought an understanding of visual loss, in the relationships between variables and attributes. The focus was on relationships that connect variables, not people. This system creates pressure to find general patterns and trends. A process that aims to be irrefutable and replicable is usually detached. It selects, classifies and measures information.

Choices of self direction and self determination would seem to be ignored in the positivist research process. Rowland (1985) asks, does the researcher remain value free, objective and restricted through procedural knowing? Do the research subjects answer interview questions, respond to surveys and questionnaires with minimal understanding of the process involved? What interest, commitment and motivation exists for the research subject, in this an unequal power relationship?

There is a danger in compartmentalising an issue as complex as visual loss. Narrow, cause and effect models of visual loss appear simplistic and can perpetuate the stigmas that the researchers are trying to address.

I have unlearned the positivist doctrines of right and wrong and absolute truths. There is no right explanation for differing adaptations to visual loss; truths are mutable. Action Research elaborates on these themes. It examines the anomalies, contradictions and ambiguities, which often produce the most fruitful questions and cogent answers.

My research approach allowed me to explore my major themes from diverse perspectives. I collaborated with small numbers of people on differing levels. The breadth of different groups helped to create a holistic view. I had to work with friends, audience members at Playback Theatre, and people with visual loss. I also collected autobiographies, written by people with visual loss, to provide a broader number of narratives. By providing individual accounts I
challenged the notion that people with visual loss adapt in a homogeneous manner. Rather than exchanging breadth for depth (Edwards 1993 p.6), I shared with two people for an extended time, using autobiographies and feedback from my songs, stories and cartoons to obtain multiple views and diversity.

My research approach varied according to what was appropriate. When I was interpreting and comparing theories of adjustment to visual loss, I examined how the theorists were influenced by their frame of reference, their research methods and the value they placed on sight. However, I used a naturalistic style when comparing autobiographical opinions on adjustment to visual loss. All the autobiographies I used were written by people with physical disabilities. I aimed to give a diversity of opinion and tried not to interpret or make judgements. I stressed individuality and uniqueness not trends, to obviate stereotyping.

Many theorists concentrate on the disability and its potential problems. In chapter one problems were redefined as stresses. I focussed on the narratives of people with visual loss. Stresses experienced were of less importance. The autobiographers and collaborators could share their authentic voice of reason and intuition. This provided a rich diversity of opinion. For example, Garland (1974) describes how his natural aggression was his main skill in adapting to visual loss; Krentz (1972) emphasises how acceptance of his own self worth was his transformation; whereas Kelvin, a collaborator, said it was a combination of his spirituality, creativity and self knowledge.

The first, daunting step of my action research process was discovering my epistemological and ontological assumptions (Kuhn-White 1993) affect my perception of the impact visual loss:

1. I was shocked to discover that I had ignored even realistic limits caused by my visual loss.
2. That I had strived for a lifestyle of super independence and hence the image of superwoman.
3. I confronted my own fears and discriminations: Blindness means dependence and being institutionalised (see "Pig Swill").
4. I acknowledged the amount of energy I wasted trying to validate myself. I had to perform better than people with full sight.
5. I had contributed to my own form of "interaction unease" (Goffman 1968). Even my close friends were unclear of what was correct, social protocol, for example when we crossed a busy road together.

I accepted my sense of limbo status in the initial stages of the research; but I realised that I re-enforced negative aspects of limbo status, by rarely asking for help, and being unclear when I asked for help.

I chose to adopt the view of Edwards (1993, page 2) by undertaking action research as a form of qualitative research, since the issues were Multi faceted
and characterised by ambiguity and indeterminacy. I had to be aware of what I was and was not, aiming for – I was not aiming to liberate the image of visual loss. I did not want to theorotype (Rowland 1985), and risk narrow, causal explanations. I did not aim to speak on behalf of, or for, people with visual loss.

My aims became more coherent in the mid-stage of research: to honour individual narratives from people with visual loss. I aimed to take personal risks, be more honest about help I required, and practise my philosophy of interdependence. I constantly challenged the notion of many theorists that blindness is saturated with problems.

I chose Action research in contrast to The methods of positivist enquiry, emphasising objectivity and seeking law like generalisations would be most unlikely to produce such a detailed and practically useful representation (Schaafsma 1993 p.5).

I wanted my research to be of practical value. I challenged Goffman’s (1968) claim that interaction unease is intractable because of stigma. To make positive changes I had to explore thirty years of habits. My primary way of dealing with the effects of visual loss, had been to deny that it had any impact on my life.

### 2.1 Social Research

My research is social, but I do not label it as humanist. I do not agree that human interest should predominate. Humans have the most choices and they exploit the earth more than any other creature. The wider, socio-ecological perspective is important because anyone with a disability is viewed as inferior in an exploitative, materialistic world view. Success is measured on output per person. A person with visual loss may work slower, need technological aids and ask for help more often. I researched with people, not on them.

I wanted to investigate the negative side effects of adaptive technology, but soon realised that this would develop into its own thesis topic. During the reflexive stages I decided to explore the more social aspects of interaction ease.

**Removing My Attitude of Discrimination**

It was arresting to confront my own attitude of discrimination. Initially I did not want to collaborate with people with visual loss, and had to ask why. What am I resisting? What are my fears? I wrote an autobiographical story (see “Pig Swill”) which recalled my first, strong feelings of discrimination.

At the age of eleven, I spent one year of rehabilitation at the Royal Victorian Institute for the Blind; and remember clearly the first day. I walked from the school to the dormitory section for lunch. The long, shiny corridor echoed with white sticks, students feeling along the walls and a crowd of students with eyes that had deformities. I felt out of place and worried, “Will I
end up looking like those people?” I also associated institutionalised behaviour with visual loss. By recognising this erroneous association, I was able to release my discrimination to collaborate honestly and empathetically with others who had vision loss.

2.2 On Collaboration

My academic consultants urged me to share the implications of visual loss, on the research process. To identify the differences between my approach and that of people with full sight, I shared with colleagues at the university residential, and produced an impressive list.

Access to resources.

Mobility.

The need to memorise.

Organisation: including editing and referencing, filing and accessing information from tapes, and problems with visual lay out and coherence when writing the final paper.

Relying on readers and electronic equipment (If my talking computer or tape recorder break down I cannot borrow friends’ equipment because mine is specially adapted for people with visual loss).

I had to be vigilant and methodical in my organisation and my networking with friends; other researchers and collaborators were invaluable.

I chose one-to-one contact in much of my collaborative work. We could choose venues to suit our needs. Places that were quiet, without the light distortions of shadows, fluorescent glare or gloominess. We could sit close to each other and see, hear clearly and appreciate body language. We could develop a personal dialogue to expand our narratives.

Initially I thought that qualitative research would be less stressful because I could work with small numbers of people, and not have to collate statistics. I have always found statistical analysis difficult because I must keep so much in my head. I cannot obtain a visual image of tables. However, qualitative research proved to be equally demanding. Our collaborative work was carried out in more depth. Many of us developed close relationships and had to constantly negotiate our action research spiral. I had to become more economic and organised (Wadsworth 1984) to cope with the growing amount of taped sessions, group notes, diary entries etc.

2.3 Appropriate research and authenticity

Appropriateness is an essential quality of my process, to avoid stereotyping or being patronising. The word blindness often evokes emotional overtones. Blackhall (1961), related that when his sight deteriorated, blindness became
the most fearsome word. In his later autobiography, (Blackhall 1971, chapter 11) his perception changed to *Blindness is neutral*. A person can make peace with his blindness or battle against it.

I wanted tact and caring but had to ensure that it was appropriate caring. I had to identify my own needs, feelings and perceptions of visual loss to empathise honestly with other people with visual loss.

Cuomo (1992) warns of the *moral danger* inherent in caring that is not defined and contextually based. Women are socialised into caring and neglecting the self. I had carried this tendency to the extremes. I did not like asking for help, but often offered help. I had to mature in my understanding of socialised gender roles and my barriers to asking for help.

I clarified my motives. My major thrust had to be autobiographical, supported by my collaborators' authentic voices. I could then use the autobiographies, written by people with visual loss, and the theorists on the adjustment to visual loss, as a contrast. Each voice was unique. By stressing this individuality throughout the research I prevented stereotyping.

I posed questions to sort through this enigma:

Is there need for social change and why?
Is change already occurring and where?
To what extent can we change and does society want to change?
Do I need to begin with personal change?

The notion of appropriateness is integral to my research; but I had to undergo a clarification of my perception of appropriateness. Research on blindness and its effects has concentrated on societal attitudes and the way people adjust to sight loss. This depicts visual loss as problem oriented and people with visual loss as beset with problems. I wanted to know why sight is so highly valued, and why blindness is steeped in fear, misconceptions and myths. After reading many books I wanted to challenge the marriage of blindness and problems. Appropriateness became my guiding principle to avoid a personal reaction. My own values advocated self reliance so strongly that I had to become aware of this tendency. The appropriate shift was from *I can do anything, to We are all interdependent. We all face life problems, with or without physical disabilities, and can support and learn from each other* (Hale 1979).

My initial assumptions and stresses became the underlying questions for my research:

What was my limbo status?
What were my barriers to accepting any physical limitations?
How is visual loss viewed by society?
What causes interaction unease between people with and without physical disabilities?
I aimed to view my collaborators stories from their frame of reference and I
did not want to speak for people with visual loss. I respect that the way I deal
with my visual loss is appropriate for me, and my needs and expectations are
individual. The dialectical process helped me discover what was significant,
what was common and yet unique to people with visual loss. Continually
looking through other peoples’ frames of reference led toward my ideas for
social change. Van Mannon (1984) suggests that it is **harder to be dishonest
when we are thinking phenomenologically**. He says we are strengthening the
relationship between life, knowledge and action by this tactful, thoughtful
learning.

The principle of appropriateness made me question my authenticity. I
accepted my sense of limbo status and experienced a personal reconciliation.
It was a metamorphosis that gave me more confidence to experiment with
humour. Authenticity (being honest about what help I required and how my
visual loss affected me) made me more vulnerable but eager to take risks
because the quality of my life was improving.

### 2.4 Avoiding elitism

Action research encourages lateral, flexible thinking. The focus is not on
trends and generalisations but on discovering the anomalies and questioning
what is significant. Rather than following fixed rules of data collection and
analysis and objective, detached thinking, I experimented with creative and
imaginative thinking. It is not about *perfection ... but about flowing with the
chaos* (Heron 1988) and confusion. However, I do question whether action
research is developing its own elitism. There are now so many choices under
the broad heading, action research. Each theorist tries to convince us of
his/her theory as preferable. I decided against a specific choice between
alternatives such as cooperative enquiry, participatory action research,
experiential learning or collaborative enquiry. My conservative element chose
action research. My radical element chose to be flexible and use different
styles when appropriate (Alinsky 1972).

I have developed the skills of scepticism by questioning and aiming to
*suspend myself from judgement* to be open to new ideas, but accept that I am
not value free (Wadsworth 1984). I was inspired by Oliver Sack’s attitude to
research.

*Our tests, our approaches I thought, as I watched her on the bench
enjoying not just a simple but a sacred view of nature. Our approach,
our evaluations are ridiculously inadequate. They only show us deficits.
They do not show us powers. They only show us puzzles and schemata,
when we need to see music, narrative, play. A being conducting itself
spontaneously, in its own natural way* (Sacks 1986 p.173).

It is Sacks’ respect for the spirit in people and the spontaneity that I
identify with. I have discovered my own attitude of discrimination during this
research and I have been vigilant not to perpetuate this attitude. I challenge
the minimalist and dramatic theories about the effects of visual loss on people's lives.

Visual loss is much more complex and yet simpler than many theorists propose. An understanding cannot be glimpsed with aggressive testing or categorising. Sacks argues that we should go further, to the depths and stop treating people as subjects. I experience the excitement and mystery described by Sacks by really living the action research process.

2.5 Overcoming blind/sighted dualism

Stories help to break down the binary models of blind and sighted. The academics who edited the women's stories in "I Always Wanted to be a Tap Dancer" (1989) and "Images of Ourselves," (1981) gave the stories of women with disabilities, and did so with minimal editing and no commentary. The aim of the editors was to include deeply felt, considered contributions (Campbell 1981 Intro). They felt that even the most skilled interviewer cannot help being directive. The stories provided insight and information. I found the autobiographical stories interesting and informative. Their messages reached deeper than my reading of academic literature. They reveal how the adjustment to disabilities varies with each individual and is cyclical.

Many writers about blindness tried to simplify a complex notion of adjustment and adaptation. Perceptions and adjustment to adventitious blindness cannot be simplified and so must be viewed holistically. Can science tell a good story? (Heron 1984).

Sacks has transformed the science of neurology into a story, and allows his patients to speak, as he listens. He is a co-learner, who asks because he wants to know.

I found Sacks inspirational because he does not see people as patients with deficits. He moves beyond disease and symptoms to personal spirit and changing narrative.

It could be said that each one of us constructs and lives a narrative, and that this narrative is us, our identities. If we wish to know about a man, we ask, what is his story, his real, innermost story? For each of us is a biography, a story. Each of us is a singular narrative that is constructed continually, unconsciously by, through and in us, through our perceptions, our feelings, our thoughts, our actions and not least, our discourse, our spoken narrations. Biologically, physiologically we are not so different from each other. Historically, as narratives, we are each of us unique (Sacks 1986 p.105).

Sacks honours these unique narratives as essential to maintain personal identity. Many of the theorists I criticised in my literature review neglected these narratives and their essential uniqueness. Theorists (Wright 1983, Hale 1979, Shearer 1981, Rowland 1985) who used a phenomenological approach embraced the narrative and the uniqueness and commonalities of individuals.
On several occasions I was asked by one of my collaborators; “Is this what you want?” The question reminded me of the unequal power relationship that often exists between school student and teacher. The teacher asks a question with a predetermined answer. Many students try hard to supply the answer the teacher wants. I used this example to reflect upon how we were collaborating. We decided to use a narrative style of enquiry to avoid the tendency to worry about what is right or wrong.

By sharing stories and anecdotes we felt more comfortable. It was easier to be honest about how we interacted and how our visual impairment affected this interaction. We began by using an unstructured interview style but the story telling provided a richer, more honest sharing.

2.6 Story Telling

Poetry demands the rigour of brevity and allows the richness of creativity. My autobiographical stories and poetry focus on specific issues that have had an impact on my research process. Each time a colleague has criticised my papers, she has commented on the insight obtained from the anecdotal stories.

A validation of story telling is arduous. I passionately believe that stories possess an intrinsic value. In so many cultures it is stories that have kept festive rituals alive. However there are many classical stories that have perpetuated the negative myths and folklore about blindness such as King Lear and Treasure Island. I reflected on the appropriateness and implications of each story.

The autobiographical stories question my world view. The stories reflected my maturing and adapting. I chose themes, significant to the themes of limbo status, self-acceptance and interaction. I have always been a natural story teller and wanted to share this skill in the research process. I have related many short anecdotes from the stories to open discussion and debate about blindness and peoples’ fears and attitudes.

Playback Theatre ⁴

In Bellingen there is a performance of Playback Theatre every quarter, and I have often told my stories. Afterwards people have discussed the issues. Having stories replayed helped me clarify issues and see my stories from other perspectives. The actors often show the “underbelly” of an anecdote. This aspect is often unspoken by the story teller, but apparent to the actors as the crux or essence of the story. In my story, Blind Woman’s Bluff, the actors

---

⁴ Playback Theatre is a form of spontaneous theatre. The actors listen to stories, then use mime, dance, music, movement and improvised acting to replay the stories. Audience stories can be one moment, a short anecdote or a long story. A conductor controls the flow and theme of the session by asking the audience questions and giving ideas and inspiration for stories.
honored into my dilemma of whether to accept the offer of a lift from friends. If I said no they may not offer lifts when I really needed them. This was picked up from the story. I did not mention the dilemma. In this way Playback adds important dimensions, and depth to the narrative.

2.7 Feminist Research Methods

In some cases feminists re-introduce passion, with its possible enthusiasm, anger and nastiness, its first person voice and its identification with the research subject. Research then reads as partly informal, engagingly personal and even confessional. Researchers frequently start with an issue that bothers them personally and then use everything they can get hold of to study (Reinharz 1992 p.260).

At first I was overwhelmed by the academic elitism and stress on rigour. I wanted passion and the first person in my process and I found these qualities in action research methodology and feminist methods. My initial collaboration was with two women who had also experienced some sense of limbo status when younger. The sharing with Mary and Maureen was my apprenticeship in feminist methods. I had a tendency to over plan and feel safe within structure, so I asked Maureen to be involved in a less structured process. Our initial sharings were informal and open ended. We then planned a radio program with the theme of self-acceptance and limbo status. This required some more structure because of time constraints and the professional standards of radio broadcasting.

By collaborating in a non-hierarchical, reciprocal manner we shared risks and mutual disclosure. It was empowering. I shared my assumptions about limbo status and self-acceptance and admitted that I was unsure of my research direction. It was a stage of chaos and confusion. I was learning to flow with this chaos. I felt exposed by my own limbo status.

Most of our sharing was informal and personal and I did begin with a problem that bothered me personally (Reinharz 1992). We had all consciously worked on our personal growth for over a decade. They helped me blend intellectual and personal questions and avoid academic rhetoric. We could then clarify and reform knowledge from a constructivist perspective.

Reinharz asserts that phenomenological interviewing requires interviewers with skills of restraint in listening as well as interviewees who are verbal and reflective. Phenomenological interviewing also tested my need for structure and control. The informal sharing had a minimum of questions. Questions were mainly to clarify or broaden the scope. I learnt to trust that the interviewee would lead in fruitful directions (Reinharz 1992). I had to unlearn the stress on results and reductionism. By dropping the need for control and experimenting with multiple methods.

The interview process gives the researcher an intimate view of this pain, and the shock of discovery may eventually force her to discover her own vulnerability (Reinharz 1993 p.27).
I only share this short excerpt from Maureen’s narrative, because Maureen feels strongly that the Australian Aboriginal person has been over researched, and mainly by whites.

*I have a really strong commitment to being a person. I don’t want to be in a box; to get treated as an Aboriginal first, and labelled.*

Maureen was reared as an Aboriginal person, on a reserve, with very close family bonds. She then experienced the rejection of the white community, when her family shifted into town. Her white skin meant she could choose when to reveal her Aboriginality, and on leaving school, she lived as a white.

*“I tend now to work out how important it is, what they’re saying to me.”*

Maureen explained that living as a white for ten years was simply easier. She had more rights and peace. After a decade of personal growth, she experiences her limbo status much less. She shares her cultural heritage more.

*“Because I’m more comfortable with it. Because I accept it more. Because I have a lot more pride in it. Because I realise I’m actually denying my own mother (if I don’t).”*

Our sharing helped me face my own vulnerability, and move onto collaborating with people with visual loss.

**Conclusions.**

The early stages of research, when I was planning what action to take, and how to take it was like making a patchwork quilt. Each patch was unique and separate but intricately interwoven. The impact of visual loss is complex. My methods had to be based on a set of open-ended questions such as, *“Why is sight so highly valued?”* There are no simple, clear, definitive answers to such a question; both the question and the answer is interpreted according to peoples’ values.

Theories about the impact of visual loss often appeared distorted, and I felt that theorists were unaware of the value they placed on sight. I had to clarify my own discriminations and choose flexible research methods which could monitor my own changing values. The plan/act/observe/reflect cycles of action research helped to ensure rigour. Appropriateness and authenticity became my guiding principles; and it proved equally important to clarify what I aimed to avoid.

Stories are the gifts offered in this thesis. They portray the vitality, the spirit that helps people to adapt to visual loss.
CHAPTER 3
TWO STORIES

3.1 Introduction

The two stories, shared by Kelvin and Mary, provided feedback for my epistemological and ontological beliefs. The clarity and frankness of their sharing inspired some assumptions. Firstly, to get rid of the limbo status would lead to self-acceptance. Secondly, that self-acceptance would lead to assertiveness and develop clearer communication, and so improve my interaction ease with people with full sight. The first assumption soon changed to accepting my sense of limbo status. However, I pursued the second assumption.

The story theme that recurred throughout my enquiry was peoples’ resistance to asking for help; so I decided to personally concentrate on improving this form of interaction.

Mary shared that she feels it dramatically if she cannot wear the prosthesis, and has to use crutches temporarily, because she is less independent, and has to ask for help. Kelvin shared that when he was young, he was not aware of his own needs. He did not want to be different and his motto was “Yeah, I can manage.” He also avoided asking for help.

Both Mary and Kelvin said that working toward self-acceptance was an ongoing issue, but it helped to improve interaction ease; that when the person with the disability feels more comfortable, this feeling is transferred, so making interaction easier.

Kelvin wanted his contribution to act as a vehicle for change. We chose the narrative genre because it is so accessible. It reveals a unique perspective, and a wider audience can appreciate the story compared with a theoretical analysis.

3.2 Mary's Story

I was asked to do a radio program for the local radio station. I had a fortnight's notice to prepare the women's program, and asked Mary and
Maureen to share their stories about the limbo status and developing self acceptance.
I asked Mary and Maureen to share because I knew them both and felt confident to interview. I knew Maureen, having taught nutrition to Koori women as part of the child care course. I had often shared the sense of limbo status with the Koori women. Maureen said that Kooris are probably the most researched society in the world and yet so much of that research is done by whites. She said that it is about time Koori people researched their own culture. To honour this comment I only included a short section of Maureen's sharing in the introduction. Maureen is continuing tertiary study, aiming to do her own research.
I knew Mary as a colleague, teaching in the TAFE system. Below is an edited version of Mary's radio interview to which I originally added a commentary. On reflection, Mary said to delete the commentary. The interview tells its own story and does not need interpretation. The interpretation intruded and did not respect the "intrinsic worth" (Naess 1989) of Mary's story.

The Radio Interview.

Self-acceptance was the theme of the interview. Mary has a below knee prosthesis due to a motorbike accident at age seventeen and began by saying, the prosthesis has become just part of my life really. Mary usually wears long dresses and pants that cover the prosthesis. Mary only limps if or when there is a problem with the prosthesis so you cannot tell that Mary has the prosthesis.

It is when Mary has to have a new leg made, and goes onto crutches that she finds it confronting.

"... because I go from an able bodied type person to one that is hopping around on crutches, and I find it a very limiting experience; limiting as to what I can do, and also I get a lot of very surprised reactions because not many people know me on crutches and they get quite a surprise that I've hurt myself, so it's quite a confronting experience for me."

Mary handles peoples' surprise by explaining "it's a permanent sort of thing and nothing to worry about. So on the whole, it's not a subject of conversation, but certainly if anyone is curious, often children are very curious and ask a lot of questions, so whenever anyone asks I'm very ready to talk about it."

"Children are very excited to come and look at it and touch it and parents try to pull them away, to say no, you can't do that but I say yes, I enjoy their honesty. They do not pretend not to see a difference. Because the difference is obvious. If I don't have shoes on, instead I have a plastic foot with plastic toes and so it is intriguing to see someone wearing it - it looks like a toy."

Mary shared about the inconvenience of sometimes relying on crutches for mobility.
"I've got the privilege of walking around, but my hands are tied up with using crutches and so simple things like doing the grocery shopping or getting from A to B, it's just a more difficult experience, I find myself having to ask for help, ask for assistance and its something I would generally avoid doing. I'd prefer to be wearing my leg even though it's painful, than to be going on crutches and losing that sense of independence I have."

"So it's a difficulty in asking for help?"

"Well yes, it means I can't do the things I've become accustomed to doing and so I feel it quite dramatically."

As mentioned, Mary generally wears a long skirt or long pants, but when her prosthesis is conspicuous the usual response is curiosity.

"Well, people are curious all the time. People always look at anything out of the normal, and so usually if I'm feeling comfortable with myself it really is no issue to me to have people observing me because generally I feel it is really with quite good intent."

Mary discussed the psychological and physical rehabilitation after the trauma of the motorbike accident.

"It's taken me a long time really to deal with and sometimes it is still an ongoing issue for me. Being seventeen, when I first lost my leg, my self esteem was very low and my self confidence very low. I was very fearful of many situations, fearful of slipping and falling as I felt very unstable on my leg. It's a long process, it was a long process for me, to get used to wearing a prosthesis, and wearing it comfortably, wearing it without pain and so I didn't have a lot of confidence in going places and doing things, but now, I'm thirty six years old now and I worked through a lot of that. I'm a lot more stable in myself, and stable on my prosthesis, and so I feel a lot more comfortable and confident in situations."

"I'm thinking of my self consciousness at age seventeen. How did you feel about socialising?"

"Right, I really didn't feel very confident to be going out and doing that sort of thing. Occasionally I teamed up with a friend and we'd go out to the nightclubs, but it really didn't bring me a lot of satisfaction as I felt very self conscious about it. I quickly got into a relationship with a man, who I felt accepted me, which I felt really meant I didn't have to confront a lot of the problems of being out there in the world and dealing with myself, and being in a committed and stable relationship really gave me a lot of support and I really didn't deal with a lot of the fears that were associated with the way I perceived myself."
“You feel you’ve gone a long way haven’t you, since you were seventeen, as far as self-acceptance goes?” (Mary and I had discussed this theme in more detail before the interview).

“Yes, that’s very true, from working from a position of not really liking myself to really learning to live with myself, to love myself and to even work with sometimes, limitations in my own body and it’s been a very exciting process for me because where I’ve arrived at, with it today, it’s you know, feeling very open and very loving towards myself.

I find that when I’m accepting myself and feeling happy and content in myself other people around me react the same way. If I’m feeling uncomfortable with myself, other people are uncomfortable, and so yes it’s true. The easier I am on myself, and the kinder I can be on myself, likewise other people are kind to me too.”

“So yes, from a practical or physical level, if you were feeling self conscious about your prosthesis, other people would feel that way.”

“Oh yes, certainly, certainly, yes.”

3.3 Kelvin’s Story

As mentioned earlier, my initial plan was to avoid collaborating with people with visual loss. I had numerous justifications. Two critics confronted me, and I had to admit fear. I asked Kelvin to collaborate because I felt trust and an established rapport. I knew that I would have to face my own discriminatory attitudes and fears about visual loss, so I wanted to share with someone empathetic.

We were both unsure of how to plan our collaboration. I was aware of my own confusion and emotions and appreciated mainly listening to Kelvin. We used the main assumption of my thesis as a guide – That a limbo status can decrease with self-acceptance and therefore improve personal interaction.

We met weekly, then fortnightly for three months, and our collaboration was an exploration and journey. Themes developed naturally. I often asked questions, but not in an interviewing style. The questions were to expand our discussion, clarify issues or reflect upon a theme.

We both felt unsure at times with the lack of structure. Our thinking moved from mainly inductive and subjective, to constructivist enquiry. We discussed ideological perspectives such as the need for a holistic view, embracing creativity, spirituality with mind, body and ecology, when exploring the main assumption.

We met mainly at Kelvin’s home so that we were comfortable and confidential. It was important for Kelvin to share his creativity and spirituality. His work as a potter and his drawing is closely connected to his spirituality. The drawings on the next page, (Figure 3.) express Kelvin’s journey of creativity and spirituality.
In this chapter I have made no commentary or analysis of our collaborative research. There has been some editing to protect confidentiality but Kelvin's story speaks for itself. The themes are expanded in other chapters of the thesis.

On June 12th 1993, Kelvin said he had appreciated our sharing but worried that it was selfish just to share. We discussed how our sharing could be a vehicle for change, and decided that our narratives held their own intrinsic worth. We did not have to reach conclusions nor seek explanatory causes. Sharing, we were developing an understanding of our personal values and fears and were developing new paradigms and reconstructing our perceptions of the world. This experiential learning could improve our interaction.

**VISUAL LOSS TAKES MORE TIME**

Like Dahl (1961), Hull (1990) and Blackhall (1971), Kelvin shared his perception of time; that he *“has not the time. I’m that much slower. I can’t jump into a car. Dealing with health, mind, and the physical is enough.”*

**LIMBO STATUS**

Kelvin shared the challenges of the limbo status, the need to balance self love, the ego and a sense of peace, to unify the spirituality in a oneness. At a school for the blind, he experienced a limbo of having more sight than the other students and so was held back, and yet not enough sight to compete with peers at home.

At times Kelvin has been a loner and his art has been his expression. He works with colour until the work stands on its own merits. He sees miracles happening in creativity and the Baha’i faith. Life, for Kelvin, is about rebuilding within, connecting dreams, intuition, vision, creativity and spirituality.

At the end of this sharing we decided to tape Kelvin’s story at our next sharing. I have transcribed our last sharing as Kelvin’s oral history. The only intrusions are some points of clarification and thematic headings.

**DENIAL**

At age 24, Kelvin’s brother said, “I do not understand why you do not do something relating to your eyesight; why it’s never an issue in your life.”

Kelvin “*and I didn’t understand what he meant, but I think it sunk in at the same time that I never did anything for myself around my eye sight. I never acquired any visual aids, so that I could go and watch the football. I went as I was and couldn’t see and asked people what was going on, and they’d eventually get pretty irritated. So I wouldn’t ask and I’d suffer quietly, either way it wasn’t very pleasurable.*

*“And I guess that was the pattern of my life. I didn’t do things that were appropriate to me and not looking after myself in terms of my eye*
sight was a symptom, or it showed me how I was unaware of my own needs. I didn’t know them or didn’t feel that they were worthwhile perhaps. It was a pattern of behaviour that did not allow me to accept myself as I was, thereby fit like everybody else.”

“So I never knew how to deal with problems in my life and my eye sight was one of them, which is really a simple issue. It’s a physical difference from other, from normal people. It can be dealt with by physical means, such as aids, so that you can better your situation. And to want more is asking too much, and that’s not having a realistic view of life.”

Kelvin explains that because he could not deal with the problems they all tangled into one, and he didn’t know what was the problem.

**SEPARATION and BELONGING**

At the school for visually impaired Kelvin saw blind people he perceived as happy.

Kelvin “So I used to think if I was blind I would be okay, I’d fit in. But in that situation I was too capable! I was restricted because I could do too many things, like riding a push bike fast, and it’s too dangerous for a blind person to do that, and because I could it created a dilemma for those in charge. The others wanted to do it too.

“So on the one hand, by being capable, I was being deprived within the school system, so I yearned to get out of that. Then with fully-sighted people I was confronted with not being able to do things as well, or poorly.

“At secondary school I sat up the front and that was about as much as I did for myself. It still meant that I could only read what was directly in front of me, and if I couldn’t read it I wouldn’t let the teacher know, and I’d copy other people’s work later if I got around to it. I developed really cunning ways to get things done if I could. But in the end, I would not front up to things. I’d just not do them and try not to get caught. I didn’t want to be different then. I wanted to be like everyone else.

“I remember going to the principal, and got one of my class mates to transcribe a book for me onto tape so that I could keep up with the work. But I wouldn’t go into the library and read, listen to the book, because I didn’t want to do it in my own time. So I didn’t even help myself that way.”

Kelvin mixed with his peers in the local neighbourhood, as a teenager. Some teased, and at times he felt he was not understood.

“Yeah, I can manage,” was one of Kelvin’s mottos. “That made me different,” Kelvin continues, “I said, yeah I can manage when I wasn’t managing well.”

40
SELF WORTH

"As a child I'd taken on things that weren't true. The negative images separated me from other people. It wasn't my vision that separated me, it was the way I viewed myself that created the problems. I was bad and God didn't love me. It was specifically a church thing that caused that.

"And the only time I felt really good was the first time I got drunk, and I felt oh wow, this is what I need! So I wanted to feel good again. I couldn't just be and alcohol and drugs changed that feeling. It took the fear away for a while and I found I could act free with my anger? I'm not ashamed of my life or where I went.

"I couldn't have been any different because of my self worth, so I was never going to change the way I dealt with my visual impairment until I love myself enough. That's why it didn't mean anything to me in terms of my direction in life.

"I'm dealing with difficulties at the moment. I've taken on a business, which is like a step forward. Personally I accept myself pretty well these days as a whole person, a whole member of the society. I'm able to handle my faults and the things I do not do very well, and the fact that I could still do things for myself, around my sight. Like I sometimes do not let people know that I do not see well, because I just do not want to deal with it. And I accept that. I do not feel guilty or lesser for it, it's probably just a bit of arrogance, like stuff you! I have got to confront this everyday, so I do not confront it everyday, but I know it's there. And over time it has been confronted and dealt with.

"I'm feeling a bit emotionally stressed at the moment. I'm not feeling all that worthy, but I go through that and all of that passes and tomorrow morning I'm feeling fine."

WHAT ARE YOU TRYING TO PROVE

"It's been said to me, what are you trying to prove, and I couldn't relate to, I couldn't understand, so there is a role. You become aware of things because it's forced upon you. I've had to seek a spiritual understanding of what is going on in my life, including my visual impairment. And understanding that it is permanent, that's mine, regardless of whether I cope in the world with my physical or emotional disability or not."

SPIRITUALITY

Kelvin shared his understanding of the deeper meanings than the physical life: caring, to love, compassion, know forgiveness, "experiences pretty essential to being a whole person."

"It's a spiritual significance. You know that behind everything there's the angels' hand, delivering divine gifts. In so many writings, wise
people talk about suffering and how it's good for you and there's something in it. That's the spiritual side of life, that you only receive a gift if you're open to see it. And you can't see it because it's not physical, and it comes out into my insights into myself; how I am as a human being, to understand why I behave the way I do. If I didn't have the pressure of not being like everyone else, I'm sure I wouldn't have looked and wanted to see what was behind things. So it's a gift, divine in itself, to experience disability.

"And wholeness in society is usually seen as being mentally and physically capable. If you're physically and mentally capable, you can be very quick and fast and clever and productive, but it can cover up a spiritual and emotional lack. You can analyse and carry on a conversation really easily and argue something that doesn't really exist. But if you're living a spiritual life that's where the wholeness stems from."

"The big turning point in my life was when I joined the Baha'i faith. It talked about the oneness of God,

the oneness of humanity,

personal investigation of truth,

equality of men and women and abolition of prejudice,

the union of science and religion,

and principles toward world peace and unity.

The personal investigation of truth and the reality that we are all one.

"I was attracted to those concepts and the healing power of the creative word of God. That was the beginning of my spiritual opening up to things and has influenced the way I've gone."

RECONCILIATION

I then asked what are your passions and where do you see the need for social change?

Kelvin said he yearned for a family and had a recurring vision of two birds that flew into the sun. He met a lady with good energy, but learnt to wait, not just act on impulse, acknowledging that it was a friendship.

He believes the birds symbolised them going into the sun together, the higher and lower self. The reconciliation was the meeting of physical and spiritual.

"Problems are good, it's not knowing how to deal with them that is the problem. It stuffs people up. It's not trusting. It's probably trust that's the biggest thing in me, so the more I trust myself my own feelings and my capacity to interpret what I experience, and follow that
and act on that, the better things go. It takes away the fear of failure and it's ongoing. I might have a small success or a big success. Once you get that you're onto the next. You've got somewhere to go.

"It's ongoing. It's attainment and growth. For social change there's so much that I've had that I believe you do not have to experience. If we understood better who we are and live according to that, not to the fantasies and illusions of what we are.

"A lot of the process I'm going through is finding out who I am and so what my needs are, but also smashing the illusions I have of myself. If I have an inner experience I start to sense inner change going on and it might come out in drawings, relationships. I get a sense of things happening in and outside myself that I do not have control of, but simultaneously I interpret that my ego has been influenced.

Kelvin said that as a child he felt hollow, of no substance. Now he accepts his meaningful qualities of perseverance and patience.

3.4 Conclusions

There are two features of significance that are evident in the above stories.

1. The unique and diverse ways that individuals deal with daily stresses.
2. That adjustment to stresses is an ongoing and fluctuating challenge.

Such features are honoured by the action researcher because the aim is not to generalise and categorise. Our aims appear similar, to work with our self-acceptance and feeling confident with a physical disability. The learning is about the different ways that people adjust and deal with stresses. To honour the fact that there are multiple ways to approach a problem. Kelvin stressed that "the problems are good. It's not knowing how to deal with them is the problem."
CHAPTER 4

Myths, Distortions and Understandings. 
A Critique of Theoretical Perspectives on 
the Impact of Visual Loss.

4.1 Introduction

In this chapter I focus on theories of the impact of visual loss on people’s lives. I chose influential theorists, dating back to Choldon in the 1950’s, to recent researchers who have published in the Journal for the Visually Impaired. Cross referencing showed how modern theorists were influenced by their predecessors. I also considered the personal values and backgrounds of the theorists, as their beliefs do affect their perception of visual loss. For example, Monbèc’s Jungian beliefs can be seen at work in his blaming blindness for a loss of individual power, control and creativity and seeing symbolism myths and folklore as providing negative stereotyping.

I challenge all such statements and definitive explanations of visual loss. I view all the theories as educated guesses, and so speculative and open to personal bias. The title of Monbèc’s book is “The Meaning of Blindness.” The book is then written from a Jungian symbolic perspective. The book should be retitled “Monbèc’s Perception of the Meaning of Blindness.”

The impact of visual loss is a complex issue. It has been compounded by centuries of myths, misconceptions and contradictory theories. By trying to define and clarify, many theorists have developed simplistic, narrow views. My argument, that the impact of visual loss depends on a personal perspective can be challenged because it is accepted that humans are visually oriented creatures, relying on sight as the primary sense. Therefore, the loss of sight will have a dramatic effect on one’s life.

I am not arguing against sight as the most important human sense. Our colloquial language often reflects its importance; I’ll see you tomorrow. Do you see what I mean? When a person loses a lot of sight they do not change such language to I’ll hear you tomorrow. It is categorising and classifying the impact of visual loss that I challenge. It must be respected that people deal with loss in different ways at different times and this alters the impact.
My present situation is an example of how the impact changes. I needed assistance to use my talking computer. To obtain help from the Royal Blind Society I needed a vision test. The test showed that my sight had halved in the last year. My sight has been stable for the last decade and so this was a shock. I had not noticed any deterioration. I considered it an aberration and so returned a fortnight later, and the same test results were obtained.

The test results had a big impact on my life during September 1994. I had to face the possibility of losing all my sight. I began to observe the effects of the decrease in sight. I could not recognise faces as well as before. It is now much harder to read even large, black print.

The interesting aspect is that I only became aware of the further visual loss because I went for an vision test. I was not expecting any change in visual acuity. This experience highlights the importance of adaptation and adjustment. I automatically peered closer, wrote in larger print and was unaware of the visual deterioration. The impact was much more onerous on hearing the test results. I then had to deal with my fears and emotions. The experience has made me acknowledge how much value I place on my remaining sight. Bill Casey, manager of the North Coast Region R.B.S. provided motivation when he explained that "We work to reach the potential with the sight you have left." This shifts the focus from loss to the capacity to adapt, and develop competencies.

Do humans have a universal obsession with sight? Theorists need to ask this question. They need to recognise the broader context of their theorising. They need to recognise their own fears of going blind and how they discriminate. What value do they place on full sight? Who paid them to research visual loss, an independent organisation or an agency providing services for people with visual loss, and how does this affect their results?

Often theorists aim to educate the public, to remove discrimination and facilitate understanding of visual loss. By using a positivist approach they separate the researcher from the researched. People with visual loss become the subjects, to be researched on. Variables and attributes are chosen to find patterns and trends. They often do not differentiate between the person and the conditions of visual loss, the lack of sight and the lack of opportunities. They concentrate on an analysis of blindness, rather than the potential of the person (Rowlands 1985).

So they perpetuate the negative stereotypes of visual loss. People with visual loss are viewed as problem saturated. The theories associate independence with full sight, and independence is placed on a continuum from independent to dependent (Lukhoff 1973), from visual loss as a disaster (Carroll 1961, Cuttsforth 1951), to a minor inconvenience (Fernigan 1970). Both are extreme views that over-dramatise or trivialise visual loss.

Our perception must metamorphose from problem saturation to the way people with visual loss adapt to extra daily "stresses" (Loenfeldt 1974). We need to respect the whole person, who experiences some physical limitations.

45
due to visual loss. The impact of visual loss varies from day to day and person to person. People with visual loss need to become egalitarian participants in the research process.

There are some truths in the range of theories as listed below. In isolation they are narrow and misleading. I view most theories as value laden and question so-called facts.

4.2 A Phenomenological View of Blindness

Rowland (1985) has the advantage of having been both a client who is blind and service provider for people with visual loss. He challenges the preconceptions of blindness and argues that we must suspend prevalent interpretations and develop personal interpretations of blindness.

I concur with the three levels that Rowland confronts: rehabilitation, stereotyping and theorotyping. He suggests that rehabilitation should be individualised and focus on assertiveness, self-reliance and versatility. I question whether rehabilitation has fulfilled these requirements in Australia since 1985.

Rowland blames stereotyping on a hierarchical system that views the people with visual loss as a needy group, who have to be helped. He argues that it is in the interests of the "system" to encourage a uniformity of behaviour. This conformity reinforces the image of dependent clients who rely on the "system". This dependence also ensures job security. The service providers see a lack of variety and so view blindness as a drawn out struggle (Rowland 1985).

I argue that centres like the Royal Blind Society are still hierarchical and huge systems, but are they being compelled to change? Are individual users insisting upon being treated as individuals. Every time I have used the services of the local R.B.S., all my requirements have been met, respecting me as an individual. It is important to note that the local branch is very small and friendly (compared with the Sydney service that has the size and layout of an institution).

You must obtain a security tag on entering the Sydney R.B.S. To obtain services you often have to move from one specialised department to another. Each department has different procedures. However the services are becoming more "user friendly". R.B.S. has had ongoing reviews of its different departments and positive changes have been made. Clients have been involved in providing constructive criticism and recommendations for change. For example, I asked that the publisher and date of publication be announced at the beginning of each talking book. This is now being done, so it is easier for people to purchase the printed copy.

The National Federation of Blind Citizens of Australia (N.F.B.C.A.A.) is an independent agency. It also reviews and monitors services provided by agencies such as R.B.S. Early in 1994, a review was done of the
library services at R.B.S. A positive change has already occurred; when a tape book is part of a sequel, the R.B.S. library now sends book one of the sequel first. This often did not occur in the past and I found it frustrating.

Rowland stresses the need to widen research from mainly technical or mobility-oriented to an attitudinal, socio-economic focus. This would appear to be occurring, as I found in my literature searches abundant recent articles on social and attitudinal research.

Is there a danger with the use of statistics? Like Rowland, I am sceptical of many statistical reports that are used to prove the need for change. Results depend on what questions are asked and on what questions are omitted. Statistics aim to find general patterns and universal answers, and in so doing underestimate the importance of individual experiences. The results of the following two hypothetical questionnaires illustrate some of the above-mentioned problems.

A large sample of R.B.S. library clients, over the age of seventy, were asked if they would like a wider range of titles or a choice of talking books. The results suggest that a wider choice of titles is required. From this, the researchers conclude that in the group sampled, people spend a lot of time reading talking books. Another questionnaire asks the same age sample of clients what problems are being experienced with the talking books. Two problems are identified by a large proportion of the sample. 1. That they are experiencing hearing as well as visual deterioration and so listening is difficult. 2. They do not feel comfortable with machines and find the four track talking book machines confusing. The researchers do not recommend an increase in talking books and titles, rather an investigation of alternative passive recreation.

Rowland blames science for the image of blind people as problem saturated. He argues that while science uses people with sight as the yardstick for measurement, the blind will always fall below the norm. The consequences are that science tends to blame the condition of blindness for all ills. He cautions against theorotyping: The researcher writes a paper with a definite theory about the impact of blindness on a person's life. Other researchers critique and test the theory. Over time the theory is discussed and eventually can be perceived as a fact, an 'established truth' or 'authority.' (Rowland 1985 p. 45).

Much sociological research is carried out on blindness and its impact. I also concur with Rowland, that theorotyping has its dangers. Recent researchers must question themselves: What is fact and what is theory? What personal preconceptions are affecting my interpretations? Am I assuming that all people who are blind will react in the same way to daily stresses? Am I differentiating between the condition and the individual's way of adapting? Even though Rowland's book is a decade old, it raises important issues for those researching blindness.
4.3 Victim Theories

Perceiving people with visual loss as the victims has evolved from a range of factors such as fear of blindness, myths and misconceptions, discriminatory attitudes and the extra stresses experienced by people with visual loss. I argue that theorists often exacerbate this image of the victim by concentrating on the problems caused by visual loss.

Most of the autobiographers I have referred to in this thesis have emphasised the need for independence, to be seen to be coping well. It could be argued that because they wrote autobiographies they had something to say. They were working through the confusion of dependence and victim interdependence, and being responsible and super independent, and denying physical limitations. This is an ongoing process for most people, but particularly those with physical or psychological disabilities.

I highlight the ability to adapt appropriately, rather than the stresses experienced, but emphasise that the capacity to adapt fluctuates. Amanda shared that "Each new situation can potentially bring up a whole set of readjustments for you." (taken from the tape enclosed in this thesis). Kelvin shared that in his early life, "It wasn't my vision that separated me. It was the way I viewed myself that created the problems." Kelvin now acknowledges his needs more, sometimes he decides not to tell people about his visual loss and does not worry about that decision. The process of adjustment is an ongoing process and so most generalisations or classifications of the impact of visual loss are misleading and distorted.

The N.F.B.C.A.A. is a professional organisation. It provides advocacy and consumer services. It presents people with visual loss as people who can obtain the same employment, education and rights as people with full sight. It is a professional political body that challenges any image of people with visual loss as the victims. It liaises with similar organisations around the world. Such bodies are affecting government policies, legislation, the service delivery of agencies for people with visual loss and public understanding of the impact of visual loss.

Perceptions are important because they have such implications on the way we make decisions and act. If the prevailing image is that losing a lot of sight makes one dependent, and often the victim, this fosters patronising attitudes and rescuers.

The loss or disaster model was made popular by Father Carroll (1961). It emphasises many major losses (as listed below) and blames blindness for this "catastrophe".
LOSSES CAUSED BY ADVENTITIOUS BLINDNESS IN ADULTS

- Body image
- Visual background
- Appreciation of visual beauty
- Light security
- Techniques of daily living
- Relating and communicating easily
  - written, spoken and reading
- Recreation
- Personal independence
- Physical tone
- Self esteem
- Whole identity

FIGURE 4. Summary of Carroll’s Analysis

I have experienced each of the losses described by Carroll, but my attitude has always been – “How do I overcome this barrier?” Carroll argues that adventitiously blind people need to experience a dying to sight. Adjustment is the rebirth to a changed life of blindness. I question whether Carroll’s religious vocation, as a Catholic priest, imposes this doctrine of death and rebirth. It erroneously associates the eye with the “I”, so that visual loss is automatically connected to a loss of personal identity.

People with visual loss are stereotyped as victims by stressing that it was not the poignancy of lack but the pain of loss (Carroll 1961). Carroll stresses the need for true sympathy, help and love. I stress empathy, self help, self-acceptance as more important prerequisites for positive adjustment.

The loss model, highlights the negative impact, and perpetuates the stereotype of blindness: the helpless or pitiful or heroic blind image. Reading Part One of Carroll’s book exemplifies the fears and emotions around blindness. We cannot deny that humans are visually oriented creatures, but is Carroll underestimating the adaptive skills of the human? Like many theorists, is Carroll unaware of the significant value he places on sight?
A dying to adult independence and a return to the immobility of creeping dependence of childhood or a forced entrance into the slow, shuffling dependence of old age (Carroll 1961).

This implies that independence equals full sight. It also evokes a stereotype image of old age as a return to dependence. It would be more appropriately described as a process of developing new skills and learning to ask for help with dignity, and being assertive when people are over solicitous. People who lose sight adventitiously, will probably need to develop patience and organisation, but the predisposition toward dependence or independence will be affected by multiple factors, particularly personality traits. (Wright 1983) and Goffman (1968) argue that the disability can simply be used as an excuse to avoid responsibility, in a person who has a predisposition toward dependence.

I could write a book with one hundred losses experienced by people who lose sight as adults, but it is devaluing the important and positive issue; people's ability to adapt and modify attitudes and actions. This modification is an ongoing challenge, emphasised by most of the autobiographers I read (sharing the impact of visual loss on their lives) and the collaborators Amanda and Kelvin.

I agree with Carroll's notion that people with visual loss are faced with the competing forces of the desire for independence and its freedom, and the desire for dependence and its security. The issue is whether all people confront these opposing forces. Are some people with visual loss more motivated toward an inner independence? Some theorists measure people's visual loss on a scale from: "Minor inconvenience to insurmountable problem." Is this patronising? Does a sense of self confidence fluctuate and so affect whether a person feels dependent or independent?

It must be agreed that blindness is indeed a most severe handicap. It is awesome in its multiple effects. It touches on all normal, external activities. It reaches close to the innermost core of personality. It is devastating and almost catastrophic (Carroll 1961).

Carroll admitted that humans fear blindness. The quote above would reflect Carroll's fear. Is it the fear that paints blindness as a catastrophe? Is it the fear that needs to be challenged? Blindness needs to be seen with its realistic limitations and our ability to adapt.

Monbec (1973) also explores the meaning of blindness, but in contrast with Carroll says that we need to distinguish between the real and irrational problems and limitations of the blind, and focus on what they can, or cannot do. He argues that sight is overvalued and explores the implications of sight loss from a Jungian, symbolic perspective.

Monbec challenges the more scientifically precise and exclusive definitions of attitude, because of the inherent bias toward viewing attitudes in only one way, and limiting the possible origins of attitude to one particular source (Monbec 1973 p.3). Monbec could be accused of this same narrow view. Like
Carroll's loss model, he concentrates on one theory of explanation for stereotype attitudes: folklore and symbology. He sees today's attitudes as a cultural evolution, that has distorted perception.

"... they view the world differently. Because they can't see they think differently. And how do they think? How can they organise things? Blind people are thought to be more contemplative and inner-directed than average people. To be given to abnormal ways of thinking and behaving and therefore, to be to some degree maladjusted." (Monbect 1973 p.15).

Monbect blames an undervalued, irrational element in the attitude to blindness and blind people that persists even with facts and education; that blind people are 'fascinating' and have a 'bewitching effect' on sighted people.

It is this idea, that blind people are mysterious and that blindness has certain magical or secret aspects that forms the corner stone of all the other attitudes toward blindness (Monbect 1973).

Is Monbect overstating the resistance to societal change? Monbect argues that people often react negatively to people with visual loss because of the prevalent dominant perception of blindness. The condition of blindness is feared and not understood, and, when interacting, people see the "blindness" and its associated connotations. Therefore we need to shift perceptions; see the person and not just the disability. People with full sight need to revise their expectations of people who are blind.

I would argue that there is a simultaneous need for people with visual loss to review their own stereotypes, role and expectations. I have been fascinated, but shocked by my own stereotypes as I became aware of them during this research process.

Both Carroll and Monbect create a perception of blind people being the victims. Carroll emphasises losses and Monbect emphasises stereotypes ranging from the foolish, weak, evil to heroic and magical. The symbology of light and positive equals sight, dark and negative equals blind. FIGURE 5 below summarises Monbect's analysis.
Common Myths and Symbolism Related to Blindness

<table>
<thead>
<tr>
<th>LIGHT</th>
<th>DARK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guidance and confidence.</td>
<td>Fearful.</td>
</tr>
<tr>
<td>To be sought.</td>
<td>To be avoided.</td>
</tr>
<tr>
<td>Consciousness.</td>
<td>Unconsciousness.</td>
</tr>
<tr>
<td>Mental and spiritual illumination.</td>
<td>Ignorance.</td>
</tr>
<tr>
<td>Creation.</td>
<td>Death.</td>
</tr>
<tr>
<td><strong>To see is to:</strong></td>
<td><strong>Blindness is associated with:</strong></td>
</tr>
<tr>
<td>Understand and recognise.</td>
<td>Sullen and evil.</td>
</tr>
<tr>
<td>Learn and have insight &amp; culture.</td>
<td>Destructive of knowledge and culture.</td>
</tr>
<tr>
<td></td>
<td>Castration, punishment and loss of potency.</td>
</tr>
<tr>
<td></td>
<td>Blindness = Loss of Identity.</td>
</tr>
</tbody>
</table>

Eye = "I" = Identity.

FIGURE 5 Summary of Monbec's Analysis

We cannot just blame stereotypes and symbols for society's resistance to change negative attitudes to loss of sight.

...the over insistent pitters and helpers of blind people are reacting to projections, that are their own sense of inferiority and helplessness (Monbec 1973).

Monbec's Jungian bias stresses that our resistance to change is because symbols, mythology and folklore are fixed in the subconscious, and we understand that blindness symbolises a loss of power, of individual creativity, of control. It also symbolises the terrible sacrifice that is often necessary for certain gains in knowledge, insight, revelation or growth. To him that is symbolised by blindness as the loss of his own identity, of his sense of who and what he is, in short the death of his consciousness (Monbec 1973 p.143).

In the loss of identity Monbec is supporting the loss model. So Monbec's thesis depicts insurmountable barriers to social change, this then is precisely where the difficulty lies, for what is encountered in the projection is that which the individual is unable or unwilling to identify as his own. It is in short from his unconscious (Monbec 1973 p.154).

Hence, a Jungian interpretation says there is no point in telling people their belief is nonsensical. It is nonsensical, but only in as far as
it refers to actual blind people. Symbolically it is quite accurate (Monbec 1973 p.154).

Monbec argues that it requires a great deal of self awareness and moral courage to recognise the projection and make its contents conscious, because this process is often 'disagreeable and painful'. (Monbec 1973 p.154).

Monbec's solution is to present the blind person as a happy, productive and responsible member of society (Monbec 1973 p.151). He argues for positive media presentations and rehabilitation that show people who are blind, going about their normal routines, and provide information on more positive interactions between people with visual loss and those with full sight. I question the happy, responsible and productive member of society. Why happy? Is this equally as condescending as negative and miserable? How do we define productive? If it means earning and acquiring as a capitalist norm, what about the increasing aging population? This is the growing population of people with visual loss, and many are retired and past the common definition of "productive".

While we are stuck in a reductionist connection of cause and effect we can blame visual loss or myths and symbolism on maladjustment. Scott (1969) argues that the common stereotype of the helpless, dependent blind is a consequence of socialisation. If we treat the blind as dependent, and so over-protect, they cannot develop the necessary skills to function in a visually oriented world.

Like Carroll, Scott sees blindness and the blind as a problem, but his emphasis is more on sighted people's reactions and the ramifications of these, rather than blaming visual loss itself. He aimed to overview the problems experienced by American people with visual loss, the effectiveness of intervention and consequences of these people becoming clients of service agencies.

The disability of blindness is a learned social role. The various attitudes and patterns of behaviour that characterise people who are blind, are not inherent in their condition but are acquired through ordinary processes of social learning. Thus there is nothing inherent in the condition of blindness that requires a person to be docile, dependent, melancholy or helpless or anything about him that should lead him to become independent or assertive. Blind men are made and by the same processes of socialisation that have made us all (Scott 1969).

Scott argues that an individual perceives others' evaluations, internalises them and learns a set of roles that becomes the personal identity. Hence the blind wonders: How am I supposed to feel? Am I different or like others? The blind person thus becomes aware of the rewards of conformity and sanctions. Scott stresses the socialising influence of large agencies that offer services to blind people, that he describes as complex, bureaucratic structures.
The distinctive feature of much of this role learning is that it is overt and goal directed. Its explicit aim is to instil in blind people certain model behaviour patterns and attitudes (Scott p.19).

In his theory of socialisation, Scott makes a series of claims.

- That the blind can internalise stereotypes or reject them, but not ignore them.
- We are all affected by social identity, so the way a person looks or their behaviour gives us some clue to their identity.
- There is a lack of accepted norms and so confusion of roles between blind and sighted people.
- There is a lack of reciprocity between sighted and blind, so the sighted tend to avoid interactions because they do not bring many rewards. Therefore, blind people find it difficult to develop enduring associations with the sighted persons who are otherwise their intellectual, psychological and social equals (Scott 1969 p.37).

I would broaden this cause and effect analysis to include the effects of institutionalisation (for example, boarding schools and sheltered workshops for the blind that were much more prevalent in Scott’s days), and individual personalities. He describes a manipulation where the blind must disavow their disability or have power and wealth to overcome the stigma.

The socialisation model ignores the capacity for self determination in people with visual loss. Society is blamed for maladjustment, but people with visual loss are still being stereotyped as victims.

Hough Kim (1970) describes a “universal phenomenon of the blind” in America, that creates mental and moral characteristics from stereotypes. He distinguishes between people with visual impairments and those who are totally blind. People with visual impairments can hide their disability and choose to belong to the blind sub-culture or the sighted world, but be marginalised in both (Hough Kim 1970 p.16).

It is relevant to note that Scott researched for an independent company, Transaction Books, and Hough Kim researched for the American Blind Foundation. They developed contrasting interpretations for why people who are blind tend to socialise in a sub-culture. Scott (1969) proposed that many agencies for the blind encouraged or perpetuated the stereotype of helplessness by offering accommodative rehabilitation, to ensure the continuation of the agency staff jobs. Therefore, the agencies can be seen to foster the blind sub-culture.

Hough Kim proposes that sub-cultures often have attitudes that are negative, hostile and stereotyped. Hence the blind sub-culture is a reaction to the sighted world and its exclusion of the blind world. People with visual loss are still perceived as the victims and have the added negative stereotype of persecutors. Both theorists were researching the same phenomenon of subcultures and socialisation and provide different interpretations. Hough Kim
places more blame on people with visual loss for their alienation and discrimination from people with full sight.

"Blindness, like all other forms of physical disability restrict certain behaviours and functions of the person afflicted by it. The social effects of sightlessness however, extend far beyond those areas where sight is essential to adequate functioning, involving the total social life of the person" (Hough Kim 1970).

I challenge the word afflicted, which connotes pain or troubles. The Oxford Dictionary gives gout as an example of an affliction. I also challenge whether stereotypes affect the total social life of blind people. Hough Kim is another problem oriented writer. His cause and effect approach argues that the promotion of stereotypes creates a reaction by "the blind" group of society. This in turn colours interaction and creates social distance and self closure by minority groups such as the blind. Minority groups then create sub-cultures.

Have all the victim theorists ignored the influence of personal proclivities? Do people with visual loss react to stress according to their personal proclivities? That is, if they tend to be dependent, a physical disability could be used as an excuse to pander to that dependence. Hough Kim generalises whole minority groups saying that their attitudes toward the majority community are often negative, hostile and stereotyped, to the extent that they are rejected by the former. He trivialises the many factors that will affect how a blind person will deal with being stereotyped by generalising sub-cultures.

He describes powerful and wealthy blind people and people with visual loss as aspirant groups, who aim to be accepted by the wider community. What about self contained, satisfied people with visual loss, who do consider themselves part of the wider community, or those who do not feel marginalised or aspire to assimilation? Or those who have developed the satisfaction of self acceptance and are no longer aspiring? Would Hough Kim call these people the anomalies?

"It is we who have brought on our own identity crises by renouncing and repudiating our identity as the helpless blind. It is we who are demanding that we be called by our rightful and true name such as competent, normal and equal" (Jernigan 1970).


"We have won it by finding our own voice, finding our own direction and finding our own doctrine. That doctrine may be simply stated. It is that the blind people are normal people who cannot see. It is that blindness is not a dying but a challenge to make a new life" (Jernigan 1970).

Jernigan's revolution for people with visual loss is independence. His articles are powerful and stimulating to read but have the revolutionary
overtones. He assumes to be talking for blind people. I contest his aspiration toward the normal and stress the paradoxes:

- The balance between denying the impact of a disability by striving for total independence, and asking for appropriate help and acknowledging physical limitations.
- Honouring the unique individual and sharing common stresses and ways to adapt to visual loss.

The charismatic style tends toward paternalism. One voice supposedly representing the views of diverse personalities.

The book, Stigma, Notes on Spoilt Identity, by Ervin Goffman (1968) is an example of my concept of the vicious circle. It was one of the first books I read in the research process. I reacted to the cynicism and cause/effect interpretation. Does Goffman have a pessimistic view of human nature? He describes a judgemental society that automatically stigmatises any person deviating from the perceived norm. The perceived deviant then reacts to this judgement, so creating a vicious circle. Is this vicious circle a fixed state? Are humans intransigent?

Goffman assumes a status of normal and says the stigmatised person must know their role and place. There is a limited and conditional acceptance by the normals. So society puts people apart as less than human, and the stigma code becomes, I’m not different (Goffman 1968).

Goffman draws heavily on vignettes and other writers, to highlight the uneasiness of interaction between the stigmatised and normal, the concept of discredited and discreditable, the accepted and rejected.

I took umbrage at Goffman’s vicious circle, and had to put the book aside for months. After re-reading the book, I still reacted and asked more questions. Is this book telling truths I cannot accept? Is my idealism conflicting with Goffman’s cynical style? I feel that Goffman’s cynicism has coloured his interpretation of stigma. His critique does not offer alternatives or potential for social change, but concentrates on the strategies used to disavow stigma or avoid the stigmatised.

The stigmatised individual chiefly and unselfconsciously accepts himself essentially the same as normals, while at the same time he voluntarily withholds himself from those situations in which normals would find it difficult to give lip service to their similar acceptance of him. Since the good adjustment line is presented by those who take the standpoint of the wider society, one should ask what the following of it by the stigmatised means to normals. It means that the unfairness and pain of having to carry the pain will never be presented to them. It means that normals will not have to admit to themselves how limited their tactfulness and tolerance is, and it means that normals can remain relatively uncontaminated by intimate contact with the stigmatised and relatively unthreatened in their identity beliefs. It is
from just these meanings in fact, that specifications of a good adjustment arrive (Goffman 1968 p.147-8).

Goffman is didactic and indicted all of society. He made me question my own stereotypes, my own concept of adjustment. What people do I avoid and why? Do I try to protect people by accepting oversolicitous help? Reading autobiographies by people with visual loss helped me clarify these questions. Goffman's cynical world view helped me question my optimistic world view.

I do not debate the notion that there is often an interaction unease between people who are seen as normal and those seen as stigmatised. I do challenge the vicious circle concept. The stigmatised people do not have to remain the victims nor become the aggressors.

If people with visual loss want to improve interaction they need to develop that spirit, essence, inner strength of self acceptance, recognising that the inner strength will wane and grow with life's cycles.

My world view is the antithesis of Goffman's vicious circle. He has stigmatised people continually judging, deciding what strategies will work and how to manipulate the situation. I argue that the stigmatised people can develop the self-confidence to challenge what is normal; to challenge the dominant culture that aspires to the perfect physique and affluence. The assumption underlying my thesis is that strengthening self-acceptance and understanding personal identity will help to de-condition the individual and remove the unease of interaction. I am experimenting with this process. The quality of my life has improved because I am more realistic about what extra needs I have as a person with visual loss.

I began this process many years ago when I realised that ticket attendants would not believe that I had a visual loss. I did not fit the stereotype image and often felt defensive, having to prove myself, when showing my blind pass. I wrote the story, "The Impersonator" to help me clarify the process. The guilt disappeared and I realised it was their problem, and I used the interrogation as an opportunity to educate.

It is well appreciated that in small, long standing social circles, each member comes to be known to the others as a 'unique' person. The term unique is subject to pressure from maiden social scientists, who would make something warm and creative out of it (Goffman 1968) pp.73-4.

Goffman uses cynical terms such as a benevolent social action Goffman (1968 p. 30). He contests that each individual has their own essence or core, a view which is fundamental to my world view; although, I also encompass the paradox that we are all unique and yet also the same. We need to accept the opposites and contradictions with optimism.

Can we maintain positive ideals if we perceive society as diseased? English (1971) suggests a diseased society, where social stigma is a symptom. Without stigma there would be less disabilities as the task of rehabilitating an
Amputee would involve little more than surgery and prosthetic fitting. The shame, embarrassment and interaction uneasiness happens because of stigma and stereotyped attitudes. However, English does promote bringing about an improved situation, through -

- educating people who experience stigma on how to deal with it,
- making television soap operas more responsible and not perpetuating stigma,
- educating people to be more aware of their discrimination,
- and advocating the ongoing evaluation of professional staff and agencies.

Stigma is a problem of overwhelming proportion, where realism blurs with pessimism and where it is easy to despair and collapse into a state of hopelessness. Functionally this can be avoided by developing a case of therapeutic tunnel vision, including the identification and concentration of energies on a single, potentially realisable objective (English 1971).

English argues that society should change as a whole, to develop egalitarian relationships between the disabled and the able, with a process and sharing that is mutually rewarding. The challenge is to work out what methods are appropriate. How do we de-stigmatise society's attitudes? We need a holistic approach that is already occurring - from a personal, public, private and governmental level. For example, the Disabilities Discrimination Act 1992, the N.E.B.C.A.A. and its advocacy and information services, Local Council Access Committees, which monitor and improve access to shire buildings, parks, toilets, paths etc. and individuals who ask questions, challenge stereotypes and interact with people with disabilities.

**SUMMARY**

The limbo status can create a confused identity. The person with a disability may often act a role of pretence, so that the energy and determination to prove herself counteracts positive independence.

*In the Source book for the Disabled,* Gloria Hale said that most people want to manage on their own and experience the freedom of choice that independence offers, but not if *it is independence for independence sake.*

*In modern society an individual's ability to be self sufficient is usually encouraged from childhood. By the time we are adults, we are supposed to have learned to depend on ourselves, to be as quick on the draw as the next person and to be ready to hold our own in a more or less hostile world. Independence is also considered a civic virtue, for self reliance means pulling your own weight, paying your taxes and not being a burden on your hard pressed, fellow countrymen.*

Economic rationalism says that every person must be productive or they are considered a drain on the tax payers. We need to change values of
economic worth to considering every thing and person on its intrinsic value. We need to de-myth the myths.

The individual experiencing a limbo status needs to find the balances between the contradictions, to acknowledge that no matter what happens to the body, we still have an identity and a self worth.

Common contradictory images of people with vision loss that I have observed

saints     sinners
heroines  helpless
wise      stupid

Gloria Hale suggests we need to use more common sense.

Common sense is nevertheless something which people with disabilities should try to develop to the full. It takes common sense to know when to ask for help and when to turn it down, when to say 'Let me try' and when to say 'I can't do it.' It's common sense to save your strength for important things and to recognise the things that are important. It takes common sense to acknowledge your physical limitations and to know when to discount them. It takes common sense to know when a failure is due to your disability, and when it's due to a failure in yourself. Above all it takes common sense to know when to suffer thoughtless remarks in silence, 'How on earth do you bear it? I'd die if I couldn't walk, see, hear, think', and when to retaliate.

I believe that personal and social change can occur in a plethora of ways. Common sense and intuition are essential and empowered with the intellect to develop constructivist knowing. Even the word disability needs to be scrutinised and understood. Do we all have disabilities of some sort? The important issue is how we deal with these disabilities and the extra stresses they create.

I finish this section with a song I wrote last year. It expresses my empowerment and the growth of my inner independence. The song is saying that if you acknowledge your contradictions you can reconcile them or accept them. The chorus blends work, play, the individual and the group to create a space for quality living.
LET'S START A SCHOOL FOR ECOLOGICAL RETRAINING.

A sensitive, new aged womin,
Is a multi skilled raconteur,
An intellectual peasant and mother
and an expert woodchopper.
I started in the comfortable suburbs,
With a Commodore and Country Road clothes,
Friday to the theatre and cafe
and Sunday out on the road.

CHORUS.

Let's start a school for ecological retraining,
We'll learn in the wind and sun dance when it's raining.
Womin have to teach a green survival.
So let's go solar and start a peace revival,
We have to laugh and dance and sing
And turn the world into a cooperative ring.
For ecological retraining girls,
For ecological retraining.

I was enlightened on dandelion coffee,
Radish sprouts and fried tofu,
I questioned the patriarchy
And led a capitalistic coup.
I lived in a tent full of insects
Connected to nature's core,
Gas lamp and no running water
and I still put out for more.

Next came a three walled cow bales,
With the rain and the wind and the frogs!
It's a new aged agony and ecstasy,
Dancing on a dreamer's bog,
Now in a mud brick cottage,
Sane behind fly wire screens.
Sharing land with other dreamers,
Still in my cosmic teens, oh yeah. repeat

I'm a wild, new aged womin,
Experimenting with who am I?
Divorced as the sole housekeeper,
On my ecological high,
I grow organic lettuce
and grind wheat into flour,
But I like some sophistication,
So sip port at the sunset hour, oh yeah repeat.
4.4 The Value Placed on Full Sight

Many writers are adamant that sight is the most important sense. By idolising sight, the other senses have been denigrated. Roper (1970) sought to trace the influence of altered vision on the personality of man (sic), and by reflecting on some artists and painters, whose sight was impaired, to harness the nature of this impediment to the nature of their artistry.

Roper is an eye surgeon and I would speculate that he has a bias toward the sense of sight, even more than the average person. He describes the human as a visual animal, and explains that about half of the fibres that extend messages to our brains stem from the optic nerves. We live in a world almost wholly oriented by sight and we seek our food, sex and shelter through information provided by our retinal images.

The sense of smell, which dominated the life of most of our vertebrate ancestors has so shrank in importance that it now gives us little beyond the minor aesthetic pleasure, principally when we are eating, and has a negligible sexual or survival value (Roper 1970).

He is fascinated by the art and poetry of people with visual loss and yet he denigrates the sense of smell, arguing that it is used mainly to identify food. Is food not a creative art? Even if you are not a person who enjoys culinary delights, eating is a survival habit. A sales manager in a large department chain told me that they use pellets in the air conditioning at lunch time. The pellets smell like freshly cooked cakes or biscuits and people are attracted by the aroma.

... a visitor from outer space would discover that the human has scent producing glands all over their body. It is far better endowed with scent-producing organs and produces a lot more odour than its closest relatives ... There would be no failure in your logic if you concluded that the sense of smell and communication through odour was important for that species (Stoddard 1993 p.23).

Stoddard (1993) admits that the reason we produce odour is equivocal, but says it has been proven that mammalian reproduction is under olfactory control.

Are the senses of touch, hearing and smell important for their intrinsic value? The other senses provide joy and aesthetic value as well as assisting in survival.

Can anyone prove that sight is the most important sense for the human, and hence its loss the most devastating? The argument that sight is the most important sense reappears, ad nauseam, in the literature on vision and visual loss. Can we create a continuum of disabilities from least to worst? Who decides the severity of the disability? What affects their value systems and needs? Is the worst or least disabling, the important question? Or is it how each person deals with, or responds to disability?
Vader (1990) explores the value and influence of sight, for the human. I feel the article is reflecting the value that Vader places on vision. The opening three sentences set the tone of the article –

The incredible role that sight plays in everyday life is often never appreciated until it is compromised or lost. The extent to which a person can independently perform the duties of everyday living is, to the most part, related to an ability to see, and interact with the environment. To better understand vision and visual loss, it is essential to understand its value and influence on life (Vader 1990 p.705).

I would argue that the extent to which a person can independently perform the duties of everyday living is related to a complex number of variables such as personal self esteem and self concept, appropriate support from friends, family and professional staff when dealing with a disability, financial support, service and access in the local community. If independent living relies on an ability “to see”, does this suggest that people with visual loss cannot live independently?

This notion reminds me of a public telephone conversation, twelve years ago. I was at a railway station in Western Sydney, and all the telephones were out of order. I rang the Telecom 1100 service assistance, and asked to be put through to my husband.

“You’ll have to read the cabinet number.” the voice said.

“I have less than ten percent sight and cannot read the number.”

“We have to have the cabinet number.” the voice repeated.

“I’m afraid I cannot physically read the numbers.”

“Well, we have to have the number to connect you.”

“So what do you suggest I do?” I asked.

“Haven’t you got someone there to help you?” she asked.

When I said no, she asked, “What are you doing out alone anyway?”

This question reflected the belief that a woman with less than ten percent sight should be chaperoned or stay at home. To move independently, one must have functional sight.

Vader (1990 p.708) argues that The eyes are the facial representation of deep, human needs and longings, and because of their relationship with the nervous system, actually become the transmitter of sexuality. She gives a chronological view of the values placed on sight. The ancient Greeks valued sight in terms of livelihood. The Egyptians had a wide range of medicinal cures, half of which were for eye ailments. The superstitions of the ‘evil eye’ and the ‘third eye’ engendered fear. Parents in modern times say ‘do not sit close to the television or you’ll strain your eyes’. She then discusses how the eyes and sight are associated with art, romance and sexuality.
We are influenced today by an evolution of myths and superstitions connected to the eyes and vision, but is Vader perpetuating the myths by arguing that sight is so important? She says, *The entire concept of the eye as a magical part of the body, demonstrates the attitude of fear and awe held by many about visual functions*, but then says, *The unique nature of the eyes and vision, is unparalleled in the human body. The phenomenon of sight connects the internal conception of self and the body and the world at large.* (Vader 1990).

There are contradictions that cannot be resolved. Humans are visually oriented creatures and sight loss creates challenges of adaptation and changes in daily living. However, by emphasizing the value of sight, do we increase the fear of sight loss? Does this loss move out of proportion?

*Nurses and other health care professionals have a responsibility to be knowledgeable about the unique effects of ophthalmic practices on the body, spirit and mind. It is also evident that nurses must clearly understand their own emotions and social reactions to blindness and visual loss, so they can most clearly assist their clients through adaptation.* (Vader 1990 p.713).

I ask do the health professionals need to be more discriminating? Are they aware of how much value they place on full vision, a client’s values and society’s obsession with vision?

### 4.5 Empowerment

Sacks (1989) offers a more positive portrayal of disability and sub-culture, in his book, “Seeing Voices.” He described the deaf culture as self sufficient, not isolated. They were not looking for integration; rather than resignation and bitterness, the deaf culture was described as empowered and competent. He is not detached in his research style from the deaf people, but learns from his interaction.

*I have seen a wonderful social scene, in the students’ bar, with hands flying in all directions, with a hundred conversations proceeding. I had to feel this for myself before I could be moved from my previous medical view of deafness, as a condition, a deficit that had to be treated. To a cultural view of the deaf, as forming a community with a complete language and culture of its own.*

*I had felt there was something joyful, even Arcadian about Galaday (a school with all deaf students), and I was not surprised to hear that some of the students were occasionally reluctant to leave its warmth and seclusion and protectiveness. The cosiness of a small, but completely self sufficient world, for the unkind and uncomprehending, big world outside.* (Sacks 1989).

On one occasion when some of the teachers and administrators wanted spoken language the students shut the school in protest and insisted upon a
deaf president. The students were proud of, and cherished, the sign language used at their school, and wanted to protect it.

In contrast to Hough Kim and Lukhoff and Whiteman, Sacks described the sub-culture as sharing a rich set of beliefs.

... In the years after 1817, there spread throughout the states, not just a language and a literacy, but a body of shared knowledge, shared beliefs, cherished narratives and images, which soon constituted a rich and distinctive culture. (Sacks 1989).

Sacks wanted to see the deaf culture from the frame of reference of the people constituting this culture. He honoured that the deaf were developing a bold, new consciousness of their own language. He does not see the deaf culture as a problem but a power, and acknowledged the individuality of the deaf people.

Far from being childlike or incompetent, as they were supposed to be, and as so often they suppose themselves to be, the students at Galladay showed high competence in managing the March revolt ... I let my attention wander. Taking in the scene as a whole. Thousands of people, each intensely individual, but bound and united with a single sentiment. (Sacks 1989).

Sacks is not restricted by the cause and effect thinking. I devoured more of his books and found the same open exploration of the spirit and creativity in each person. He does not have a mechanistic mind that wants to quantify and prove or falsify. Sacks leaves room for change and potential rather than seeing people as symptoms and problems.

Marion Allen (1989) provides a broad perspective in her article, "The Meaning of Visual Impairment to Visually Impaired Adults." She interviewed 25 adventitiously blind people about their adjustment to visual loss. Her research process appears to be phenomenological. The information was given in the language of the participants, from their frame of reference. The participants were able to discuss and clarify their fears, frustrations and adaptations. They gave suggestions for positive change in their adjustment and interaction.

She describes (on page 49) how many of her participants reacted with shock on being told their sight deterioration could not be improved or cured. They had been led to believe the conditions were amenable to treatment, and consequently experienced sadness, depression, insecurity, feelings of wanting to give up and feelings of being sorry for oneself. They spoke of loss and what they could no longer do. Most of the clients saw acceptance as learning to live with the disability and its permanence, but concentrating on what you CAN do.

Their experiences were often described as battles, risk-taking and frustration, and their adjustment moved in a spiral or zigzag rather than linear progress. I assert that this reflects a general life trend. Sometimes a person
uses appropriate assertiveness to deal with a discriminatory action or attitude. At other times she reacts defensively or aggressively and reinforces the prejudice.

Interaction and adjustment depends on so many variables that there is a danger in generalising. Allen stressed that the act of doing something was important for her participants’ self-confidence, rather than the outcome of having acted in a particular way. She generalised that “our society is performance oriented and performance helps us define our space in that society” (Allen 1989 p.50).

The interviewees said that adjustment would have been easier had they had support from service agencies at the beginning of their adjustment, and that they needed to talk to their specialists more about their eye conditions. They felt that they themselves were good judges of how they were going, and at setting goals.

We need to research phenomenologically to avoid espousing one, narrow theory. The transformation is from viewing people with visual loss as problem saturated to adjusting to extra life stresses (Loenfeldt 1974).

This stance allows a more open critique of different theories about visual loss. Whether it is the loss, role, socialisation or personality theory, they all create stress. There is some reality in all the theories, for some individuals, in some situations. Loenfeldt stresses that all loss demands adjustment. He says the effects of blindness will vary according to

1. The degree of sight retained.
2. The age and onset of blindness.
3. The time elapsed since the onset of blindness and
4. The cause and kind of onset of blindness (Loenfeldt 1974 p. 221).

Like Sacks (1969) he respects individual differences and personalities amongst people with visual loss.

*Individuals vary in their ability to make functional use of whatever sight they have, and thus a personal variable enters that must be considered for all practical purposes.*

He stresses the importance of critiquing adjustment theories by authors with visual loss.

*They are, by their own experience of blindness, better qualified to have their say on the problems of the blind and blindness than many others who were propelled or propelled themselves into positions of decision making.*

*This short review of the blindness interpretations of psychologists and sociologists, who are themselves blind, shows that they consider blindness an impairment that requires adaptation, adjustment, reorganisation or reprogramming. Blindness makes special demands*
THE VICIOUS CIRCLE OF STIGMA

FIGURE 7  My summary of stigma theories, Hogan (1994)
on the individual, but the continuity of his existence and of his personality have never been questioned by any of these interpretations (Loenfeldt 1974 p.226).

Is this the crux? Many theories about people with visual loss do question the continuity of identity, consciousness, personality. The theories become vicious circles. The people with visual loss and people with full sight can't move out of the games of stereotype, stigma, and disavowing the perceived stigma. I saturated my life with laughter and fun while doing this research. It was a reaction to the intensity and pessimism of the vicious circle syndrome as perceived in Goffman’s stigma theory. The reactions and adjustments of both people with visual loss and people with full sight were continually classified and coded, as shown in Figure 7.

Blaylock and Rickelman (1983) explored behaviour by people with full sight, seen by people with visual loss as a hindrance to self reliance. They gave examples of inappropriate behaviour by people with full sight such as insisting upon unwanted help.

They accepted Cuttsforth’s classification as summarised below. I argue that people with visual loss respond to stresses in varied ways, according to many factors for example, how tired they are, how many stresses are occurring at once. To accept Cuttsforth’s classification is ignoring the fluctuations in an individual’s coping mechanisms and frame of mind.

Cuttsforth’s classification (1961).

1 Those who internalise the stereotypes directed at them, and accept them as part of their own self concept.

2 Those, who because of the inability to accept the social definitions, withdraw from contact from the sighted world and confine their lives to the family of institutions.

3 Those who tend to confront the sighted world and assert their willingness to conform to the dependent and helpless roles assigned to them.

Blaylock & Rickelman (1983) argued that people with full sight should take responsibility for changing negative actions and attitudes. They found a deplorable lack of knowledge and understanding of the skills, abilities and feelings of individuals with a significant visual loss.

They described the sighted as anxious or uncomfortable causing them to avoid or act over-solicitously toward people with visual loss. They discussed how both these reactions conflicted with blind people’s views of themselves as self reliant and capable individuals. They then asked specific questions –

Do blind individuals perceive their own self reliance to be influenced by the attitudes, beliefs and actions of sighted people whom they meet in every day encounters?

What myths and stereotypes do sighted people project when they interact with the blind?
What specific behaviours of the sighted are seen by the blind as interfering with their self-reliance, and thus with the process of normalisation?

They then documented over one hundred positive strategies to improve interaction and respect the self-reliance of people with visual loss. For example:

_Do not assume that because you can do something more conveniently or quickly, you should automatically do it for the blind person._

_Blipd people often do not need help. Ask whether you can be of assistance instead of initiating help._

_Do not feel embarrassed or rejected if a blind person rejects your offer of assistance._

I believe that such hints are an excellent guide, but individual requirements and values must not be ignored. Specific ways to interact are not universally appropriate.

Wright explores the psycho-social effects of a range of physical disabilities. I concur with three major points in Wright's (1983) thesis. Firstly, she asserts that disabilities are our problems because they affect all of us. For example, we all experience illness and aging, therefore the value of sight and the impact of sight loss should be put into perspective, as an asset if you have it, and inconvenience if you do not. While I consider that viewing sight loss as an inconvenience tends to trivialise the impact of blindness, this perspective is interesting in its reaction against the tragic loss model.

Secondly, she focuses on what people with physical disabilities _can do and not what they can't do._ (Wright 1983 p. 60). She argues that adjustment and life satisfaction are hardly distinguishable whether you have or do not have a disability. Again I would temper this assumption by saying it is a combination of personal proclivities and coping mechanisms rather than particular physical difficulties alone that determine adjustment and life satisfaction.

Thirdly, she warns that by measuring people with disabilities against what is seen as normal can lead to feelings of failure and inferiority; whereas success can be determined by a person's goals, expectations and aspirations, rather than independence or normality.

We have now moved beyond the notion of normalisation, with the Disabilities Discrimination Act 1992. It is now recognised that people are motivated to accomplish, without striving for normality. _Normal_ is measured against people with full sight, so by striving for normality, people with visual loss may deny realistic limitations.

We all experience disabilities at some time. Most of us also experience being stigmatised. Our materialistic culture creates images of 'super' people; the vacuum cleaner advertisement with the slim, relaxed, blond female in a silk negligee. What percentage of even the affluent society can achieve the exceptional ideal of perfect body, health, sports acumen and financial success?
Physical disability can be expected to play an unduly precipitous role on at least two counts. First of all, a person's physique is an immediately apprehensible characteristic in face to face contact, and thereby readily conditions subsequent impressions. Second, physique is a relatively stable characteristic, so stable in fact that a person's identification largely rests on his physical appearance (Wright 1983).

Is this emphasis on body image a reflection of Wright's values? Does it ignore other aspects of personal identification such as spirituality, skills, creativity and personal values directed outside the self to the whole ecology? We must keep challenging the normal and exceptional ideals for a sustainable society. Wright (1983) admits herself that it is not so much physical deviation as such that creates a feeling of being different as psychological characteristics imputed to the person through the phenomenon of spread. This means that education, to the effect that physical anomaly does not portray personality, is of the first importance. All one knows of a disability is that the person has the disability. (Wright 1983 p. 23).

She comments that we should not swing in the opposite direction and create a preoccupation with physical disabilities. I stress this point, and always question when people say, for example, "It is your right to get a $5,000 talking computer from the Commonwealth Department of Rehabilitation." I ask, why is it my right? Who decided it is my right? Do I feel people with full sight should have the same right? What is my responsibility?

4.6 Conclusions: Metamorphosis

Research will unavoidably encompass the researcher's own values. How much value do they place on sight and other senses? What are their own fears and discriminations? Do they recognise the complexity of visual loss? I believe that the impact of blindness cannot be defined. By striving for definite explanations theorists can perpetuate the stereotypes of victims, heroes or aggressors.

There is some truth in all the theories I have discussed above - loss, socialisation, effects of sub-culture and stigma, differing adjustment and adaptation. A more holistic view would honour the trends and the anomalies, the individuality and commonality.

People exploring the effects of visual loss must discover their own fears and discriminations, by continually asking how much value they place on full sight? The metamorphosis needed is a clearer understanding of visual loss and its effects, by acknowledging that the way people deal with visual loss is as important as the stresses caused by visual loss.
CHAPTER 5

Life Stories: Learning from Biographical Writings.

5.1 Introduction

I first read autobiographies, written by people with disabilities, as a relief to the intellectual texts. I soon became fascinated by the stories, the humour, frustrations, fears and passions people share. They also highlighted the different ways people deal with challenges and cope with stresses.

I decided that the autobiographies could add another dimension to my research. They provided an insight into the unique ways that people with visual loss deal with stresses. It was also evident that people experience common stresses and sometimes responded in the same ways. On meeting an individual with a visual loss, many people still erroneously assume that this individual thinks, acts and deals with stresses in a set way. Legislatively we have moved from institutionalisation to normalisation, to integration. However, society's attitudes do not transform in symbiosis with these legislative and professional notions. I still receive the comments, "Oh well, you'd know Jan Smith." Apparently Jan Smith has low vision, and lives within one hundred kilometres. The assumption is automatic friendship because we share a physical disability.

There has been an ethical dilemma in using these autobiographies. How do I draw out what I consider is significant, without perpetuating stereotype images? Again I had to discover my bottom line. What was my aim?

5.2 Respecting Uniqueness and Commonalities

My bottom line is to respect the unique spirit and yet the common stresses experienced by each writer. I designed a number of questions on themes, that I have been frequently asked about, and which are explored in the autobiographies.

Questions.

Does loss of sight as an adult, lead to a loss of identity?
What is the correct social protocol to use when interacting with a person with visual loss?

Who needs to improve the interaction – people with visual loss or people with full sight?

How can improving your personal self acceptance make interaction more positive?

Why do people find it so hard to ask for help?

I then aimed to have the writers presenting the story. This offers multiple views on the themes, to debunk the myth of automatic homogeneity amongst people with disabilities. The excerpts reflect the diverse ways individuals deal with stresses, and how each individual varies according to the situation and their state of mind. My personal experiences and reflections serve as a commentary to expand upon the themes and quotes.

In the paper, Lives Without Lives Within, Asch and Sacks (1983), reviewed autobiographies written by men and women with visual loss. They began with a generalised assumption that much of the problem posed by disability, stems from society’s attitudes. Attitudes that cast all disabilities into what has been called the disability role. (Asch 1983).

This is a common assertion, and there is some truth in the notion that social discrimination is worse than the physical disability. However, it still undervalues the way people with visual loss deal with this discrimination. I did not have the skills nor maturity to deal with discrimination as a teenager. Now it is a minor life stress. This year my biggest stresses have been learning to ask for help and developing research techniques that cater for my physical limitations. By making realistic and appropriate changes in both cases, I experience less stress. My confidence, clarity and communication brought a reciprocal change with people with full sight.

Asch (1983) summarised their findings, saying that, each writer saw entry into the real world as their prize, as Heaven, as escape, as affirmation of membership in a human species. I read over half the autobiographies reviewed by Asch. I assert that each writer wanted to be accepted for him or herself. Each writer wished to be respected and given equal opportunities.

Asch felt it was a shame that the writers believed they had to prove themselves. Asch criticised the stories as individual solutions to individual problems, rather than group solutions. This generalisation helped me work to my own bottom line. I re-interpret their conclusions: The individual solutions aim to show there are different ways to handle problems. Some of the male writers did share male reckless exploits and conquests as described by Asch, they also revealed the questioning, the personal confusions and the passions.

Many of the writers were dealing with the extra stresses of institutionalisation and accepted discriminatory attitudes. It was also more socially approved to be chauvinistic and boast about conquests, during the 50's and 60's. I believe Asch and Sacks concentrated their interpretation too
narrowly. I agree that it is sad that people with visual loss strive to justify and validate themselves. However, again I stress the potential to adjust and recognise this striving. Most of the writers showed a maturing, of gradually coming to terms with different stresses caused by loss of sight.

I have shared excerpts of autobiographies to highlight the diverse ways that people adapt to visual loss, and to emphasise the multiple factors that affect how visual loss impacts on the individual's life. They share the angers and fears, the mistakes and successes. Some of the writers, such as Garland (1974), appear didactic, whereas Hull (1990) is sharing his personal and spiritual turmoil, after losing sight.

5.3 Loss of Sight and Personal Identity

Must I become a blank on the wall of my own gallery? To what extent is loss of the image of the face connected with loss of the image of the self? Is this one of the reasons why I often feel I am a mere spirit, a ghost, a memory? Other people have become disembodied voices speaking out of nowhere, going into nowhere. Am I not like this too now I have lost my body? (Hull 1990).

Hull's image of the "disembodied voices" has become recognisable for me in the last ten years. From eleven until twenty-six years of age, I tried to greet people and recognise people by using ninety percent hearing. It often took minutes to recognise the speaker. Retrospectively, it was like a person with full sight who converses for twenty minutes with a feeling of discomfort because she cannot remember the person's name. I then began to ask friends to greet me by saying, "Hello Claire, it's Fred." It meant less stress and pretension.

Does loss of sight mean developing a new set of social protocols? In the example above I had to acknowledge my own physical limitation and adapt accordingly. The new social protocol has created a more positive interaction. A person who knows me will say "Hello Claire it's Fred speaking." For me part of adjustment is being more honest and assertive?

Well, here I was, going blind. How many others would reject me because of it? How could I battle with the sense of still being me? The next months and years were to see great difficulties and some small triumphs. (Hewett 1987).

The accident had been a sudden and shocking event, but as soon as I began to get well and my future looked optimistic, friends flocked about me. This time the situation was quieter and had a sense of foreboding. It seemed that most people tried to ignore what I was going through. Only the more solid families, whose sense of duty perhaps overcame their feelings, came to see me. (Hewett 1987).

Is Maureen Hewett having to deal with other people's fears. Choldon and Schultz emphasised that many people are afraid of losing their sight, and so avoid the situations that force them to confront this fear. When a physical
disability is too closely associated with loss or death, people do not know how to interact. They have again lost the comfortable protocol they understand. The fear of blindness is exacerbated by the myths, misconceptions and stereotypes. This is one of many explanations why people avoid adults who are losing their sight.

Both Hewett's fiancé and her close friend, Jess left her when the sight loss was apparent as being permanent. Hewett writes of her friend Jess: Her action, of running away from what she saw was a most terrible future has been a rare response to what has happened to me. Most times I've been able to assist those whose shock is at first great and their courage faltering ... Father offered an eye transplant, not knowing it was scientifically impossible. (Hewett 1987).

Diminishing vision was for me like veil after veil descending, obscuring the clarity of shapes, indistinguishable from each other. Yellows and pinks blended together, then blues, purples and greens, until finally I could see only red. The last visual pictures I had were an amorphous mixture of sepia tints and textures, which my imagination had to interpret. With every change of visual perception were fresh adjustments to make. I lived with the possibility of my remaining sight going overnight. To live with the expectation of waking the following morning to total blindness, was like living on the edge of a precipice. Even so, when the veils become too dense to see through, there was a feeling of greater security and relief. When you are at last totally blind, you're no longer faced with the unrealistic expectations of others, and you yourself know where you are. I could then concentrate on developing my remaining senses. This tuning of sound, smell and touch added new perception which I found amazing. (Hewett 1987).

This is one level of the limbo status. Hewett had to keep adjusting to deteriorating vision, and hope that vision may return. The physical limbo is then internalised and becomes part of the process of adjustment. Hewett expanded the understanding of limbo status, to include the body, mind and spirit connection.

How would the loss theorists react to Hewett's perception of sight loss as an exciting adventure? Would Cuttsforth (1951) and Choldon (1958) describe it as compensatory attitude? Is Hewett allowing a transformation rather than the death of sight and rebirth to blindness, advocated by theorists such as Carroll (1961)?

I'm retreating into myself. I analyse my own reactions to get a clue to what lies ahead for me. I have to understand who I am for others, and if the image is distorted to try and redress it (De Montelemert 1985).

Like Hewett (1987), De Montelemert (1985) was an artist before losing his sight. De Montelemert's story shocks. He lost his sight when two thieves
entered his flat and threw acid in his face. His narrative agonises over loss of personal identity.

*A long grey road on which I may advance if courage is there, but what about joy and adventure, the source of all my energy until now? Images cross my mind. I see myself creeping down a street, feeling my way along a wall, dragging my feet. Horror, I was thirty five, in the prime of manhood, young and slim, and now I see myself a bloated body, a package of darkness, a crawling locust. I am afraid. I'm afraid to get out, to collect all my courage and still to end up like that* (De Montelembert 1985).

Is De Montelembert dealing with his own attitude of discrimination? He has just lost his sight violently. He associates blindness with black and horror. The title of his book is *Eclipse Nightmare* and his adjustment appears to be a personal nightmare, full of many fears and negative images.

*Admitted on May 25th, I am released from hospital two months later with six stitches in each eye, blind, handicapped, feeling a nausea for life, for the rest of my life. I do not say this simply to paint a gloomy picture, or to make people feel sorry for me. I am trying to explain as best I can the fear and mental anguish of those, who like me, have been stabbed in the heart of life* (De Montelembert 1985 p.57).

I appreciated De Montelembert's frankness, not asking for pity, but working through anger and frustrations. He is dealing with despair, and is wondering what is left without sight.

### 5.4 Self-Acceptance

*I will never see anything again? How can one survive this? How can anyone get used to this obscurity, this monotonous darkness, this shore black with boredom. They ask me whether I'm getting used to it or assure me that I will little by little. Deep within me I cry out never! I must never get used to it and forget what I was for that is surely more authentically myself than what they have made of me. This is irrevocable, but it is not me* (De Montelembert 1985 p.207).

De Montelembert is confronted by the concept of acceptance. I spoke to my supervisor, and friends about this issue. They suggested that my positive attitude is because I have not accepted the disabled role. It is because they forget about my disability that makes interaction easier. But can this interaction ever be so for De Montelembert? He has no sight and a conspicuous disfigurement. Goffman argues that people with conspicuous disabilities do not have as many choices. They cannot choose when to tell people and so on first meting are judged by their appearance and the associated stigma.
This research has altered my concept of self acceptance. I am celebrating my unique, normal, eccentric, blind, sighted joys and frustrations. I am no longer trying to validate or prove myself. Self-acceptance means recognising my attitude of discrimination, my fear of total blindness, my physical vanity, my resistance to being called blind. I identify with De Montelembert. I do not accept sight loss. I do not accept a disability. I accept me, and my visual loss is one facet of my whole, which causes stresses and offers challenges. De Montelembert is afraid of what they are trying to make of him.

What are some of the fears? Fear of dependence. Fear of being stereotyped. Fear of having to act out a role. Hence the process of self-acceptance is a continual and cyclical process.

... and how can I get used to anything when there is this beast lurking deep within me. This beast which is blindness itself. Not physical blindness, which is a mere mechanical accident that prevents images from reaching the brain, but the psychic blindness brought about by that privation. This beast that must be tamed every morning, pitilessly, as soon as I wake up, so that it will not invade my day.(De Montelembert 1985 p.209).

What is this psychic blindness described by De Montelembert? I argue that it is a human construction. It is the symbolism described by Monbuc. These symbols and myths can increase feelings of repulsion and fear. De Montelembert's autobiography is full of images of black and white, evil and despair. By confronting his anger, fears and despair De Montelembert is dealing with stresses, trying to maintain his own identity.

In “Blind Man’s Buff”, Garland aimed to educate people about interacting with people with visual loss. I do not agree with his aggressive stance, but recognise that perhaps that was the best way of handling prejudice during the era of institutionalisation. Garland and Blackhall reflect that it has only been the last ten years that affirmative action, rights and access for people with disabilities and equal opportunities have been developed.

I’m quite sure if I had not been aggressive no concessions could have been made.

Blindness does not change basic, personal characteristics, but it can exaggerate or suppress them. In the case of the former, what were mere quirks of personality begin to look uncommonly like eccentricities, while in the latter personality becomes colourless. In other words, the obstinate and aggressive become more obstinate and aggressive. The quiet become submissive, but there are others worse off who can’t escape at all. They are the ones who carry the terrible burden of not being able to be themselves (Garland 1974).

Conformity is the perennial question, debated by parents, rehabilitation workers, educators, theorists. Is it up to people with visual loss to conform to visually oriented conventions, or vice versa, or is it a reciprocal process? Oliver Sacks described cases where an autistic person was retrained to speak. She
immediately stopped painting. She was conforming, but the creative, spiritual levels were lost.

I lived so long as a sighted person I have no excuse for not conforming to acceptable standards of behaviour, but those who were born blind have every excuse if no one teaches them how to conform (Garland 1974).

Manners and dress are a less significant issue, but it is still complex. Garland (1974) described a young woman, Frances, who had mannerisms that were perturbing. These mannerisms are often referred to as blindisms, for example, rocking, poking at the eye, turning the head slightly. However to remove the blindisms and compel conformity, thought must be given to the implications of modifying such mannerisms.

If the rocking motion is creating a sense of balance, and turning the head slightly helps the listening process, there must be appropriate alternative behaviours. To simply remove them could cause imbalance and hearing problems.

Garland advocates honest observations, particularly for those who have never seen. I remember seeing a student at the Royal Victorian Institute for the Blind, when I was eleven. She picked her nose with great deliberation, and I was horrified. I like to know if my clothes are soiled or my labels are sticking out, or my posture is stooped. However, these are cultural and visual values.

Any edict against blindisms is forcing conformity and normalisation. I believe that institutionalisation does perpetuate blindisms. No one teases, or confronts the behaviours. Less institutions may mean less blindisms. The question remains, why should people with visual loss conform to sighted standards.

We were expected to walk around like we were sighted. We had to avoid the ornaments in the hall. We couldn’t run into things. We weren’t allowed to have any of the “blindisms”. I still have one of them. I press my fists against my eye lids. I do not know why. I guess because it is restful, and like other blind people I rock, but we weren’t allowed to do those things in my parents’ house. (Dark 1989).

I still have a discriminatory attitude toward feeling things in public. When I first arrived at the Royal Victorian Institute for the Blind, I was disturbed by seeing so many people feeling rather than looking. I made a subconscious decision to never feel things. Sue Wagner (1986) had the same reaction on losing her sight, except that she was an adult. Her friends compelled her to feel people, to help identify them. Wagner said she was acculturated to hand shaking, and would stick to it.

The contradictions are striking. Garland advocates conformity to certain behaviours, and yet visual loss requires certain behavioural modifications such as feeling, using a white stick or not maintaining eye contact. It is anathema. People are disturbed by unconformist behaviour. People who use a white stick
and use tactile information instead of visual cues, can be subconsciously classified as deviant because of the unfamiliarity, but the situation is more complex. There are so many reasons as to why there is interaction unease—discriminatory attitudes, fear of going blind, not knowing what to do and how to interact. The person with visual loss often has to deal with her own resistance and fear of dependence.

"Where are all your friends?" people would say loudly, as they threw some candy into my shopping bag.

"I have no friends," I would answer quite honestly. The door would close and I would head back to the car where my parents were waiting for me, to be driven to another street corner to begin the ordeal all over again.

"Having fun?" Dad would ask hopefully.

"Sure" I said reassuringly, "This is real fun!"

The Halloweens that followed were all very much the same. For several years I went out triple treating with loneliness. That night I lay there and argued the pros and cons of a life of dependence on others, or a life of independence. Of course the argument was handled at a nine year old level, but the problem was wrestled with none the less.

I grew up that night and made a choice. I was not going to be a blind man in a blind world (Krentz 1972).

Krentz is working through the paradox. He does not want to be a "blind man" in a "blind world." What is his image of the blind man and the blind world? Asch (1983) describes it as a fear of filling the disabled role of dependence and submission. Krentz tried to please his parents, participating in the Halloween Triple Treat. Nine-year-old decisions are affected by role models and adult expectations. Perhaps self-acceptance can develop more freely as an adult. Changing values and habits can be harder, but the choices are often more available.

In learning how to accept blindness and to accommodate myself to its limitations I have rediscovered my own identity (Garland 1974).
Chapter 6

Interaction Challenges

6.1 Introduction

It is an ongoing challenge to educate people about interaction. Social protocol is already unclear in a modern western society, where traditional values such as the role of the family, religion and education are being challenged. I continually checked what language I was using, to write this thesis – Was it sexist or discriminatory? The same questions had to be asked when I was collaborating and interacting with friends. I aimed to improve my own interaction by asking for help more clearly and stating the limits to the help I required. However I could not generalise that this form of interaction was appropriate for all people with visual loss.

Pamphlets written by blindness agencies, government departments and videos such as “How To Treat A Blind Person” can be used as guidelines only. The message that comes loudest from most of the autobiographies is to treat people with visual loss as people first.

When Hewett had a car accident, the interaction with friends and colleagues remained much the same. Later, when her eye condition was recognised as permanent, a physical disability, the interaction changed. People then viewed her as disabled first. They then reacted to their fears and prejudices. Gradually they stopped interacting.

There is a need for reciprocity to create interaction ease but I believe that people with visual loss usually have to educate. We deal with it every day and tend to be more skilled. People with full sight would need motivation to confront their fears and prejudices. However, I have found that most people I interact with are interested in understanding positive interaction. They do not want to be awkward or patronising.

*Because I cannot see, I cannot be seen. I can be ignored, treated as if I don’t exist, spoken about in the third person.*

“Will you look after him?”

“Will you put him by the lift?”
When in a hurry, one can rush past a blind friend, without the inconvenience of having to greet him. He does not see you, therefore he does not know, therefore you can pretend you don’t see him, and that is somewhere between being ignored and being the centre of attention.

It is so hard to be a normal person when one is not a normal person. It is also hard to avoid the situation which arises, when because of one’s very powerlessness one does have a kind of power over people. The disabled person does seem to cause other peoples’ powerlessness. One flusters them, reduces them to confusion, covers them with uncertainty, makes them feel gauche and insensitive, awkward and intrusive." (Hull 1990).

Hull’s beliefs are affected by his symbolic and religious beliefs. He studies and teaches theology. His autobiography, Touching the Rock, is a diary of his adaptation and questioning, over three years, after losing his sight as an adult. Is he connecting sight with existence and normality? This pressure to aspire to normality can cause stress and identity confusion. I always ask what is normal and according to whom?

I have observed my interactions and kept a diary. I had never noticed being introduced in the third person. It happened at a recent dinner.

“Claire has very little sight.” my host told his friends. I was preoccupied and thought, “So what?” Did his friend need to know? Perhaps I would have told him; possibly, if it had occurred naturally in the conversation.

Immediately after the announcement about my sight, there was a tension. The friend did not quite know how to respond. I considered what would be an appropriate response. Another diner then spoke. There was something ridiculous about the interaction unease. No one knew how to respond.

What happens when people are interacting with people with disabilities? If this is not a usual interaction, there is sometimes discomfort.

... running toward me, but am too absorbed to pay attention to it. There is a shout. The animal in me rears up, I am afraid. I throw my hands and cane in front of me to protect myself from a collision, within me my heart has stopped. Everything stands still, frozen with fear. It is a jogger wishing me good morning. He goes on, shouting sorry over his shoulder. I pause to catch my breath, to overcome the humiliation. Harmony shattered by so little.

A little farther on, just as I am getting over this shock, a small boy, on a bicycle on the other side of the road says to me: “Hello, do you remember me? You came a long time ago to see my horse.”

“Oh yes, how is he?”

“We sold him.”

“Why?”

In a hurt, voice, “He ate too much.”
"How sad that is, you must be very sad."

"Oh yes I am very sad," he says after thinking for a moment.

I hear the bicycle moving away and his small voice saying, "goodbye. Happy New Year. So little and harmony is restored" (Hull 1990 pp. 165-66).

I transcribed the anecdote above to place the concept of interaction unease in perspective. Reading Goffman (1968) one would assume that stigmatised people spend their lives battling with interaction unease, trying to hide their perceived deviance or disability. I would assert that everyone experiences interaction unease. Feeling tentative and being cautious is a natural precaution against rejection or recrimination or simply not following correct protocol.

The interaction unease just happens more for people with disabilities, particularly conspicuous disabilities. People are faced with an unknown. I am challenging the degree of interaction unease, the degree of problems faced by people with visual loss. On the one walk Hull is frightened by a jogger, but minutes later feels at peace by the innocent sadness of a young boy. The positives counteract the negatives, so it depends, to some extent, upon personal traits how a person with a visual loss copes with negative or frightening interactions.

Interaction unease does not need to be a problem, but rather an opportunity to use appropriate assertiveness, humour, or at other times to think, "So what?". That is their problem and prejudice, not mine. I am making this statement, having had twenty-five years to mature and adapt to my visual loss. I speculate that interaction unease is more significant to people who lose sight as adults and are in the early stages of adjustment.

I have discovered that the actuality of blindness is less frightening than the concept I had of it before I went blind. I shared a view common amongst sighted people, for whom the whole idea of blindness is surrounded by an aura of mystery, arousing irrational emotions, inhibiting rational thought, and when I could run from the idea I was compelled to run, seeking escape from it in the wasteland of my own ignorance ... A physical defect that makes me vulnerable but not delicate. If I can learn to live with it, I'll be no less a human being than I was before I went blind, no less a human being than I would be had I lost a limb, developed a weak heart or acquired some debilitating disease (Garland 1974 p.29).

I argue for a holistic approach to improving interaction ease. Individual and group stresses and solutions are of equal importance. By criticising individual solutions, Asch (1983) ignored an essential point; That each person with visual loss is unique and yet can experience common stresses. Their individual solutions offer a diverse range of alternatives.
The autobiographies reviewed by Asch would lose much vigour and richness if the writers aimed to find group solutions. Group solutions are often inappropriate for individual requirements, and can perpetuate stereotyped images.

6.2 Asking for Help

The resistance to asking for help has proved a confronting and fascinating issue in my research process. Allen (1993) interviewed people with visual loss, who had lost sight as adults and had been blind for at least twenty years. She summarised, for most persons, dependence on others and the necessity of asking for help, was the hardest thing to which they had to adjust.

It was not until the writing stage of the research that I could analyse this issue. I had to work through my personal reactions to asking for help. It was an emotional process, acknowledging that I had been acting the role of "superwoman". I'm tough. I'm always alright. I'll help you, I do not need any help. I spoke to friends, parents, counsellors and my collaborators, then recognised some similar reactions in the autobiographies.

In my research network group we discussed how most people find it hard asking for help. It is exaggerated for people with disabilities because usually we have to ask so much more. My next question evolved automatically: Why do people find it so hard to ask for help?

Allen proposed that it was hard for the people she interviewed with visual loss to ask for help because they could not maintain a balance of give and take in the relationship (1993 p.645).

She emphasised the feelings of indebtedness and obligation that leads to a lack of equity. This is an explanation for what was one of my constant fatigue. "How can I repay that person? When will I find time to support that person to the same degree?" Many of Allen's participants said they would have appreciated sharing with other people with visual loss during the initial adjustment stage. I argue that a major challenge people with visual loss need to deal with is the issue of asking for help. Personal attitudes to this issue will have an impact on positive or negative adjustment.

If asking for help is associated with dependence, lack of equity, obligation and being a nuisance, the responses may decrease life quality. People pretend they do not need help. People do not ask for help clearly, so perpetuate interaction unease. People waste time and energy doing things that could be done more efficiently and faster by others. It is such a balancing trick between maintaining dignity and knowing when and how to ask for help. There is always the challenge of whom you ask. Some people do not listen, are over solicitous or patronising.

Casual meetings and encounters are made more stressful for people with disabilities because they often have to ask strangers for help. When there is a
hidden disability, you decide whether or not to tell the person or use tactics such as "I left my glasses behind."

The conflict experienced when asking for help needs to be acknowledged. People can then choose whether to change their communication and action to promote quality interaction.

The person with visual loss needs to work out her own perception of what are realistic standards, to avoid always trying to prove and validate herself. The person with visual loss then identifies what is appropriate help, how to ask and give directions and the limits to the help needed. If the person with visual loss obtains support during the initial adjustment stages to loss, or during childhood, to overcome the guilt caused by feelings of obligation or indebtedness, asking for appropriate help may come more naturally.

It is simplistic to advocate public education, without assisting people with disabilities to work through the resistance to asking for help. To say, "People like to help, that is their thanks," does not benefit people with visual loss. This is a generalisation and a platitude. Some people do not want to help. They are frightened or it is an encumbrance. Others need so much thanks and support themselves that it is draining for the people with visual loss.

I looked for a plethora of views on the issue of asking for help. It is the range and richness that is important rather than whether I concur or challenge their views.

_It was all self imposed or self imagined, a feeling that I was a voice chanting in a vacant room, that no one in the world could come close to me. If I asked for something to be read to me, and it happened that it wasn't convenient at that moment I sat bleakly in my work room. This room where I sit now, the dining room of the house, and wondered after a while whether I dared to ask again, and there was only one thing I was afraid of, only one thing that I hated more than anything else, amongst all the frustrations and agonies and breast beating. I hated and feared the prospect of my family being impatient with me. Sometimes, simply because they were human beings they said something like, "Alright, alright, do not nag", and I couldn't contain my anger. Except for a little man inside me, who knew it would be alright in the end, I could have smashed the house to pieces (Blackhall 1971 chapter 12)._

Garland was standing at a railway station one evening when he suddenly lost all vision. He asked seven people to assist him and only the seventh person did. The fellow guided Garland to a seat and then found the station master for him.

_I tried to thank him but he brushes my thanks aside. “Good Heavens, that's nothing, anyone would have done the same.”_

_He knows nothing of my seven earlier encounters (Garland 1974)._
I begin to think that I really do have a sort of a litmus test. What degree of freedom will this new person be prepared to allow me? Will this sighted person find ways of letting me preserve as much independence and dignity as possible? Will this person want to possess me, control me, to make me feel even more handicapped by refusing to admit that I can do the slightest thing for myself. For my part, how can I make it easier for sighted people? (Hull 1990).

... if I'm unfamiliar with the surroundings, I ask someone. I rest the handle of the harness on her back and hold the lead. I stand perfectly still and wait for footsteps. Excuse me, can you tell me where I can find the post office? Very often I'm sorry to say the answer will be something like “Yes, it's just past that yellow building or it's over there.

"Is the yellow building in this road?"

"There it is!" Try again.

"Please tell me how far it is to the yellow building."

"It's just there." I'm afraid it's no good pointing.

Either the passer-by has given it up and moved on, totally bewildered by this obtuse stranger or the dawn breaks and he is profuse with apologies.

"Oh I'm sorry. I didn't realise. Let me show you. Would you like me to go with you? Be careful how you cross the road. Are you sure you'll be alright?"

People are automatically kind if you catch them on the hop, and nearly always they are over solicitous (Blackhall 1971).

6.3 How Help is Offered?

The excerpts in this section are summarised by Garland (1974) when he said that “... there is only one way to treat disabled people, to treat each one as he wants to be treated.”

However this assertion is not absolute because the person with the disability is often going through her own conflict as described by Dark.

Although I regard myself as being very independent, in the back of my mind I wish there was someone to go around with me. I wish I didn't have to do it by myself all the time. If someone offers to help however, I say no, unless they are going in my direction. It all depends on the mood I'm in, the day I've had and how much I need, or am prepared to accept another person's help (Dark. S 1989).

Dark admits that it would be good to have someone going around with her, but usually her independence is the priority. Each writer experiences a similar dilemma, the need to be self reliant and independent. This is made difficult because people with full sight tend to be patronising, unsure and act the role
of parent protecting an infant. Each offer of help needs to be considered; would I be better to do this by myself? Will this person understand the limits to the help I require? Can I trust that this person will assist me across the road safely?

So many people expect me to be more in control of my emotions than they are of their own. It doesn’t occur to them that no one has the right to do anything for me without first obtaining my consent. To give that consent is not simply a privilege, it is my inalienable right as a human being (Garland 1974).

How to ask for and accept help, appeared to be the most common and frequent stress experienced by people with visual loss.

I want to be treated as myself and not act passively nor fearfully. I still find this challenging, because so many people have good intentions. Often when I am appropriately assertive, people are hurt. For example, recently a friend held my arm and wanted to guide me across a parking lot, at night. Due to clear contrasts I usually do not have difficulties seeing at night. I said “No, thank you,” and my friend was hurt. We had to talk for an hour to overcome the interaction unease. My friend had to understand that the issue was of my dignity and independence, rather than a rejection of her as a person.

I can’t help noticing how frequently my new found friend will not only lead me over the road to the taxi, but will give the taxi driver instructions. As we’re walking along towards the taxi rank, my guide will ask me where I am going. Then when he has got me into the taxi, making sure that I don’t bang my head, he will then relay these instructions to the driver. The sighted person is caring for me. He is looking after me. The relationship of caring makes him feel that he is an adult and I am a child (Hull 1990).

Learning to say no is an essential skill for positive interaction. By clarifying the limits, people with visual loss can maintain dignity. People with full sight also need to feel comfortable saying no when they are asked for help.

The new patient saw Bill turn the plate and called Bill abusive names. “I’m the one who’s blind,” I said, “I do not object, why should you?” An embarrassing silence pursued. Realising my own culpability I tried to break the tension by asking Bill to pass the salt. From across the table, incorrigible as ever came his voice, “You find it for yourself; you need some practice.” It could have been an outrageous remark, but the way Bill said it, removed all sense of outrage, and everyone laughed, including the new patient. Now, like the others he understands that there is only one way to treat disabled people; to treat each one as he wants to be treated (Garland 1974).

I want to cross the road but there is a stream of traffic roaring past. I stand at the curb side. A beringed talon grasps my wrist. A high pitched voice cuts through the vibrating roar “Mind, you can’t cross yet, there’s a lot of traffic going by.”
She can say that again, does she think my white stick means that I am deaf? Well meaning people who insist upon doing my thinking for me really do not appear to think for themselves, otherwise they would realise that although I have lost my sight, I am a mature man, not a helpless child (Garland 1974).

A porter opened the door of the cab and asked if I needed any assistance inside. "No, thanks," I replied, "I can manage fine by myself." I have repeated that phrase over and over again during the last twenty-five years. Being self sufficient means the world to me. If I should ever lose my desire to be independent, I believe that at that moment I would also lose my desire to live (Krentz 1972).

People in the street don't have much of a concept of what it is to be a person with a disability. They don't see beyond my disability because it is the first thing that is presented to them. They have no concept of me. They can't think past my blindness. Yet, those people, strangers, grab my arm. I just wish they would speak to me first. If a person is afraid of me, "a blind person", then why do they have to have physical contact with me before announcing their presence verbally (Dark 1989).

The range of anecdotes above is to emphasise that there is no one way to deal with the issue of asking for and offering help. Every person is unique and personal needs will vary at different times. I argue that people need to act according to what is appropriate at the time. Absolutes and assumptions can be based on stereotyped attitudes, so that the help offered is oversolicitous and inappropriate.

There are a number of skills that need to be acquired to ask for help when it is appropriate and to direct the person being asked. Reciprocal skills need to be developed by people with full sight. Basic skills such as offering one's arm for the blind person to hold, rather than grabbing (Grabbing causes the blind person to lose the sense of balance and dignity).

Someone standing on the other side of the road, caught sight of me, and wanted to help and decided to let me know that he was there, and take command of the situation.

"Right Mr. Blackhall!" he called out.

It turned out that what he meant by this was "Hold everything, I'm coming." I took it to mean that the coast was clear. I stepped off the curb and a double decker bus braked frantically and screeched to a protesting, rocking stop. I could have put out my right hand and touched it. The driver, panic stricken, was almost breathing down my neck.

It's an interesting fact that when someone else takes over, the blind person usually stops concentrating, not consciously but automatically (Blackhall Chapter 2 1971).
I have developed strict rules for myself in relation to road safety. I have told friends never to toot or yell a greeting to me from their car. I use 90% hearing when crossing the road, to be distracted is dangerous. Blackhall was caught off guard, he thought the man was giving the all clear to cross the road. These are the valid fears that cause interaction unease. When traffic or similar danger is involved, communication must be absolutely clear.

6.4 Conversations

Even though I have some sight I do not take the initiative to begin a conversation when I am at a large gathering, unless I know to whom I am speaking. There are expected protocols of how one greets a close friend, associate or stranger. Listening to voices is not as accurate as recognising faces and there is always the risk of giving a stranger a hug and asking a friend, “Do you live in this area?” At parties I prefer to dance or remain at my seat and wait for friends to join me.

One of the most difficult aspects of blindness is the way it tends to make you passive in getting to know people. Not to be able to choose freely whom you want to speak with, not to be able to get to know somebody better by making a special point of greeting him or her. This problem has always worried me since I lost my sight (Hull 1990).

During the four hour trip he does not say another word. I’m afraid he feels embarrassed about having revealed so much. I had already noticed this phenomenon at the hospital. People would come in, friends and strangers alike, sit down and disclose themselves without the slightest warning. This behaviour, quite new to me, occurred so often that I questioned Dr. T.

“What do you think Dr. Freud sat behind the couch?” he said. “I am the ideal garbage can because I cannot look since I can’t look. Ideal because looking is judging. They confide their burdens, never their joys. My anonymous quality reassures them. My blindness is the darkness and the grill of the confessional. Most of them avoid me if we have to meet later on.

Among these people who intrude into my life, there are several types. The pest, who can’t conceive of my not being at the total disposition of everyone. He sits down, tells me about himself, his ailments, his life, his friends whom I do not know, all this for hours. When completely exhausted I protest. He becomes violent, because after all he has come all the way to entertain me. Not to accept his charity is unacceptable to him. Garbage can I am. Garbage can I must remain.

The frustrated one, who throws himself at me in an attempt to fill up a void. Out of self interest he wants to please me by arranging my
things, which enrages me. Exasperated I am forced to mark out my territory in order not to be dispossessed.

Finally a more amusing variety who takes advantage of the situation to live out a fantasy. He describes a flight where his neighbour shouted drinks and sentimentalised about his Scottish heritage. Later the attendant told him the man was Chinese (De Montelembert 1985 pp. 226-227).

The conversation theme provided much insight. I arranged a lift with an acquaintance, following a research sharing. On the drive home, the woman shared intimate and private problems. I asked why she trusted me. She replied, “I feel you have an extra sense because you cannot see. You can understand more deeply.”

Some people with visual loss will develop personal qualities and skills because there are more daily challenges to overcome. This does not create automatic counsellors, and extra senses. A physical disability does not automatically make you a better or more giving person. They are myths and generalisations that can feed the ego but create a burden of responsibility to rescue people, to listen to strangers’ hassles.

I have travelled long distances with and without a guide dog; without her it is hardly an exaggeration to say that nobody speaks to me, with her, everybody speaks to me ... As between one human being and another, providing they have souls to lose as well as bodies to be kicked, any kind of dog, especially a guide dog, acts as a catalyst (Blackhall 1971).

Blackhall viewed his guide dog as a positive conversation starter. Other people with visual loss considered it aggravating that they would only be greeted through the guide dog, for example, “Isn’t he lovely. What’s his name?”

6.5 Getting Things Done

I am unconditioning or reconditioning my attitude to time. Collaborating with Kelvin and reading the autobiographies, I recognise that I have stressed myself by expecting the time standards of a person with full sight. Hull, in the quote below, describes how the activities of daily living take longer. My sense of limbo status involved me in trying to do things as quickly and efficiently as people with full sight, not acknowledging that it takes longer to organise lifts, prepare meals, listen rather than read etc. By acknowledging that it takes longer, I am more realistic. The balance is always between maintaining independence and choosing to take longer, and recognising when to ask for help.

The passage quoted below highlights the need for concentration and conscious thought in carrying out daily activities. I see a difference between losing sight as an adult and as a child. I adapted without realising the extra effort required. It seemed normal to be vigilant when I was walking. Observers
often say I look purposeful when I am at the shops. I am concentrating absolutely on what I am doing, and shut out other noises and distractions. This happens automatically.

Sighted people can bend time. For sighted people time is sometimes slow, sometimes rapid. They can make up for being lazy by rushing later on. Things can be gathered up in a few minutes. It is a bit like the change in your time when you go by car. Journeys that previously took two hours, now take twenty minutes. You are amazed at how much more you can squeeze in. In this way you force time to your will.

Hull explains that his space is confined to his body or the extent of the cane.

Most things are fiendishly more difficult. What the Americans call peripodology, which seems to mean the science of going around on foot, is probably the most difficult enterprise for the newly blind person to tackle. If you lose your sight in mid-life there are not enough years left for you to develop that almost acute awareness of obstacles that most children acquire without trying, in the twinkling of an ear. I will tell you later about hearing the lampposts coming.

It is so infuriating when things that have been childishly easy, requiring no effort at all, become dangerous and nearly impossible, demanding the most concentration and skill (Hull 1990).

6.6 CONCLUSION

It feels trite to conclude a subject as complex as interaction ease. The skill of interacting can be refined, but it requires effort, motivation and judgement. Positive interaction is challenged by people’s fears and misconceptions about visual loss, the tedium of bureaucracies, discriminatory attitudes and the personal stresses experienced by people with visual loss. After consciously aiming to improve my own interaction I still argue that stigma can be whittled down. Each small gain can expand like the rings when a stone is thrown into a pool.
CHAPTER 7

Do you think it is funny? A role for humour

Precis of the Chapter

This chapter is tuned like a semi-automatic washing machine. It reflects definite cycles in my understanding of humour. Each cycle ruminates then interconnects. It explores the diverse purposes of humour:

To question.
To educate and inform.
To heal and transform.
To confront fears and discrimination and the notion that academic research should be painful.
To create catharsis and release, by laughing at oneself.
To provide a tool for personal and social empowerment.
To help with self-acceptance and clarifying personal identity.
To improve interaction.

The second wash cycle grows chaotic when I draw a parallel between the environment, humour, visual loss and the concept of normal. Each of these issues often provokes intense responses. They involve strong human values; but must be acknowledged as intangible and ultimately undefinable. The wash rests for a while. What is the most important issue regarding humour? - Appropriateness - We press the button to start the last cycle. The dirt and suds have gone and the water is emptying. We are left with cartoons after the spin dry. The cartoon themes are – discrimination, super independence, resistance to asking for help, the concept of normal and deviance. The responses are as diverse as the themes.

The machine stops vibrating as I elaborate on the debate of what is normal. The clothes are clean and ready to be hung up. They can flap in the freedom of sun and wind, pegged, and grounded, but dancing.
7.1 Humour – The Balancing Mechanism

Are the research results on impact of visual loss interpreted too seriously? This question is too broad, and invites generalisations. However I had to formulate questions to investigate the need for humour in the research process. My procedural brain has lectured to me about rigour, clarity and discipline. My constructivist voice has said “You are missing the point.” Why can’t rigour include humour and fun? Why can’t I use humour as a methodology? “But you must take it seriously,” the procedural brain insists.

My thoughts about humour remained in the subconscious throughout my qualifying year. I wrote two humorous songs: “I’m a V.I.P.” and “What is IT All About?” The V.I.P song is a personal celebration of recognising humour as one of the ways I adapt to daily stresses. This does not mean laughing when I hurt myself. I use humour to question, confront, educate and heal. Many of the autobiographical accounts, in chapters five and six share the grief and anger about visual loss and the humour. Most of the theories I investigated on the impact of visual loss, concentrated on the losses or problems. Is this a symptom of academic enquiry? Researchers are compelled to find problems.

I argue that the pressure to find problems creates its own problem! It is equally important to highlight what is going well, otherwise the issues can become problem saturated. I have used humour as a balancing mechanism.

In exploring different methodologies and reading masters theses, an element was often missing – humour! I passionately want to use humour in my thesis writing. I have discovered the many fears that create the attitude of discrimination. People are afraid of going blind themselves. The fear is of the stigma, not being normal, being imperfect, less mobile, helpless. The stereotypes and misconceptions have built an archetypical image of blindness. Associations are with light and dark, magic and evil, pathetic and heroic. Blindness is associated with contradictions and confusions, therefore people are scared of blindness. We are visually oriented creatures, which adds to the complexity. I ask whether research targets the individuals and attitudes that are non-discriminatory and positive. The irony is that such scenarios do not have the same need for social change and so less need for research and improvement.

The challenge with using humour is to ensure it is appropriate. I used humour in the research process and writing the thesis, always asking–

Why am I using humour in this circumstance?

What is the appropriate form of humour?

How will I test whether people have understood my message?

Does effective humour always need to give a message?

I see the major functions of humour, in my research, to confront the fears about blindness. I assert that the themes of self-acceptance and personal identity are connected with humour. The less we worry about what others
think, the less we strive toward universal approval. We can become more discerning when we laugh at ourselves or confront the offensive joke. Laughing at appropriate humour has helped me to mature in my own eccentricity.

7.2 Pleasure and Pain

Lectures were delivered at University of Western Sydney, on how to write a thesis. One speaker said that all research work must involve pain to be of significance. Does this principle come from the religious belief that suffering leads to salvation? How would a theatre of post graduates react to the following statement? All research work must involve pleasure to be of significance. Either statement is a moral presumption.

The need for rigour in the research process is continually emphasised. Is rigour associated with pain? I have experienced sufficient pain already, in the research process. I aim to maintain the professional approach with a symbiosis of humour and rigour.

The ability to laugh, even in the face of disfigurement, blindness or other serious handicap is remarkable in its effects, both for handicapped persons and for those close to them. Examples of persons laughing in the midst of their own pain and handicaps are several, but by no means universal. Indeed, the contrast between say, a blind person, whose life is infected by laughter, and one whose life is infected by bitterness, makes the point. The difference is not the fact of blindness. It is the way a sense of humour provides a healthy acceptance of the handicap (Mullens 1983).

My story, “The Impersonator”, is funny now, but was traumatic at the time. Time and a sense of humour transforms them into anecdotes, and healing occurs (Mullens 1983) I began this research with my own attitude of discrimination. “I am not blind.” I quickly discovered my own ignorance and prejudices. I had to use humour to understand the attitude of discrimination. Writing my stories was definitely a healing process.

Those able to see the humour of a situation are usually more understanding of a human condition than those who can’t. Seeing the funny or ironic side of events is a way of seeing the truth they contain (Mullens 1983).

This statement sounds simple in theory but demands a complex reality. What is appropriate humour? How can we use tact and sensitivity when assessing humour?

With the uninhibited cruelty of former times, people laughed freely at cripples, paraplegics, amputees, midgets, monsters, the deaf and the mute, the dying, the poor and the crazy ... Today this is hardly possible in western culture, where pity and compassion replace the free expression of hostility. In order to laugh at the cripple, we have to
disguise our superiority in a difficult and different way (Gruner 1978 p.92).

I encourage laughter at my own tenacious independence and the societal stereotyping. Stressing humour seems to be a risk! Most of the books I have read on humour have spent pages justifying the significance of humour and why it should be taken seriously. What would an alien researcher say about a species on earth that has a sense of humour, but questions its academic validity.

In reviewing the skills and qualities I have developed to achieve self-acceptance and develop appropriate assertiveness, my sense of humour has been enlightening.

... we are less egotistic and more realistic in our view of the world. We are more humble in moments of success, less defeated in times of trouble and in general more accepting of things the way they are (Morreall 1983).

Humour makes us more open and accepting of others. It does not deny suffering but accepts the incongruity of life (Morreall 1983).

I parallel these assertions with action research. By embracing reflexive thinking, we are studying from the inside, from personal and participatory experience. Hence we must be open to multiple viewpoints and can only make modest claims, therefore avoiding rigidity. We question the generalisations and investigate the anomalies.

7.3 The Intangible Nature of Humour and Visual Loss

Paton (1988) indicates that the researcher of humour is often seen as lacking a sense of humour, and so the butt of jokes, or the wit of the party. The study of humour is seen as liberal and permissive, because it depends on individual creativity and expression. It is not tangible, but more ephemeral and effervescent. Hence it is considered a marginalised topic and the researchers try to prove its social significance.

I argue that a study of people with visual loss is equally as ephemeral and intangible as humour. Specific theories to explain the adjustment or adaptation to blindness concentrate on specific variables. This deductive approach ignores the whole picture. For example, the loss model, advocated by Carroll, blames blindness itself. It assumes a high value on sight and ignores the variation in personal adaptation to life's changes. This creates a simplistic or narrow view.

Humour, like the environment, has a rich set of paradigms. The same richness applies to people with visual loss. It needs to be honoured that often the only characteristic we have in common is our visual loss.

Humour can be a form of social control, and so can be used by minority groups to deal with more serious questions (Paton 1988).
It can be suggested that humour plays a fundamental role in these negotiations, as such it can be seen as the base line of social control, an initial defining mechanism which clarifies and differentiates normal or abnormal, humorous or serious, sighted or blind, tragic or wonderful, all reflect the binary model. Our mechanistic paradigms that must always choose and classify and categorise. A binary model cannot accept opposites, their polarities and unity. There is even a lack of consensus about humour. The only elements agreed upon appear to be the need for surprise and incongruity (Chapman 1976).

7.4 Who Can Make Jokes?

Do Australians have a propensity to derisive laughter? The comedian can break the taboos about topics such as sex or racism. Can non-disabled people make jokes about people with disabilities, and maintain tact and appropriateness.

Andrew Denton won a prize for the program “Money and the Gun.” The theme was a spoof on the Year of the Disabled. Denton interviewed several people with disabilities and people in the street about The Year of the Patronising Bastard. Denton said he was taking the risks, to ask all the taboo questions for the viewers.

I watched Denton’s program with several friends and discussed their reactions. It is interesting to note one moment that everyone remembered. Denton asked a young woman, Evonne, who was congenitally blind, what were some of the most annoying things people did. When she said it was walking away and not letting her know, Denton rose and sneaked away. Evonne heard him and reprimanded. This was a fine line joke as described by Groth (1968) p.28, but it worked. The audience laughed and hopefully they remembered the protocol, as did my friends, to tell a person who is blind when you are leaving her company.

It is harder for a non-disabled person to tell a joke about people with disabilities because it can easily be interpreted as offensive or patronising. It can be done well, with skill and an appropriate intent. No individual can prove that something is funny. It depends on one’s sense of humour and personal values. Ten members of an audience can have a different reaction and interpretation of the same humour.

7.5 Appropriate Humour

This is a subjective issue. I have used continual feedback and reactions from others to determine whether my humour is appropriate. There are particular forms of humour that I find unacceptable, such as practical joking. On rare occasions people have held objects just beyond my reach to test how much I can see. I voice my objections.
We are often told that a sense of humour will see us through all our difficulties. It's no use laughing like mad when we bump into a lamp post or fall flat on our faces. There is a time for laughing and a time for swearing and all of the time is a time for learning ... Everyone has a secret and quiet place at the very centre of his being, a quiet sanctuary where nothing can hurt or destroy. We do well to let our sense of humour bear on the pinpricks and irritations of the day, but we need something more profound than laughter when we have to face the great crises of life (Blackhall 1971 ch 1).

There are definite boundaries to humour. Jokes are often crass, crude and childish. Humour and laughter should never be forced upon people as therapeutic. It can easily become patronising.

Every member of the staff is making a tremendous effort to show us what a jolly place this is. Their actions, if not their words say clearly, Are we down hearted? No, let's show the world how cheerful we all are.

It's all much too folksy for my liking. So far when we've been publicly addressed, every member of the staff has started with the phrase, "Well folks",. This is a phrase that I am to become heartily sick of in the forthcoming weeks. They mean to leave no stone unturned in trying to convince us that to be blind can be fun (Garland 1974).

Garland was undergoing rehabilitation after suddenly losing sight standing at a railway station. He was angry and insulted when the staff kept wanting participants to be happy, and have fun. I emphasise the importance of time, place and form of humour, to convey effective messages and create positive social change.

Egan (1993) reviewed the humour of a controversial cartoonist, John Callahan. The controversy is over whether Callahan's cartoons are funny or just preying on the vulnerable. He asks how far can Callahan push the edges of humour?

Callahan has lost the use of his legs and only retains minimum use of his hands and arms, due to a car accident. He is developing a reputation in America for his cartoons depicting people with visual loss, in wheelchairs, with anorexia etc. Most of Callahan's cartoon's are cynical and often exaggerate stereotype images of dependence.

The issues for me are how far we can push the edges of humour, and most importantly, will the cartoons lead to positive social change?

Do they highlight the patronising bastard, as on the Andrew Denton ABC Program?

Do they confront the benevolence that tries to help the disabled overcome their multiple perceived problems?

Does Callahan's cynical humour confront the fears, hostility and aggression that leads to interaction unease between blind stigmatised and non stigmatised people?
Is he revealing the polarity of people with full sight being scared of people with visual loss, and people with visual loss scared of people with full sight?

7.6 The Ethics of Humour

I felt the dilemma of moral judgement in deciding to use humour and recognise that the humorist's attitude can distort the message. I believe in taking risks and being radical when it is appropriate. The question is, when is it appropriate? When is it ethical to make jokes, design cartoons and comedy skits about people with visual loss? I aim for the humour to be professional, and to highlight the fears, contradictions and stereotypes associated with blindness.

MY BOTTOM LINE

Does this humour improve human interaction and empathy, or perpetuate differences and separation?

7.7 Feedback on my Cartoons

I designed five cartoons to use randomly during the research process. They covered the themes of

- independence
- stereotype images
- the notion of what is normal
- the notion of deviance and trying to prove oneself

I sketched stick figure cartoons with suggested captions, but gave the artist, Gabrielle Tindal, room to alter the captions and drawings to make the cartoons humorous. I was excited to see my sketches transformed and laughed at all the cartoons.

There have been mixed reactions to the cartoons. Peoples' humour varies. Some people interpreted the cartoons in exactly the way I had intended and others perceived different meanings. I wanted to test my ethical bottom line. Did my cartoons improve human interaction and empathy or perpetuate differences and separation?

I showed the cartoons to individuals and groups of people as listed below.

- friends and relatives
- research colleagues and collaborators
- friends in my support group
- strangers, not all of whom knew that I had a visual loss
- school students
- audience members when I have given talks about visual loss
Initially I kept the responses under headings, as in the list, with some idea of age range. However this appeared to be irrelevant. The differing reactions depended on so many factors, such as maturity, understanding of concepts, how much contact and understanding people had of visual loss and its effects on people's lives. How long I spent with the people and whether we had developed a rapport. These variables seemed to be infinite. I tried to design a questionnaire but it was inappropriate. Closed questions and multiple choice were the most practical but also inappropriate.

After showing the cartoons to a number of friends and colleagues we decided upon three open-ended questions:

What are your responses or reactions to this cartoon?

Describe what message it is sending if any.

Explain how you find it humorous or to the contrary.

**CARTOON ONE**

Cartoon one confronts my own discriminatory attitudes. I told the artist to have the person with visual loss being patronising toward an unemployed person. I purposely played with the stereotype image of the blind beggar. I swapped the roles and mixed themes.

Responses:

Most people found the cartoon funny, but often people had to look at it for a while before understanding the humour. People laughed at the facial expressions, and the incongruity – A person with visual loss being patronising.

Comments:

"I suppose people with disabilities can be just as discriminating as the rest of us."

"It's just turning the blind beggar cliche around."

"One minority person giving to another, but I think she's being patronising."

These comments covered the range of responses, and the cartoon did not lead to deeper discussion except that people talked about experiencing many "blind beggars" in underdeveloped countries such as India.

**CARTOON TWO**

In this dog cartoon, the artist used her own captions. I wanted to portray the message of “super independence.” A reflection of my own striving to show that “I was tough.” “I could overcome anything.” This tendency is recounted in many of the autobiographies.

Comments:

"I feel sorry for the dog."

"It doesn't really look like a guide dog."
CARTOON ONE

CARTOON TWO

'TRINNER, ROVER. FASTER'
"I do not like the word git."

This cartoon highlighted different senses of humour. Some people laughed immediately. Others laughed when I explained my "super independence". Others did not laugh. They felt sorry for the dog or did not like the word git.

The dog cartoon did not lead to deeper discussion with any groups. However I was often asked why people with visual loss choose to use a guide dog, a white cane or no mobility assistance.

**CARTOON THREE**

*I can manage thank you* is a cartoon that developed its own character with the artist's interpretation. I asked the artist to portray my resistance to asking for help to cross the road.

I emphasised my pride and stubbornness (There is an element of self preservation and avoiding inconvenience).

Responses:

My friends and relatives rejected the woman who is about to cross the road, because she is so aggressive and "bitter looking." It was seen as the antithesis of my nature and so the cartoon was not accepted as humorous.

People who did not know me also commented on the "kind little boy" and the woman's aggression. Even those who laughed made comments such as "She's a hard, old biddy isn't she?"

One person felt the cartoon could be counter productive because it depicts a person who is so aggressive and angry. She compared it with Al Pacino, who acted as an embittered man who had lost his sight, (in the film the *Scent of Woman*).

A twenty-six year old male said, "I get cheesed off like that. The last time I opened a door for a woman she bared her teeth. You get bamboozled with all this new language and laws and things. No matter what you do you'll make someone agro."

He was referring to the anti discrimination, equal opportunities legislation and the care people must take with their terms and language. He said the cartoon depicted: "you want to have your cake and eat it too." The "blind woman wants to walk around independently but she'll probably cause a prang. Women want you to open doors but they want to be equal."

He concluded - "I think we all have to work out our own stuff before the new legislation and language is going to really work. You have to know where you're coming from."

Some people described the cartoon image as "sad", "irresponsible", "negative" and "funny."

I believe it is the hostile image of the woman about to cross the busy road that confused the message of the cartoon. I appreciated it because of my
background understanding and information. Most people reacted to her aggression. I asked some people to be involved in further discussions about asking for help and the balance between being passive, assertive and aggressive.

**CARTOON FOUR**

Cartoon four was designed by the artist after a discussion we had about what is normal. I have always been interested in people's perceptions of normality. I believe that to question what is normal helps to clarify personal values.

Responses:

Everyone responded positively to this cartoon, most laughed, particularly those who know me.

Comments:

“Well, she's obviously not worried about what is normal. Her disability is just part of her whole.”

“I love the eyes!”

“She looks relaxed, not worried about what other people think.”

Several of my friends and relatives observed that the image portrayed my eccentricity well - that even with no visual loss I would still be considered an eccentric. My visual loss just adds "an extra dimension."

A 65-year-old woman commented, “I like being in the white-haired vintage. I do not feel as though I have to live up to the norm, whatever that is. I am excused for forgetting things. I do not worry about make-up. I think it’s hard on all young people, disability or not. You all have to live up to an image ... and that costs money.” (The points show a long pause when Norma looked at the cartoon and smiled).

I enjoyed sharing this cartoon with people because it was a surprise. I had not commissioned it, Gabrielle sketched it after our conversation about the concept of normal.

**CARTOON FIVE**

The bus stop cartoon was the favourite. Everyone laughed and said it was very clever. I aimed to depict the strategies I used as a teenager to avoid being labelled as deviant or disabled. The teenager, who pretended to read when at the bus stop or on public transport. It was before the days of Sony "walkpersons".

People enjoyed the cartoon. There were many comments like - “It's good to be able to laugh at yourself.”

“I love the bird.”

“It’s something about winning acceptance.”

“She looks so pleased with herself.”
I CAN MANAGE, THANKYOU!

WHAT ARE YA LADY? BLIND OR SOMETHING!

NORMAL? NO THANKS!
SUMMARY

Cartoons 4 and 5 were the most effective in maintaining a positive image of people with visual loss. They both opened spontaneous discussion about themes such as asking for help, independence, the concept of normal. There were no negative feelings or confusion about the images.

The concepts of some of the cartoons could have worked more effectively if the images were altered. The woman crossing the road could be made more acceptable with a less aggressive facial expression. Some people did not realise that the dog was a guide dog. If the image was more like a Labrador or German Shepherd, with a more obvious harness, the images would connect more readily with the captions.

The genre of cartoons proved to be non-threatening for people I did not know. People were interested in the images and gave comments freely. I did not always ask the questions listed above. It depended on how much rapport I had with the people, and how much time we could spend together.

The messages I wanted to convey were made more accessible by the use of cartoons. The cartoons did break down barriers because people could laugh or criticise the images. I carried them with me for months and so could obtain feedback from a wide range of people. On some occasions we flicked through the cartoons and obtained spontaneous reactions. In some groups such as my support group we had discussion and developed the themes. The most
frequent response to using cartoons in the research process can be
summarised by this comment from a friend — “I feel comfortable with
cartoons because I do not associate them with university or academia. We
could just be discussing a film. They stimulated, but didn’t strain my brain.”

*Debating the Concept of Normal*

Normalisation is a rational approach attempt to deal with the very
conditions which have tended to deepen and reinforce prejudice and
tended to set the severely handicapped apart from the rest of society.
Elements of normalisation involve:

1. **Righting the wrongs of the past.**
2. **Bringing the handicapped back into the mainstream of society.**
3. **Developing the “normal” as a risk process that involves the elimination**
   **of the “sanitised life” and substituting for it the possibility of failure, as**
   **well as the possibility of greater rewards** (Park 1975).

Instead of righting the wrongs of the past, normalisation often perpetuated
them. It was too often translated into – making people normal (normal
meaning able bodied). Society was not ready to accept people with disabilities
on their own terms.

Even with the present policy of integration, attitudes supporting
institutionalisation and normalisation remain. However these attitudes are
more readily confronted and challenged. I consider normalisation as a
transition stage. Like the assimilation process of Aboriginal Australians, it is
patronising. Historically, people with visual loss were institutionalised, the
accepted policy then switched to normalisation, and now integration.

In the 70’s, theorists advocated, *The time is rapidly coming when
governments will waken to the fact that rehabilitation is not only the*  
*humanitarian thing to do, but the economical thing to do* (Park 1975 p.33).

Is “normal” still being measured on economic terms? Is it still normal in
Australia to aim to buy a home, obtain a job, have a partner and economic
security?

When I visited the Commonwealth Rehabilitation Centre, in 1992, they
explained that the service is now vocationally oriented. I wanted assistance to
purchase a talking computer as I had obtained a regular, paid writing job.
They said I was “too articulate, competent and qualified”, and I did not receive
assistance. Does this response assume that I should be inarticulate,
unqualified and incompetent to obtain financial assistance? Were my self-
reliant qualities abnormal?

What are the consequences of the normal ideal? Since starting this
research, many friends and associates have said, “We forget you have a sight
impairment. You act so normally.” Does normality mean conformity as a
means of social stability? Many of my autobiographical stories explore the
pressures to act normally. The humour is in the paradox. Some people are
comfortable with me acting in the manner of a sighted person because I'm not acting in the expected manner of a person with visual loss. I do not fit their stereotyped image of stigma or deviance.

If I do not feel like a deviant, then I am not a deviant, regardless of what other people's perceptions may be. Conspicuous sight defects can be a threat to social interaction. People know that they should be oriented to the whole person, not a specific attribute, but this does not control the subconscious fascination or repulsion of visible defects, hence we have the taboos, people feeling awkward. Do I experience less stigmatising because I have no visible sight defect? I definitely receive more awkward responses, on the rare occasions that I use a white cane (see story, "The Impersonator").

I love striding along a bush track by myself, riding a two wheeler bicycle, and travelling alone. I believe humour can help to remove the narrow, stereotyped role expectations of what is normal for a person with a visual loss.

CONCLUSION

Does this humour improve human interaction and empathy or perpetuate differences and separation?

Humour can serve many purposes, such as empowerment and education. It is an excellent tool to balance the exaggerated the problems of visual loss. Using songs, cartoons and funny anecdotes, I was able to confront discriminatory attitudes, and yet people were not threatened. Whether this interaction creates long lasting social change is a broader issue. However it raises awareness, and I was continually asked questions. The answers helped to demystify erroneous concepts, reduce fears and provide practical guides on how to interact with people with visual loss.

The crucial learning was how to determine whether my humour was appropriate. Obtaining a laugh became less important. I continue to use humour and ask for feedback.
CHAPTER 8

Toward Interaction Ease Through Stories, Poems and Songs

8.1 Introduction

I have experienced much change over the last five years. Humour and storytelling have become important personal tools. Sharing stories helps to change discriminatory attitudes. I often laugh about interactions that were upsetting at the time. As a teenager I felt confused about what role was expected. Did I have to act as a blind or sighted person? My images of a ‘blind person’ were stereotyped, the dependent image. I have found that people can read and listen to my stories, then laugh and ask questions. Storytelling is accessible and non-threatening.

Writing the stories shifted my consciousness to question any supposed absolutes. For example, interaction unease can transform to interaction ease, with self-confidence and improved communication, the use of humour and clarifying personal values. Even if someone acts in a patronising or inappropriate manner, in reference to my visual loss, I now experience less uneasiness. It is a personal maturing and acceptance that says I do not have to prove nor validate myself because I am a person with visual loss. The supposed absolute of interaction unease (Goffmann 1968) is a construct, and with education and motivation it can be transformed to interaction ease.

I believe that positive social change is occurring in Australia, in support of people with visual loss, and it needs to be expanded and maintained. The myths and stereotypes must constantly be debunked, because such images as the heroic or helpless blind person are still perpetuated, even by agencies providing services for people with visual loss. The stereotypes can be perpetuated for fund-raising campaigns, or to maintain a status quo of the needy and the helpers (Rowland, 1985 Scott, 1969).

The authors of “Womens’ Ways of Knowing”, (Belenky et al.) have best described the evolution of my ways of knowing. Initially I reacted to two fears – a fear of academic jargon, and a resistance to my epistemological understanding as a person with visual loss. I asked how is it different?
Exploring and stretching my perspectives as a person with visual loss, has been liberating. I now recognise that it does require more daily effort. I resisted asking for help, and now recognise the stress of lack of reciprocity in social interactions. I often have to ask for help, and do not have the time nor resources to always offer reciprocal help.

The basic win/win skills of conflict resolution, that I have practised for ten years supported the dialectic and reflexive skills of action research – empathy, active listening, negotiation, brainstorming and developing options. I moved from a positivist vision to a knowledge “that is constructed, not given, textual not absolute, mutable not fixed.” (Belenky et al 1986 p.10) Simultaneously I had to distinguish between the effortless intution of subjectivism in which one identifies with positions that feel right and the deliberate, imaginative extension of ones understanding into positions that initially feel wrong or remote (ibid). My academic transformation was the integration of reason and feelings.

My thesis topic suggests the need to reassess the impact that visual loss has on people’s lives. There is still need for increased awareness, improved access and an understanding of the possible side effects of the use of adaptive technology by people with disabilities. I consider that personal change needs to complement these educative and physical changes. Political and societal awareness of visual loss is growing. Each individual needs to ask questions and challenge personal values and actions, to help maintain and promote positive, social interaction.

I have told my stories at Playback Theatre and had them read on the local radio station. They aim to make people curious, to encourage questions and interest, to have people reflect upon their own interaction ease and unease. I want my stories to stimulate questions such as: What is your concept of normal? Do you feel comfortable when you meet a person with a conspicuous physical disability? These are not simple questions with simple answers, but involve the contradictions, ambiguity and complexity of human interaction.

Like action research, storytelling focuses on the particular rather than the general; the particular people, circumstances and issues. Positivist theory seeks to present the general or universal theory with an authoritarian generalisation such as “The impact of visual loss on ageing women in Australia is..............”

The narrative genre offers a flexible tool for shared learning. The readers/listeners can identify more readily with the story characters and their experiences. Stories can portray a rich and colourful view of complex, theoretical problems. In contrast with measured, controlled experiments and data collection, my stories aim to embrace the pain and passion of human interaction. They ask the same questions, challenge the same misconceptions, explore the same complexities as in a theoretical report. However stories change from one moment to the next. The distinctions between fact and fiction become less crucial. By concentrating on the particular, they can develop a rapport with the audience. This rapport raises awareness and so can lead to positive social change.
I collaborated with a friend to write the story below. I kept a list of questions that were asked by people who read my stories, heard them on the radio or saw them acted at Playback Theatre. The question – “What’s the worst thing about being visually impaired?” was asked on several occasions, so I wanted to research this question. I began to ask people why this was important. Two teenagers said, “Well it makes it easier if you hear what’s worst, then you feel you can cope with it somehow if it ever happened to you.”

The story proposes that the “worst thing” depends on a variety of factors. At age eleven, the worst thing was losing my ability to read, and not being allowed to race off on a two wheeler bicycle. At age seventeen, it was the pain of watching my friends learning to drive. The value you place on activities and independence will affect what is perceived as the worst thing and that will vary with age, mood at the time, self confidence and the amount of stresses being experienced at one time.

8.2 The Worst Things for People with Visual Loss

“What’s the worst thing about your visual loss?” people ask.

“Losing things,” I say. Burying trowels in the garden, and hunting for elusive cassettes in the depths of the bed. Local retailers often ring me first, when a bag is handed in, because I have developed a reputation! But hang on, I can think of something worse.

Cords in the study. They’re everywhere. Black, grey, orange, white, all tangled. The telephone rings and I trip on the pink cord.”

They say that people with visual loss should be more organised, and I do try. Rubber bands around the streams of lamp cord. Recharge the battery on my tape recorder, so I can dispense with the cord. Microphone on one side of the desk and headphones on the other; but cords like tangling.

They hook around the wheels of my up-market, roll-along, backless chair, and sneak into the wrong plug holes, so that I tape nothing with the headphones, while the microphone listens.

Technology may reform me, with the lap top, portable, talking computers, they have no cords! The robot bleats commands and reminds me when the batteries are running low. It is a thrill to press the button and the voice tells you the last word you typed.

There are headphones without cords too. Yes, you can listen to Elizabeth Jolly, with a little black box to substitute for the cord. The drawback is that Sennheiser, the comfortable, quality headphones – do not come cordless.

I haven’t finished. There are still plenty of things that can drive people with visual loss bonkers. You are enthralled by a Leon Uris adventure. The hero is about to die, when the tape says: “This is the end of side two. Change the side selector switch, which is located third from the top on the control panel,
and turn the cassette over. Please do this now." I dive for the stop button and tell the good reader to shut up.

I ring a friend, who has 3% sight, and ask for a dose of the worst things.

"Toe nails." says Amanda. "Diabetics with visual loss are not supposed to cut our toe nails in case we miss, and cut the skin. Then it could be the toe that goes. I can file my finger nails, but the toe nails are like steel. It's awful to go into town with gunk under your nails."

"I fare well with lipstick, eye shadow and mascara, the only defect is the denser spread on one eye, but eye liner is beyond the tactile territory." Amanda explains.

Amanda would love to wear eye liner, but it is too risky for the image and the eyes.

"Dining can be the real pits," Amanda says.

The smorgasbord, where I add a dollop of cheesecake to my coleslaw; or the mouthful of burning sauce I thought was dip."

At the local markets, Amanda cannot read the stall signs. She follows enticing smells and waits in queues, to hear the orders.

"It's okay to eat," she says, "but I still make a mess. Things fly off the plate, and there's always something left on my place mat."

"I remember the starched, white bib we had to wear at the Royal Victorian Institute for the Blind," I reminisce.

I'd still prefer to drop beetroot on a silk designer label skirt, than wear a napkin bib.

Peas and bony fish are also hazards for many people with visual loss. Peas roll, and fish bones choke.

Transport is the bush dilemma. I can catch the school bus, and have lifts with friends, but Amanda has to fit into dialysis timetables. We both get sick of asking people and thanking people, and fitting into their schedules. "You can feel appreciative and stroppy at the same time", says Amanda.

My worst hang-up is false pride. I would rather be run over than ask for assistance to cross the road. I thought a white stick could halt traffic and fix my problem, but half the drivers don't notice it. I'm in that limbo category of too much sight for a white stick. I was taught by a mobility officer, to use 90% hearing and 10% sight, and to walk an extra one hundred metres to the crossing, but I soon resumed old patterns.

The intake of breath. Ears on full alert. Limbs stiffening, then hurtle across, or plant on the white line, and quake. It's worse to be guided across the road by a person who panics halfway. Drivers don't wait for explanations. Striding down the middle of a quiet, dirt road is my image of bliss.
There is often an unrealistic expectation of people with visual loss, the inspirers, overcoming great odds. I often fulfil the role of super person, the achievers. I do not really need help. By acting as the super coper I match the stereotype.

After a day of losing my bag, stubbing my toes, missing the bus, and trotting off with someone else’s supermarket trolley I drop the role. I need to unwind. I play the tantrumming, cranky hag. My husband doesn’t take it personally. Home is the safe place to curse and feel sorry for myself.

The question “What is the worst thing about your visual loss?” is often asked, and has made me look at my own fears. The super coper image I strive to fulfil. Maybe my worst thing about visual loss is the role playing.

“The Worst Thing about Visual Loss” questions the loss and tragedy theorists I reviewed in my literary review. Severe visual loss or total blindness can be perceived as a disaster and multiple loss for an adult. In many cases this perception alters just as dramatically because people adapt. They learn new skills, are given personal support and technological aids.

It is important not to trivialise nor dramatise blindness and visual loss. The story shares “the worst things” for me and Amanda, and they change regularly. Today my “worst thing” is having a letter from a good friend and no one handy to read it. I’ll have to be patient until Martin, my husband, arrives home.

The “worst things” for a person with visual loss can change depending on the challenges of the day. I do not call them problems after reading the theorists about adjustment to visual loss. Many label people with visual loss as saturated in problems. I suggest that it is problem oriented to people who place a high value on sight and physical independence.

Blackhall (1961) said the blind have a motto, “I can manage”. This is the issue I explored. When is it appropriate to ask for help? When does it become false pride to resist help?

I assert that asking for help becomes one of the biggest challenges for people with visual loss. Amanda summarised it well by saying – “You can feel appreciative and stroppy at the same time.” Many of my friends who have read the article were surprised and can empathise with this sentiment.

Most people with visual loss do have to organise more and be more vigilant, just for safety. Asking for help is an extra challenge. Rehabilitation needs to deal with this issue:

How to ask for help and maintain dignity.
Choosing who is safest to give help when crossing a road.
Dealing with the stressful feeling that we are not always reciprocating.
Giving clear directions about what help is required.
Being assertive about the limits to help required.
Exploring why people resist asking for help.

Over the last two years, I have experienced a noticeable decrease in stress by dealing with this issue. I am now much clearer and tell people to give honest answers when I ask for help. A personal rule is that I do not feel rejected or take it personally when someone says no. Just this standard has made it easier. I no longer feel guilty nor anxious when I ask for help. I am de-programming as a 'super person'.

8.3 'The Impersonator'

A silver coated fountain pen was poised above the next question on the government form.

"Do you think you need an escort, Claire?"

"No thanks," I replied. The question invoked images of guide dogs and wheel chairs; just I and the Blind pass would suffice.

"This will be handy," he commented. It says you can use it on trams, trains or buses, you know."

"Yes ..." I pondered. Part of me liked the idea. It was my right after all, I deserved it. The other part of me felt distaste. "I’m not blind, I do not need a blind pass. I’m as mobile as anyone with full sight."

The form was sent away and I received an ugly orange Blind Pass in the mail. Somehow it symbolised independence. My substitute for a driver’s licence. It did have its advantages. I didn’t have to wait in queues, or hunt around ticket boxes. It meant free travel on the “Honourable Metropolitan Public Transport."

I felt satisfied when I walked through the ticket gates at peak hour. The uniform, in the ticket box, would look at the ticket and examine my face, but would not have time to put me through the third degree. I was the impersonator.

How dare I walk the streets of Melbourne like a normal person. Where was my uniform? No guide dog, no white stick, no deformed eyes, not even a pair of spectacles; my clear blue eyes met theirs.

The first attack occurred on a tram.

“You’re not blind!” the uniform accused.

I, the Impersonator, felt guilty, confused; the mind began to justify.

“Well, I’m not totally blind, but I have less than ten percent sight, so I am.”

The stomach turned to spin dry. The mouth confessed.

“Well I have less than ten percent sight. You can’t tell by looking at me.” I confessed.
"You're right there, young lady," she decreed. "I can't prove you're a fraud here, can I? I'll just have to let you go in."

Claire Daly provided some afternoon drama for the passengers. Their eyes admonished or inspected. Sometimes they joined in the attack, sometimes they defended. "Leave the poor, little thing alone!" Attack and defence were equally offensive. I smarted and put my head in the air, nose turned up.

The most aggravating emotion was the guilt. I felt as though I should look blind, should peer or feel around the seat to justify myself. The challenges were frequent enough to make me dread showing the ticket. I didn't know appropriate assertiveness then.

I considered a white stick as a possible solution. It was a plastic, fold up creature that flicked out like an anaemic sword. It was a uniform. Holding it I was publicly blind, but it didn't work. I became an authentic Impersonator. The first attempt was the last.

It was peak hour in Swanston Street, Melbourne. I tapped the irritating thing in front of me, the way I'd seen them do at the blind school. Their reaction amazed me. People moved away from the white creature, aghast.

"Why does she need that white stick, Mummy?" a youngster enquired, pointing at my sword.

"Do not stare at the lady, Billy." Mummy scolded, as she stared fixedly at me.

It was comforting to reach the train carriage and dispose of the label. Impersonating the blind was not for me.

I discovered an excellent one-liner quite accidentally one day in Sydney. I had the delight of hailing a bus myself as I heard a woman announce, "Here comes the 423." The driver was overdosed with garlic and sweat.

"Why have you got a Blind Pass?" he demanded.

I sighed; another futile exchange.

"Because I've got a brain tumour," was my resigned response. His reaction was magic.

"Oh, I'm sorry, I'm sorry, I didn't know. I'm so sorry," he looked stricken, and flipped into his own language. "Madonna! Ecosibella! Che peccato."

I felt no compassion, but rather a sense of propriety. I strutted to the last remaining seat.

My new one liner for the interrogators is, "I'm legally entitled to a pass and not all visual impairments are conspicuous," but I haven't had the opportunity to try it.

It's now called a Visually Impaired Person's Pass, but you can't use a pass in the bush. Now they think I'm impersonating a tourist because I carry a back
pack around Coffs Harbour. There’s that friendly smile, and, “Are you travelling around here?”

I explain that I do not drive and the backpack is my shopping bag, brief case and handbag. Some feel cheated and others consider it quaint. No one knows – I’m really impersonating the sighted!

“The Impersonator” is a retrospective story of the self conscious teenager, who was confused about roles. I felt guilty about my independence. I did not fit the visual stereotype image of a person with visual loss. My eyes look clear and I usually maintain eye contact. When I asked for help or showed my travel pass I often had to justify and defend my status.

However, I argue that there is reciprocal responsibility to alter attitudes and actions. I had to understand my sense of limbo status. Was I an Impersonator by choice or was society compelling me to play specific roles? Positive interaction must be holistic. The individual and society need to re-educate toward interaction ease and self-acceptance.

8.4 What is IT all about?

Does society compel people to validate? I kept returning to this question as I explored different stages of the research process. I was aware of my past challenges, having to prove myself, as shown in the story, so I discussed the issue of validation with my research collaborators.

Those studying course masters often had to prove the worth of Social Ecology to employers, interested people and other tertiary students. Social Ecology is still seen by many as an unorthodox, radical paradigm.

I chose Action Research because it honours creativity, cooperation, holism, and a radical approach. However I challenge the academic process that insists upon validation. I had to justify why I had chosen Action Research and the methods of story telling, cartoons, unstructured sharing etc.

The argument is that you must validate and justify, to prove rigour, and that your research is worthwhile. Is it a contribution to knowledge? Can it be falsified and debated and questioned? Do you have a quantitative literature review? I was questioned by supervisors –

Why are your personal stories important?

How do you measure whether your interaction has improved?

Why have you written your paper this way?

What is the value of your increased self-acceptance to the wider community?
I had to confront my responses and clarify whether they were reactions or actions. When was my intuitive voice sending clear messages and when did I need the support of reason and objective questioning?

My response to all these questions was that there was an "intrinsic worth" (Naess 1989) in my stories, and increased self acceptance. How does one measure the success of interaction? My non academic answer is that two people are mutually satisfied. There is less role confusion. Those who are asked for help can say 'no' more clearly. The person asking does not feel offended. I have become more assertive and informed and so can educate people about visual loss. I do not believe this can be measured in a positivist sense.

Is the pressure to prove, validate, justify, measure, a reflection of a society that reveses materialism, and exponential growth, the need to achieve to be worthwhile? This question has even more impact for people with disabilities. There is more perceived need to justify and validate in a society that values body image, mobility and ambition. The humorous edge to this debate was when I read texts on humour. The first ten texts I read had paragraphs or pages justifying why humour was worth researching! How idealistic is the value of "intrinsic worth" (Naess 1989)? Following many discussions on the question of validation I responded with the song below.

What is IT all about?

People go to university,
And they think they're really smart.
They sit and talk and deliberate,
They worry and study and collaborate,
Their spirits are oh so very intense!
But our lost dears
Are not so clear
On what life is all about.

People try to intellectualise,
It's a lifelong skill to acquire,
With "isms" and "ologies", it's problematic
And turns them into jargon fanatics,
Full of pedagogic paradigms,
Is it worth the slaving,
For distinction gradings,
Achievement is what it's all about!

Science peaks the top of the echelons,
It's discovering absolute truths,
With logical facts they hypothesise,
Experiment and rationalise,
The trouble is the truth just keeps on changing,
From Euclid to Newton
To Quantum Physics, and now they’re sure it’s Chaos.

Universities offer discipline,
And disciplined they are.
At planning and recruiting new students,
Then teaching them the finest rudiments,
But will our learned feel confronted,
When a smart child
With an innocent smile,
Explains what IT is all about!

University wastes heaps of paper,
But it’s all justified.
They research recycling strategies,
But are not quite ready to implement these,
We’ll have to maintain the elite traditions,
Or intuitions
Will come to fruition
And threaten what IT is all about.

8.5 Brave Little People

“Isn’t she brave?” exclaimed the social worker. “She’ll be walking by herself soon, won’t you Judy?”

“Yes,” puffed Judy, as she gave us the big smile.

Relief for the adults. The adults smiled back and she continued her performance, dragging mangled feet between two rails, her sweat-covered face reset with concentration. The sightseers continued their tour.

Feeling shaken, I followed my colleagues down the rehabilitation centre’s shiny corridor. “This is the interview room,” piped our guide. Twelve eyes peered through the window where a client was being “privately” interviewed. I still dwell on Judy’s smile. The one I could not return. Her bravery game was transparent. Had I once played that game, too?

The masking tape had been ripped off, leaving fine, blonde hairs. “I’ll just move your head this way dear. Good girl, hold still.” Another tape was plastered across my forehead and ears; at least it would tear less hairs. The masking tape was the villain, not Doctor Armon. She called me a “brave girl” and the ripping was always quick.

I wanted to ask so many questions: “Will it take much longer? Why do I feel so fuzzy?” “Can I have a blanket on the steel bed?” “Will the hair grow
back soon?” But there wasn’t time to talk. I had to stay still and be brave in the X-ray room.

Dear Claire Bear, We are all thinking of you and have heard what a brave girl you are. Get well soon, love Aunty Molly, Uncle Bill, Frances and Betty.

There were rewards for bravery in the hospital wards. You got chocolate and flowers and visitors; but I wasn’t really sick. It was the tests that made me sick. The lumbar punctures, the injections, the horrible stuff that made me feel sick and drowsy and the food that came on a big steel tray. I wanted Mum’s porridge and lettuce with chicken salad that was served on a blue plate with flowers around the edge. Hospital plates were always white and you had to eat even if you were not hungry.

One day there were lots of visitors: Mum, Dad, Gran, Kath and Bob. Everyone was merry and I got more chocolate and flowers. They told me what a “special person” I was and that my favourite doctor was going to make a “special visit” that night. It was a “special day” and I was being given “special presents”. When everyone left I felt “special”. It had half worked.

By myself I asked, “Why am I special? What do ‘special’ people have to do? Is everyone else ‘special’ too? Why am I to have a ‘special visit’ from the doctor? Why can’t I go home and not be special any more?"

Doctor Smith arrived by himself and it was much better without the parade of nurses and other white coats. “I must be special because I have him all to myself tonight.” The room was dimly lit and Doctor Smith removed his glasses. He only did that when he was having a chat but he did look concerned. It was duty time. Time to be brave.

My curiosity waited whilst we talked about the family and what I had eaten for lunch. Brave people are always meant to be patient. Eventually he enlightened me: It was to be a “special operation”.

I knew Doctor Smith always told the truth so I asked, “Will I go blind? Will I die?” He did not know. No one knew, that was why they had to open up my skull and have a look. Next I launched the dreadful question: “Will you have to shave my hair?”

The truth was out. Catastrophe for an eleven year old with long, golden locks. I tried to forget the image of a little boy sitting on the steps, with a bald head. Danny Kaye singing kind songs and the children being cruel. I might become like that little boy in the film, The Ugly Duckling. The bravery stunt was shattered and I burst into tears. Doctor Smith looked lost. A crying child. Vanity was my only worry. Death, blindness, even a craniotomy did not perturb me but I refused to be brave about having my head shaved. That was asking too much. Even a “special, brave person” would not go that far.

It was two months later: another “special day”. I was going home. Dracula, the blood sampling sister, had taken me for a wheelchair tour of the hospital on the way to the exit. My flowers and presents were placed in the front seat of
the station wagon and I was lifted into the back. The queen sat amongst her pillows gowned in a new, pink nightie and negligee.

Dad was so soft. He showed all the signs: tenderness, anxiety, too many. The signal for bravery duty.

The fantasies began. Dad has the job of telling me I am going to die. The church is overflowing with mourners. Father Peter will extol my bravery. The cedar coffin with gold handles is gently laid in the grave surrounded by black figures bewailing my demise. The only pain was that I was not there to participate.

We drove around the Yarra River and admired the trees and birds. I continually asked about home. We both knew I was being prepared, but it finally came: the bad news or maybe good news. Going to the Blind School was better than dying. We drove to the school, and I made all the right comments because Dad was so raw. “Wow, it’s got a swimming pool and bikes and ...” That was all I could pretend. It was so huge and cold. It was much easier to think about going home today.

Our guide at the rehabilitation centre clasped her manicured hands and clicked her tongue. “I shall leave you here for ten minutes and you can chat to some of our clients. They do some wonderful work here.”

Her high heels marched from the craft room and I sat next to a twelve year old boy. He was in pain, with bone cancer, and was trying to use his limp left arm.

“Are you writing a thesis?” he asked, giving me a resigned glance.

“No,” I replied, “just having a look around.”

“So now you’re going to look at me, are you?”

His frankness shocked me. I was repeating the invasions that were perpetrated on me during my childhood rehabilitation.

“Are you sick of sightseers?” I asked.

“I’m sick of questions,” he replied.

He was sick of sickness, sick of hospitals, sick of sightseers and sick of specialists. He was fed up with being brave.

We drew pictures together for a while, in silence, and he gave me his to take home. His aim in life was to ride a motor bike. The picture showed a motor bike rolling down a cliff toward the sea with Tom chasing but not quite catching it. He drew tears all over the face.

“Brave Little People” is exploring Scott’s (1969) theory of socialisation, that we learn as children, what roles we are supposed to play. Shirley Maclaine was interviewed at the Canberra Press Gallery, in 1993. She said that our whole lives are an act and we keep playing different roles.
I believe that whether or what roles we play depends on so many factors: societal, family or peer pressure and support, personal will, whether we feel drawn to or reject the role, whether the role is clear. There were advantages and disadvantages about being called “special” and “brave”.

I have no expertise in how to work with children who feel the need to play roles. In retrospect, acting as though brave and special meant that I thought more of others and forgot about my own problems. Experts may say it is a child denying her feelings. There are also problems in acting bravely, from a feminist perspective. Thinking of the adults first can set a chauvinistic pattern where the woman puts the man first (Freidman 1965). Over the last five years I have confronted this tendency and de-rolled. It had become a gender issue.

In recent years I have de-rolled from the brave and special person. It has overtones of superiority and my philosophies are toward being cooperative and developing a sense of community. There are contradictions in the brave and special roles. Half the person thinks of others, the other half is special, and I often asked “What is special?”

Discussing these issues with my collaborators I have reached a personal reconciliation. Several close friends have said, “I can hear what you’re saying, but you are still special.” I now see it as a compliment and as an adult I do not have to play any role except being myself.

8.6 How Much Can You See?

“How much can you see?” is a common question I am asked, and it is not easy to answer. I had a student once who appeared to have blond hair and blue eyes at first meeting. In the second class her eyes and hair were brown. By the third class I was amazed to discover she had red hair, and green eyes. The light, the room, the distance and my emotional state all affect what I can see.

Children usually take the practical approach. They stick up fingers, “How many?”, or ask “What colour is my jumper?”

“Can you see that bird over there?”

“What does this say?”

A child observed me making a telephone call one day.

I know how you dial the right number,” he said, “You count the holes.”

I hadn’t even realised this myself. It was a skill I had acquired involuntarily.

Government departments have defined my sight as less than 10% acuity. I could not find one number in the colour blind book. I could not see the eye chart with my left eye and only the top row with my right eye. For side and depth perception I rated nil, but I do see colours and depths, my way.
I have my own sort of sight, a sight that sees castles and space ships in inner Sydney. I was deflated to discover it was a house being demolished and a rubbish truck.

I can see cars, but I was stunned one morning when I saw a woman sitting in the drivers seat of a holden. Cars had always appeared empty. I was so excited I stared at the driver, grinning. She must have experienced some reservations about her appearance or my sanity.

I had full sight until the age of nine, when a glioma of the optic chiasm started to affect my vision. If someone describes something, my imagination and visual memory can create the scene, but some people are obstinate.

On a school trip, a teacher pointed out some beautiful, red flowering gums."

"Can you see it, Claire?"

I said "No." The next twenty minutes were spent, trying to force my eyes to see the blossoms. He moved the bus, pointed, and gave compass readings and marched me around the cliff edge. If it had been physically possible, we would have abseiled down to see the tree.

I like to comment on scenery and flora and fauna, so I call anything with four legs a baa moo. I'm then protected. Could be a sheep or a cow or a camel! I'm non-committal.

On many occasions I've gasped with wonder, "Isn't that a beautiful ...." then the shape focuses. The beautiful is a piece of rubbish. My eyes had created a delicate wild flower.

I like cloudy days. Shadows and lights mix everything. Faces become pasty balloons and shadows can become like branches or rocks; but even more than cloudy days I like questions.

"How Much Can I See" is an information story. It attempts to give my visual perception of the world. When people ask me whether I appreciate beautiful scenery, the answer is yes. I do not know what I am missing out on. I see the mountains and greenery, and clouds. I only know about the tiny flowers, birds and farm house on the hill if they are spoken about.

The government tests do not give a realistic impression of what I see. The story explains how contrasts and cloudy days help my vision. I have a low light intolerance and my eyes tire, so do the other senses. By the end of the day my senses are often overloaded from concentration.

This research has made me interested in visual memory. Last week I was waiting for a friend to pick me up. A white station wagon pulled up at the corner, and I opened the door to climb in. My eyes saw Carole, my supervisor, sitting in the passenger seat. I clearly saw her curly hair and the dress she had on the night before. The person then spoke and the phantom vision transformed. It was the wrong car and the wrong person.
I often find that my vision is most obliging, it creates what I want. Other writers who have no functional vision provide an interesting comparison on the issue of visual memory.

People I knew before I lost my sight have faces but the people I have met since don’t have faces. I used to find the contrast between the two groups of people disturbed me. I could not relate one set to the other set. I knew how I knew the first lot, by their faces. How could I ever feel that I really knew the second lot? As time went by the proportion of people with no faces increased (Hull 1990).

Hull was stressed when he realised he was forgetting what his wife and child looked like, I had wanted to defy blindness.

I had sworn to myself that I would always carry their faces hidden in my heart even if everything else in the gallery was stolen. To recapture the face to those close to him Hull now visualises a photograph, he remembers from his sighted day. Experiment yourself. Try visualising a close one who died some years ago, now visualise a photograph. Which is easier?

Increasingly I am no longer even trying to imagine what people look like. My knowledge of you is based upon what we have been through together, not on what you look like. There is a further development; not only do I not know or care what you look like, although I still have a few qualms and doubts in the case of women, I’m beginning to lose the category itself. I’m finding it more and more difficult to realise that people look like anything (Hull 1990).

No, I do not want to get used to this, and I struggle so that I will not be overwhelmed by the invisible. Every day I force my brain to perceive visually. Since I can’t constantly ask questions I arbitrarily assign colours to flowers, to taxis, to women’s hair, to sarongs, to dogs (De Montelembert 1985 p.208).

Throughout the book, “Eclipse Nightmare”, De Montelembert acknowledges that he places a strong value on the importance of visual concepts. He was an artist before losing his sight and so colour and visual aesthetics were probably observed more keenly than the non-artist.

I am blind but I see through memory. I cannot imagine a world devoid of visual images (De Montelembert 1985 p.69).

8.7 Blind Woman’s Bluff

I strode down the bush road with lungs pumping. I strode down the bush road, full of exhilaration. Each step was a declaration, swinging from my hips and crunching on the gravel. I was walking to Kalang Hall. No sun to distort shapes and create blurring shadows. No cars to spew their nausea and confuse the quiet, the perfect combination for my eye sight. The road was
mine; I was the vehicle and my striding became a dance. I wanted to tell the moon, "I'm the driver. I'm in control."

The trees understood. They watched me stride past. No listening for cars, peering at sign posts, avoiding rubbish bins. It was straight down the middle of the road. Even if the bitumen was hard, it was my declaration. I'm walking to Kalang Hall.

I was much more drugged than the stoned people I had left back at the cottage. Moon had captured everything in its silk. I could even see a letterbox and an empty branch, that showed off its nakedness. Wouldn't it be good to throw off my red dress and become the hills, the trees, the cow. She stood and I stopped. We both chewed a while. I resumed the rhythm of my dance.

I'm walking to Kalang Hall. I'm walking by myself and can see better than in the day. I can't get lost and there is no-one I have to recognise, nor greet nor share my feelings with.

It was the thrilling delight of being alone. I could see, smell, hear, experience. I laughed at the moon and pirouetted in the middle of the road. It was hard to stop, just for a moment, but even foot-steps interfered with the stillness. I needed the paws of a cat.

A car passed and I hid in the bush. I felt like the nature nymph, watching a grotesque creature. Its eyes glared at the bush as it snorted and rumbled by, leaving its stench.

Following the moonlight I skipped and zig-zagged up the hill. I stood at the top and felt a zephyr fluff through my hair. I could pirouette and feel my red dress float. The moon understood my declaration. It showed me special treats, like a shining, corrugated roof and a luminous fungus winking on a bank.

Underneath, the road turned to dirt. Soft, danceable stuff that welcomes the walker. The road shone like a tinsel rope that twisted round the next hill. I played trapeze artists, balancing on the rope. Then came the cars, making dust and spitting lights.

"Would you like a lift?"

"No thanks, I'm enjoying the walk."

"Are you sure?"

"Yes, but thanks anyway."

It became a recorded message. The cars were going to Kalang Hall too. They were mystified. Surely no-one in her right mind would want to walk to the Kalang Hall, in the dark, by herself, without a jumper. And so many cars going to the concert. To top it all off, she can't see!

The drivers worried. There must be something wrong. They must protect her from her own wildness, the audacity to walk to Kalang Hall. I was in a dilemma. I was always looking for lifts. If I said "no" to their kindness would
they ever ask me again? Maybe it was too far to Kalang Hall. Maybe it would be easier to be driven. I hid again.

"I can see you!" the voice called. "Come on, I'll give you a lift."

"No thanks," I answered, "I'm enjoying the walk;" but I thought it probably did look strange. A woman standing in the bush, on the edge of a bush road.

"You can't be enjoying a walk at this hour," came the voice. "Come on, there's plenty of room."

"Thanks again, but I really am enjoying myself."

"You really want to walk all that way?"

Two more cars arrived and the driver gave up. I crossed to the other side and it did have some effect. Only half the number of drivers offered.

I arrived at Kalang Hall with red cheeks to match my red dress.

"Are you alright?" greeted a compassionate voice.

"Yes thanks, I feel fantastic."

She squeezed my hand and nodded. I receive more overtures of concern, and at interval I discover the reason. The drivers have decided that Claire Hogan had fought with husband, Martin Hogan. After all no normal person would choose to walk to Kalang Hall.

The declaration referred to in the story, was for independence and being myself. The assumptions were that it was not right nor normal for a woman to walk a long distance, on a quiet, bush road, at night. Putting aside my visual loss I believe that women should be able to walk alone at night in safety. Friends decided that I had fought with Martin. This explained my strange behaviour.

I shared this anecdote to be performed by Playback Theatre performers. It helped to show the "underbelly", the deeper significance. I had broken several rules of social interaction.

☞ A woman walking alone at night.
☞ Saying no to offers of lifts.
☞ A person with visual loss walking alone, out in the bush.

The enigma was that I chose to, I was thoroughly enjoying myself. My story challenges what is viewed as "normal" behaviour. It is normal for me to walk along a bush track or road at night, with or without a full moon. The full moon provides contrast and magic but I appreciate the quiet and aloneness of night. My eyes are intolerant to light; bright glare and shadows confuse. It is usually quiet at night, in the bush, and this makes it even easier for me to orient.
I wrote this story straight after seeing the Playback performance. I then had the story published in Earth Garden magazine (Hogan 1993). Many of my friends read the story and spoke to me about it. We had many laughs but it was also informative, and I worked out a code with my friends on Boggy Creek Road. If I am walking on the opposite side of the road they know I do not want a lift. I used to worry about saying “no” to a lift because I am always needing lifts. In this case my story and the Playback performance helped overcome an “interaction unease.” It is now accepted as normal for me to choose to sometimes walk long distances, even at night.

8.8 Space to see

I'm allowing space to see the stars
and awe the moon,
and fly my butterfly uncooconed.
Winged, I'm flying anywhere,
Purposeless and full,
Caring not to care.
Ecologising inside out,
Dancing tiptoed in puddles,
An intuitive intellect of muddles,
I whisper a shout of joy.

Yet years allow the fears to fade,
The crux of love
to swell your heady heart unfestooned.
Love is laughing everywhere,
Quietness to share,
Caring just to care.
Fighting fights inside out,
Finding solutions in trouble,
Intuitive intellect of muddles,
I whisper a shout of joy.

Plant your trees to shed their seeds
and heal the earth
a gentle nurturing recuperates.
Saplings stretch everywhere,
Caterpillar and bird,
Daring not to dare. Ecologising inside out,
Spider weaves without troubles
Nature's magic doubles,
I whisper a shout of joy.

I'm allowing space to be a wommin
unconditioned
discovering limits limitless.
Free exploring everywhere
Purposeless and full,
Caring not to care.
Feminising inside out,
Dancing tiptoed in puddles,
An intuitive intellect of muddles,
I whisper a shout of joy.

My song writing is like a therapy to cope with the demands of intellectual thought. I find it a challenge combining my creative, intuitive thought with the intellectual reasoning. During this research so many personal changes have occurred. Reflexive and dialectic thinking meant that changes had to occur. I had already been dropping my sexist roles and studying feminism for four years before undertaking this research. It just amplified these changes as I was returning to tertiary study after fifteen years.

My songs usually arrive without intellectual thought. I often do not even plan rhyming, it occurs naturally too. During my qualifying year I took my academic work overly seriously and became stressed. I then began to dance in puddles and use my creative and intuitive thought more. This enhanced my intellectual thought to develop a constructivist approach to knowing.

8.9 Transformed

Relaxing, our lime, green caterpillar,
Scrumps along and chews leaves.
Camouflaged on verdant mosses,
In its insectivorous nappies,
Procrastinate not!
As caterpillar bumps shine
or bright eyed butcher bird gobbles.
Prevaricating, green and succulent
to shrivelled carcass

Chorus

Degrub your inflated caterpillar
From pillars of society,
Who fill with food and empty of spirit,
Spin your shimmering cocoon,
And soar as plumed butterfly.

Carefree our lime, green caterpillar,
Its life's about chewing leaves,
No pseudo sophistication,
So its wants are easily pleased.
Communicate not!
With other caterpillars,
As they might chew leaves too,
Devouring your share of dinner,
To shrivelled plant stems.

Chorus

Elegant our gem, blue butterfly,
Glides along and lays eggs.
It's life is oh so transitory,
No time to promise and renege.
Fecundity yes!
Now butterfly is dying.
As human consumers collect,
Squabbling, fat and succulent,
To embalmed corpses.

Chorus

"Transformed" is a metaphorical blues song. The caterpillar represents a
developed, modern lifestyle where wants and needs are easily pleased. It
challenges pseudo sophistication and pretension. The inflated caterpillar are
people who judge others according to rank, money, power and outward
appearance. A minority that would say people with physical disabilities are a
burden on society and tax payers. I consider it a fun song rather than a deep,
political message.

8.10 It's easy being zany

We're going to eat junk food,
And climb a fat tree,
We're going to chant out of tune,
A crazy melody,
We're going to walk back to front
And wave at a train,
And rock on the roof when it starts to rain.

Chorus

It's easy being zany,
Especially when you're all in the mood,
People think we're drunk when we're sober,
Making faces at the moon!
We laugh and do not know why we're laughing.
We're eating when our bellies are full,
The marvellous, invincible, amazing point in principle,
Is that zaniness has no rules.

We're going to wear flash clothes,
But inside out.
We're going to find a clear echo
And make it shout ou ou ou out!
We'll mousse our hair pink,
And stand on our heads,
And play somersaults on our messy beds.

We're going to talk with t's,
To it toon't take tense,
T'everyone till tink te're
Toff tour teads.
We're going to read a book
Upside down,
And sing about nonsense right out loud!

We're going to prove a point,
That no point exists,
Make haters into lovers
With a whimsical kiss,
This song is very serious
As it's all about fun!
Insaney, brainy, zaney songs for everyone!

Chorus

"It's Easy Being Zany" is a nonsense song. I wrote it for my support group. We had been discussing taking life too seriously. I was overwhelmed by academia at the time. It is also about self acceptance; for me it has been blossoming as an eccentric person, and no longer feeling self conscious about that eccentricity.

8.11 The Impact of Adaptive Technology

I wrote the article below in response to two consultants who asked what are the advantages and disadvantages of adaptive technology. I do challenge the focus on technology as the panacea.

What is most important is education and research about the possible side effects of technology, for example spoonerisms, accelerated speech, nausea and repetitive strain injury. This would make a fascinating research topic;
collaborating with users, service providers, technology and ergonomic and kinaesthetic experts.

**Liberation or frustration**

The aims of most of the adaptive technology is to make it easy to function more independently in the community. This independence would create more job opportunities, increase recreational choices and assist with daily living. If measured on these utilitarian principles, adaptive technology has been successful for the visually impaired.

At high school, I had a large, heavy, four-track reel-to-reel tape recorder with a cumbersome speed machine. By the time I reached university, technology had produced a cassette recorder with an inbuilt microphone and variable speed machine. It allowed me to quickly increase the spoken voice to what most people would consider chipmunk. However I soon noticed neurological disturbances. I was continually using 'isms and my behaviour patterns were also speeding: my speech, walking and general lifestyle increased in speed. It took some years to recognise the connection, and some years to unlearn speed listening.

*People say can it be done, it must be done, then it is done.* (Schumacher 1974). Do we accept without question innovation or do we question their ecological ramifications? In "A Matter of Survival", Suzuki gave the example of a frog, being heated slowly from cold to boiling water. A frog’s metabolism adapts to the heating water, so it does not jump out, and is boiled to death. What disturbances are occurring to people who listen regularly to the monotone voice of a talking computer? Is there more impact when the speed of the voice is increased? Do people adjust so gradually that they are unaware of slight changes in behaviour or concentration?

The responsibility to warn users of the potential side effects of technology should begin with the suppliers, and the service providers. People with visual loss need to learn the possible negative consequences of the adaptive technology.

I prevaricated for six years about purchasing a talking computer. My excuse was: "Technology is changing so quickly, I will wait." The real reason was an intuitive suspicion. I then asked, "Will a talking computer create more frustration than liberation?"

It is liberating to know what you typed last, to never again type on the roller because you didn’t notice the paper fall out. It is liberating to know exactly when you have made a mistake. It is not liberating to have an electronic voice with no intonation or soul. It is tedious to do a spell check as all the alternatives must be read aloud. A talking computer can never substitute a laughing, sharing friend. Even though I would not do without the talking computer, it does create stress, with the monotone voice and the tedium of editing by sound.
My enthusiasm for the technology gave me repetitive strain injury (R.S.I.). It seems to work against the organic or physical skills of the person. I now produce my creative writing on tape recorder first. This had to occur because of the R.S.I. but it is using a simpler technology. The computer then becomes the editor.

I collaborated with Amanda who relies on technological aids to check her diabetic condition. Amanda said that regularly she needs the assistance of her partner or a community nurse because inevitably one device breaks down. They are expensive pieces of equipment and so she cannot have back-ups. They usually have to be sent back to the manufacturers and it can be months before they are returned.

Amanda uses a closed circuit television to read pages on information. It increases the print size and scrolls it across the screen. She said “Everyone expected it to give me such independence.” However, after one page, she suffers nausea, and apparently for some users only one line causes nausea; so the equipment is of limited value.

My personal experience with adaptive technology has had more positive consequences than negative. Technology reads my books and edits my research work. However it provides cords to trip over, batteries to go flat, screams and crackles and vocal distortions, and buttons to produce repetitive strain injury.

There may be more liberation than frustration if preventative education was made available. A user could then limit the amount of speed listening and the rate of the speech. She could begin word processing with an appropriate computer table and ergonomic chair. She could also share the common problems of many people with disabilities, feeling “okay” about asking for help. Technological aids can make people with visual loss even more reticent about asking for help, because they are seen as being so liberating!

8.12 Pig Swill

Lunch time at the institute was punishment for me. We would all straggle down the long, shining corridor. Tapping sticks, rolling white eyes; those with multiple disabilities would slobber and open their mouths like tortured fish.

Nurse Glob was always there. Standing at the top of the stairs, chin up and peering through her half spectacles. I could see she had a face like a toad and I could see the seam lines down the back of her stockings, but nurse didn’t know I could see. She lumped us all together. To her, we were all blind.

I often jumped the steps by threes to vary the march. Boys, first to the left, girls, second to the left. What forbidden wonders lurked down the boys’ corridor: black curtains and white shag pile carpet? A pet tiger? We reached the bathroom. Another long shiny room. Each door was the size of a cupboard. Sister Patch was down there with her hunched shoulders and detective eye. I felt like yelling, “Come and join me in the dunny, there’s room
for two!” But inside I was scared. If I did not do everything right here I might be institutionalised forever.

Back up the steps, usually in the same order. Some of us liked to hurry, others couldn’t. A white stick does not let you run too fast. Nurse Glob gave another inspection then stalked back to her poky office.

Lunchtime in the shining, bare dining room; it was filled with tables and chairs, all the same shape, all the same colour, all crammed together, but it was still bare. I shut my nose and hoped the pumpkin and meat loaf could not penetrate through my ears or the slit of my mouth. At our tables we waited for the stragglers, then said Grace. But I never said Grace. They did not say the same Grace we said at home, and Grace was to bless food, not this muck!

“Where’s your serviette, Claire?” I smarted and fretted and gave in. The horrid white bib was removed from the pink holder and stuck in my neck. It was a starchy insult that labelled you “baby”. The serviette ring was made from pieces of pink plastic threaded onto wire. It was ugly but I had made it. It was something of mine, and a different colour from all the other rings. It was the first item we made at occupational therapy. I knew it was occupational therapy because I could see the reports they wrote. “Claire’s co-ordination is improving, but needs more exercises for peripheral vision.”

The bib balanced on my neck ready to accidentally fall into my lap when sister was busy. Then came the real punishment. A white plate filled with a large brown blob, enough Deb potato to feed three eleven-year-olds, and brussels sprouts. Dad would have called it pig’s swill. The garnish was a diarrhoea-coloured gravy with large lumps of fat. My friends licked their lips, craned their heads close to the plates and tucked in. Lisa held her cutlery in a strange manner and shovelled the food, chewed twice and swallowed. Alice dropped a third of her muck on her bib and around the plate. That could have been a way to waste some muck, but I was too proud.

The slow process began. Minute quantities of the cold muck entered my mouth. I blew air into my cheeks and tried to keep the food under my tongue so that there would be less taste. I found that holding my nose also decreased taste sensation but that only caused trouble with Sister. It horrified me when Lisa would put her hand up and ask for more. I tried unloading half of mine to Heather one day and was given a kitchen tour.

“Look at how hard the cook works for you every lunch time. You’re a fussy little Miss, aren’t you. Pies and ice cream would satisfy you, would they? Well, we only serve healthy food here. Think of all those starving children . . . .” And the sermon continued. I saw the huge stainless steel tureen of frozen carrot slices, the stainless steel bowl of Deb powder and the crate of fish fingers.

If that was healthy food I would prefer to starve. I sulked and said, “Yes sister, yes sister, no sister, alright sister.” I thought of my mother’s meals. Chunky rye bread for lunch with salad, home-made oat biscuits and a big, juicy orange. At home we had proper serviettes: bright orange ones that were small and soft.
Sister sent me back to the dining room. I had forced one third of the muck down my oesophagus when I felt a rumbling in my stomach. It was so sudden. The vomit gushed from my innards and for the first time I appreciated the starchy protection of the bib. Sister pounced.

“Oh dear, oh dear! Alice, Lisa, Heather go and join the girls at the back table. Why didn’t you try to stop it? You didn’t tell me you were feeling sick. What a dreadful mess. Go to the sick bay.”

“It became my survival. For thirteen months I chewed, swallowed, emptied my plate, then filled the toilet with my punishment.

Sister considered me a reformed character. I no longer battled with my meal. She did not have to tell me to hurry up or check that I had finished everything on the plate before the dessert. Eating all the food earned me praise. Praise meant I was rehabilitating quickly and could leave the institution soon and never again be forced to face pigs’ swill.

Pig Swill aims to emphasise the personal damage that can occur at institutions. Fortunately my parents drove me to and from the institution each day, so I only had to move from the school to the dormitory section at lunch hour.

I blame some interaction unease on institutional living. Many of the students found it difficult to interact easily because, except for me and one other child, they had all been institutionalised for a minimum of ten years, (unless younger than ten). I was determined at eleven, to maintain my free spirit. The dormitory institution tried to force conformity and sameness. We had to say the same grace, wear the same white bibs and follow a set timetable. I only boarded for three nights.

Fortunately the Australian government has accepted that institutions are not successful. Most people with visual loss adjust much more successfully in their usual environment. Government funding now pays for technological aids and teaching assistants where necessary, to assist people with visual loss who attend schools catering for students with full vision.

Chronologically we have evolved from institutionalisation to normalisation. In Australia today, the emphasis is shifting from normalisation to respecting the individual. In 1983 and '84, the Handicap Programs Review enabled people with disabilities to have their own say about the services they needed. The Commonwealth, Disability Services Act, 1986, offered more flexible services for people with visual loss, such as home nursing and individual rehabilitation programs.

The government manual, “Disability, Society and Change”, stated that the main principle of the act was to empower people with disabilities, and those “who support and advocate for them.” The manual challenged stereotypes and myths and provided practical information. The crucial message was “that
increased resources are best utilised when an attitudinal framework of positive outcomes for individuals, is the driving philosophy, policy and practice of service providers."

There is now a focus on technology by agencies such as the Royal Blind Society. Government services are trying to balance individual needs and economic restraints. Political groups such as the N.F.B.C.A.A represent blind, visually impaired and Australians with print disabilities. N.F.B.C.A.A has made representations to governments, both nationally and state on such matters as concessions and benefits, discrimination, access to goods and services and physical access. I believe that social change occurs in a matrix of individual and systemic motivation.

It is imperative that we question whether changes are positive. I question the vocational emphasis of Commonwealth rehabilitation. Where does this leave the growing population of people with visual loss, over the age of 60? I question the obsession with adaptive technology. Are agencies aware of the possible side effects? A participatory process of reflexive and dialectic enquiry helps to challenge and monitor the effects of social change and interested people with visual loss need to be involved.

8.13 Celebration

This is not a conclusion, but an ongoing venture. I will write a book after completing this thesis, and will continue to adapt to daily stresses, to co-research and challenge my own and others' discriminatory attitudes.

If all the theories on the impact of visual loss were accepted as individual viewpoints, affected by values, we could achieve a more realistic concept. The impact can be viewed as a severe loss or minor inconvenience, depending on fluctuating circumstances and personal adaptation.

Empathy and positive interaction has increased for me and my co-researchers, as we clarified:

The value we placed on sight.
The fear of losing sight.
The images we had of blindness.
Our understanding of myths and stereotyped attitudes.

I have purposely emphasised the importance of personal proclivities and the capacity to adapt. This emphasis is not underestimating the extra stresses experienced by people with visual loss, rather it shifts the focus from being problem oriented.

I believe that Australian culture is in a transition stage, regarding an overall acceptance of people with disabilities. Generally the law lags behind cultural change, but legislation appears to have moved ahead regarding people with
disabilities with the principles of integration and equality. Positive interaction and cultural expectations need to realise these objectives.

Accepting my sense of limbo status helped me to work toward these principles. My communication is clearer, specifically in asking for help and defining the limits of help required. I have become more aware of my own needs (as a person with limited sight) and physical limitations, and no longer strive for total independence.

By respecting my limbo status I still have the choices of when to tell people I have a visual impairment. Hence I have the benefits of anonymity and more independence.

Action research vitalised the enquiry process. We collaborated as equal participants and grew together. Our personal changes created a positive spiral, (from personal to family and friends and out to the wider community). It was satisfying to achieve my research passion:

To re-educate myself and others about positive interaction, I continue to challenge perceptions of how visual loss impacts on peoples’ lives. Humour provides a non-threatening genre to confront controversial issues and expand understanding.

The song “I’m a V.I.P” celebrates the challenges of visual loss.

**VIP – VISUALLY IMPAIRED PERSON**

I’m visually impaired, but that doesn’t make me scared,
In fact I think it makes me motivated.
I like to test my limitations in life,
Even though it often leads to strife!
I pondered on a label that suited me
And titled myself a V.I.P

Chorus.
I’m a VIP and I can see,
It’s just with 90% less clarity.

I’m a VIP and I can see,
It’s just the world looks a different place to me.
I see a space ship with its flashing lights,
It’s my own spectacular suburban sight,
Everyone else sees a garbage truck,
So I say my sight’s my good luck.

(Chorus)

· V.I.P and my only greed,
   amount of books I like to read,
People think it must be so relaxing,
To listen to a talking book a chattering,
It can be relaxing, but painful too,
At the end of a side they tell you to —
"Turn the cassette over
And change the side selector switch,
Which is located third from the top on the control panel.
Please do this now."

(Chorus)

I'm a V.I.P and I can't drive cars,
In my teens I found it really hard.
Now I'm an environmental buff,
So driving cars is polluting stuff.
I use my legs or I ride a bike
And if I'm desperate I'll hitch hike.

(Chorus)

I'm a V.I.P with not much sight
But my eyes are shining blue and bright,
People ask why I do not wear specs —
I say a brain tumour and they can't accept.
I do not look blind and I'm not blind either,
It's a well behaved, quiescent tumour.

(Chorus)

I'm a V.I.P and I hate crossing roads,
Things on wheels just like to goad.
They toot and growl and I rely on hearing,
So it's difficult to hear when there's a clearing.
I pirouette onto the centre line
And act as though the road is mine.

(Chorus)
PLEASE NOTE

The greatest amount of care has been taken while scanning the following pages. The best possible results have been obtained.
Bibliography

ALINSKY, S. D. (1972), Rules for Radicals, Vintage Books, USA.

ASSOCIATION FOR THE BLIND IN VICTORIA, (1990), A Feeling for Life, (Video)


BELENKY FIELD, M; MATUCK TARULE, J; McVICKER CLINCHY, B; RULE GOLDBERGER, N; (1986), Women’s Ways of Knowing, Basic Books/Harper and Collins. U.S.

BLACKHALL, D.S. (1961), This House has Windows, Parrish, London.


CUOMO, C.J. (1992), Unravelling the Problems in Eco Feminism Environmental Ethics 14, 351-363.


HOGAN, C. (1992), Blind Woman's Bluff, Earth Garden 81 (Spring), 53-54.


SMALL, F. (1987), Talking Wheel-Chair Blues, A song on 'The Heart of the Appaloosa'. Cassette


Annotated Bibliography

Allen, Marion N. (1989), ‘The meaning of visual impairment to visually impaired adults.’ Journal of Advanced Nursing, 14, 640-646. Aimed to explore the subjective meaning of vision impairment to adults whose visual impairment began in their adult years. 25 people were interviewed, and the transcribed interviews interpreted by a hermeneutical approach, which allows attention to be directed towards the symbolic and social context of vision impairment as an illness and life event, and leads to the understanding and explanation of the world of vision impaired people.

Allen, Marion N. (1990), ‘Adjusting to visual impairment.’ Journal of Ophthalmic Nursing and Technology, 9(2), 47-51. This research was designed to explore people’s perceptions of adjustment as they went through the process of becoming and being vision impaired. Six adults were followed for a year following the onset of their visual impairment. One finding was a hesitancy by several interviewees to share the knowledge of their loss of vision with others. It was difficult for them to state why they did not share this information.


Asch, A, and Sacks, L. H. (1983), ‘Lives without, lives within: autobiographies of blind women and men.’ Journal of Visual Impairment and Blindness, 77 (6), June, 242-247. Examines the autobiographies of 25 blind and vision impaired women and men, and assesses the influence of gender upon disability. The authors examine how these authors’ lives exemplify the roles of ideal woman or man and disabled person in society, and how their views about themselves and the world compare with those of other marginal people who have revealed themselves in autobiographical form.

Begg, F. (1992), ‘NFBCA women’s forum: disabilities as portrayed through forms of popular culture.’ Insight (Association of Blind Citizens of NSW) Winter/Spring, pp.27,29,31,33,35. How are people with disabilities portrayed and what role is there for people with disabilities in forms of popular culture? Very rarely are people with disabilities portrayed by someone who has a disability. Many traits given to characters who have a disability in forms of popular culture have no factual basis. Unless there is a change in how people with disabilities are portrayed in factual and fictional forms of popular culture, attitudes and images will not change. Presented at the National Federation of Blind Citizens of Australia Women’s Forum, Sydney, 16-17 May 1992.

136
BLAYLOCK, J.N. AND RICKELMAN, B.L.; (1983), 'Behaviours of sighted individuals perceived by blind persons as hindrances to self-reliance in blind persons.' Journal of Visual Impairment and Blindness, Vol. 77, No. 1, January 1983, 8-11. Describes several situations in which sighted people behave inappropriately towards blind people, assuming they necessarily have other disabilities, dealing with sighted companions instead of directly with the blind persons, insisting on the blind person accepting unwanted assistance, and so on. The study looks at how blind people felt in these situations and how they responded, and reports suggestions on how sighted individuals could act so as to respect and encourage feelings of self-reliance in blind people.

DELAFIELD, GEORGE L.(1976), 'Adjustment to blindness.' New Outlook for the Blind, Vol. 70, No. 2, February, pp. 64-68. Examines various factors that can or should be used to determine adjustment to a disability such as blindness, and discusses the need for developing ways to accurately measure the process. Emphasises that adjustment is a broad concept that embraces many, such as self-concept, nature of blindness, attitudes of significant others. It is suggested that self-concept or self-esteem is the central concern, but is neglected.

DIXON, JUDITH M. (1983), 'Attitudinal barriers and strategies for overcoming them.' Journal of Visual Impairment and Blindness, Vol. 77, No. 6, June, pp.290-292. Women and disabled people are both stigmatised by today's culture. In the general population of the United States, 58 per cent of women are in the labour force; among blind or vision impaired people, only 29 percent of women are employed or looking for work. One factor in this situation is the disincentive to work built into the disability benefit programs, although women are apt to receive a lower level of benefits than men. Other factors are employer attitudes towards blindness, and sex-role stereotyping. Major strategies for overcoming barriers include timely and accurate vocational preparation, assertiveness training, and support networks.

EVANS, BARBARA M. (1985), 'The hardest burden.' New Beacon, Vol. 69, No. 820, August, pp.227-229. Attitudes towards visual loss may affect the behaviour of the person with little or no sight. This article examines attitudes to and images and stereotypes of blind and vision impaired people.

FEINMAN, SAUL. (1979), 'Do sighted people respond to different levels of visual loss?' Journal of Visual Impairment and Blindness, Vol. 73, No. 5, May 1979, pp.185-190. Survey of people's attitudes. Respondents did not distinguish between the term "blind" and the specified conditions of partially sighted and totally blind. The results were discussed within the context of other research on attitudes towards disability and attitudes toward racial and ethnic minorities.
FRENCH, SALLY. (1992), ‘Simulation exercises in disability awareness training: a critique.’ Disability, Handicap and Society, Vol. 7, No. 3, 1992. pp.257-266. Little evidence exists that disability simulation exercises have a positive effect on either attitudes or behaviour, but despite this, they are used extensively in disability awareness training. It is argued in this paper that by individualising and medicalising disability, and by focusing excessively on problems and difficulties, simulation exercises provide false and misleading information, and inculcate negative, rather than positive, attitudes towards disabled people. It is suggested that simulation exercises fail to simulate impairment correctly, and address neither the coping strategies and skills disabled people develop in living with impairment, nor the cumulative social and psychological effect (Petaling Jaya: Malaysian Association for the Blind, pp. 34-39). “The title of this paper seems to imply that there will be psychological problems associated with a diagnosis of low vision. As clinicians, educators or rehabilitation teachers, we may assume that a person who does not see perfectly or has a reduced level of acuity is distressed by that. Is it possible that we may create problems of stress or negative feelings by our own attitudes or emphasis on what they do not see rather than on what they can see? … I shall focus on facts about low vision, and things we need to consider if we are to minimise the potential for psychological problems to arise.” Considers the ‘assault on the ego’ of the person losing vision, and becoming a ‘marginal person’.

GOLDIN, CAROL S. (1984), ‘The community of the blind: social organisation, advocacy and cultural redefinition.’ Human Organisation, Vol. 43, No. 2, Summer 1984, 121-131. Based on a two year study of an advocacy organisation, this paper describes a social community of prevocationally blind people. Characteristics of the community include identification, shared experiences and participation, lifelong economic dependence on blindness institutions, and mass participation in the blindness advocacy movement. Activists create new meanings of blindness and associated concepts as they work out effective means to change their socioeconomic status. Suggests that advocacy group membership creates a social community, and provides a realistic environment in which members lessen the negative effects of stigmatisation.

GORMAN, MARYLICH A. (1979), ‘The effect of blindness on self-concepts.’ Blindness and Low Vision: papers selected by the Orientation and Mobility Instructors’ Association of Australia. Volume 2, October 1979, pp.32-46. A reflection of our individual self-concept is our own body image, and within that, the fact that we have two seeing eyes. If this situation should change, then our body image changes, and with that, our view of ourselves. The basis of this paper is what happens to people who lose their sight adventitiously and why. How does their
self-concept change, and what form will it now take? Also discussed are the implications for mobility instructors.


JERNIGAN, KENNETH. Blindness – the myth and the image. Baltimore, MD: National Federation Of The Blind, 1970. “We do not object to being known as blind, for that is what we are. What we protest is that we are not also known as people …”. This paper outlines some of the myths of blindness, such as the image of the blind person as a tragic figure. “We know that with training and opportunity we can compete on terms of equality with our sighted neighbours – and that blindness is merely a physical nuisance.”

HOUGH KIM, YOON. (1970), The community of the blind: applying the theory of community formation. New York: American Foundation of the Blind, 1970. Investigated the validity of the widely held view that while there are a large number of blind people whose social lives are centred in the mainstream, that is with sighted people, there are an equally large number of blind people whose social lives are restricted mainly to other blind people. The author attempted to prove that this polarisation is largely the result of two conflicting forces, the sighted person’s acceptance or rejection of the blind person, and the blind person’s different reactions to the sighted person. KEARSLEY, ALAN. (1989), ‘Seeing things from both sides.’ New Beacon, Vol. 73, No. 870, November 1989, pp.385-386. The author is a social worker who also has a visual impairment; he provides an insight into the negative effects of stereotyping, for example Blind people are submissive and peaceable. He is convinced of the need for disadvantaged and minority groups to ‘educate the professional support-givers.


LANGDON, MARYANN. (1979), ‘What do you do when you meet a sighted person?’ Journal of Visual impairment and Blindness, Vol. 73, No. 10, December 1979, 419, 421. “Tolerance is the word when dealing with visually dependent people.”


MANCIL, GARY L. (1987) ‘Socialization, stigmatisation and self-concept of blindness: a service and health care professional’s dilemma.’ *Journal of Vision Rehabilitation*, Vol. 1, No. 2, April 1987, 51-56. In our culture specific social roles and expected behaviours are assigned to blind and vision impaired people through the socialisation process. The social roles and expectations which society assigns to those with a vision impairment often influence the self-concept of a vision impaired person. This article discusses socialisation, stigmatisation and stereotyping of blind and vision impaired people, to draw the attention of health professionals to avoid inadvertently reinforcing such stereotypes.

NEEDHAM, WALTER E. AND EHMER, MARY N., (1980) ‘Irrational thinking and adjustment to loss of vision.’ *Journal of Visual Impairment and Blindness*, Vol. 74, No. 2, February 1980, 57-61. Individual differences in adjusting to or coping with blindness appear related to the presence or absence of certain irrational belief statements about this disability. As a whole, these appear to constitute much of the mythology of blindness. The statements fall into four general categories: 1) Blind people are different from sighted people in their self-worth and value; 2) Blind people have a unique psychological constitution; 3) Blind people have a special relationship with other people and society in general; 4) There are magical circumstances about blindness. Each statement is discussed and methods by which individuals can rid themselves of or be helped to eliminate these irrational beliefs are described.

EXPLORING THE SOCIAL EFFECTS OF VISUAL LOSS ON HUMAN INTERACTION

Candidate: Claire Louise HOGAN
Title of Degree: Master of Science (Honours)
University Member: University of Western Sydney, Hawkesbury
Date: 1st April 1995
Candidate Number: 926166

THIS THESIS HAS NOT BEEN SUBMITTED TO ANY OTHER INSTITUTION FOR EXAMINATION.
PLEASE NOTE

The greatest amount of care has been taken while scanning this thesis,

and the best possible result has been obtained.
ERRATA SHEET

- §1.2; points 1 & 2 need to be de-emphasised, they currently look like headings.
- p.12, Par.3, L8: then, not that.
- p25, Par.4, L1: "discovering how my ...".
  L6: striven not strived.
- p29, Par.1: van Manen not Mannen.
- p32, first word should be homed not honed.
- p43, §3.4.2: fluctuating
- p.45 Par.3, L2: vision test.
- p.57, 2nd. last par. L1: delete second "Goffman".
- p76, Par.5, L3: less and less to be replaced with fewer and fewer.
- p.117, L5: the driver’s seat of a Holden.

Bibliographic addition:
  SMALL, Fred (1987)
  *The Heart of the Appaloosa* (Record Album)
  Rounder Records C - 4014
The Passion of my research.

She paws the earth and skirts around her true passions. Stuck in the planning stage she resists – then leaps. “But what impact does visual loss have on her life?” “How do people adapt to visual loss?”

She bucks and cavorts. Half wants the safety and structure of positivism, and researching community life. Half wants the chaos of action research and exploring visual loss.

Action:- and she stampedes into the second half. “What is my sense of limbo?” “How can interaction unease change to interaction ease?”

Hair flying, she gallops to the summit to observe. Visual loss is not a disaster, beset with problems. The ways people adapt, and so the impact on their lives is as diverse as personalities.

She gallops with people who experience a sense of limbo, people with visual loss and others who are interested and engaging. They listen and share and discuss and debate. She is shocked by her own fears and discrimination. Accepting her own limbo status, she is free. Accepting the limits of her visual loss, she is joyous!

She explodes with story and song and humour. People laugh and frown and give feedback. Expanding, she embraces eccentricities, unique and common. She expounds that the effects of visual loss cannot be standardised but can be demystified.

Keep some questions in mind as you share in my research. What are your personal fears about losing sight? How do you discriminate against people with visual loss? What interests do you have in visual loss? What value do you place on full sight?
Acknowledgments.

There are so many people I want to thank for their encouragement and support. Their combined skills, enthusiasm and interest helped to produce this thesis.

Lesley Kuhn White, my academic supervisor, gave so much attention to detail. At the critical point when I had decided to give up, Lesley's short note described my work as exciting and important. It provided the inspiration to continue.

Carole Helman, my second supervisor – and I, enjoyed the ongoing editing stages. We laughed, ate treats and rewrote slabs of text.

Staff at the tape library and student request service at N.S.W. Royal Blind Society were invaluable. They searched for and sent all the books I requested in taped form. The reference librarian, Claire Pillar, produced the informative annotated bibliography included in this thesis. It saved me so much time and stress. Bill discussed semantics with me. This was essential to avoid stereotyping.

A staff member was always available to assist, at the University of Western Sydney, even when they were very busy. The librarians have to do my searches on the computer and then find the books. I thank all the staff at the School of Social Ecology. Heather Dietrich helped me to reach my bottom line regarding the ethics of humour. Roger Packham spent time editing my thesis.

In the final proof-reading Martin Mulligan suggested changes that enhanced the layout and flow of my thesis. The checking was done with meticulous care. Thank you to Francis Parker for your administrative support and for the warmth and competence offered by the secretarial staff at the School of Social Ecology.

Thank you also to Ann O'Brien, the Bellingen Librarian, and her assistants, for helping to find resources.

Thank you to the artists, Gabrielle Tindall who transformed my stick figure cartoons, and Judy Baderle who produced clear and neat overhead transparencies for my talks. Sharyn Colette who supported me with my new venture in song writing. Penelope Gamble spent many hours on a portrait painting to be used in the front page of my thesis. It is a beautiful and dynamic painting, and reflects my passionate nature.

Gail Wheaton, Barbara Byng and Michael Ahern were members of our research study group. Together we demystified academic concepts, acted as sounding boards and critiqued each others papers. It was of practical and moral support.
I thank my many friends for their patience, their love and practical help. Ross Macleay helped with my referencing. I appreciated his scholarly mind and eagerness to share when I could not understand concepts. Miriam Broadfoot helped me to sort and label cassettes and Chatan provided critique and editing. There are advantages in needing other peoples’ eyes to assist. Paula Collard, another editor has become a friend. We spend half of our time laughing. Thank you to my readers and drivers. Colin Broadfoot, Katherine Wood, Caroline Worton, June Jones, Lyn O’Brien, Julia Nolan and Annika Faber were always there when I needed them. Thank you to Angela McCarthy for your interest in my topic and the action research methodology.

My collaborators, Mary Thornycroft, Maureen McCarthy, Kelvin Thornycroft and Amanda Jones gave so much insight and frank sharing in this research. I also received immediate feedback and inspiration from the members of the Bellingen Playback Theatre Company, who would replay my stories, and immediately provide another perspective.

I feel honoured by the enthusiasm with which my external examiners agreed to examine my thesis, two of whom I have not met before.

I thank my husband, Martin, who earned the name of Mr Fix It, by spending many hours finding lost files and fixing mistakes. He should also be awarded a Masters Thesis.

Thank you to my mother, Patricia Daly, who always gave positive feedback and taped sections of my typing that were unclear. Patricia and Ian Daly, my father, spent many hours in proof-reading. My thesis was polished with their excellent grammar and logical thinking.

A special thank you is given to my family and all my friends who supported me during the hard times of this research. It was so needed when I experienced the double disability of repetitive strain injury, then discovered that my sight had reduced dramatically. It was at these stressful times when I could not have continued without your love.

**Reasonable Adjustment Disclaimer.**

I apologise to the readers of this thesis, writers and publishers for any errors in the transcribing of quotes. The books were listened to on cassette recorder and so could not be copied exactly. Some quotes do not have page references. These faults are accepted under the Equal Opportunities Act which allows for “reasonable adjustment, when a physical disability is the limiting factor.”
CONTENTS

CHAPTER 1 Introduction 1
  1.1 Motivation for this Research 1
  1.2 A Perception of Limbo Status 4
  1.3 Definitions of Terms 6
  1.4 A Question of Semantics 8
  1.5 Social Myths About Visual Loss 9
  1.6 Action Research on Two Levels 17
  1.7 Outline of Thesis 21

CHAPTER 2 Research Process: A Patchwork Quilt of Approaches 24
  2.1 Social Research 26
  2.2 On Collaboration 27
  2.3 Appropriate research and authenticity 27
  2.4 Avoiding elitism 29
  2.5 Overcoming blind/sighted dualism 30
  2.6 Story Telling 31
  2.7 Feminist Research Methods 32

CHAPTER 3 Two Stories 34
  3.1 Introduction 34
  3.2 Mary's Story 34
  3.3 Kelvin's Story 37
  3.4 Conclusions 43

CHAPTER 4 Myths, Distortions and Understandings. A Critique of Theoretical Perspectives on the Impact of Visual Loss 44
  4.1 Introduction 44
  4.2 A Phenomenological View of Blindness 46
  4.3 Victim Theories 48
  4.4 The Value Placed on Full Sight 61
  4.5 Empowerment 63
  4.6 Conclusions: metamorphosis 69

CHAPTER 5 Life Stories: Learning from Biographical Writings 70
  5.1 Introduction 70
  5.2 Respecting Uniqueness and Commonalities 70
  5.3 Loss of Sight and Personal Identity 72
  5.4 Self-Acceptance 74

CHAPTER 6 Interaction Challenges 78
  6.1 Introduction 78
  6.2 Asking for Help 81
  6.3 How Help is Offered? 83
  6.4 Conversations 86
  6.5 Getting Things Done 87
  6.6 Conclusion 88
CHAPTER 7 Do you think it is funny? A role for humour
7.1 Humour – The Balancing Mechanism. 90
7.2 Pleasure and Pain 91
7.3 The Intangible Nature of Humour and Visual Loss 92
7.4 Who Can Make Jokes? 93
7.5 Appropriate Humour 93
7.6 The Ethics of Humour 95
7.7 Feedback on my Cartoons 95

CHAPTER 8 Toward Interaction Ease Through Stories
Poems and Songs 104
8.1 Introduction 104
8.2 The Worst Things for People with Visual Loss 106
8.3 ‘The Impersonator.’ 109
8.4 What is it all about? 111
8.5 Brave Little People 113
8.6 How Much Can You See? 116
8.7 Blind Woman’s Bluff 118
8.8 Space to See. 121
8.9 Transformed 122
8.10 It’s Easy Being Zany 123
8.11 The Impact of Adaptive Technology. 124
8.12 Pig Swill 126
8.13 Celebration. 129

BIBLIOGRAPHY 132
Synopsis

I have less than ten percent sight, and my thesis has an autobiographical and experiential focus.

The theories on the impact of visual loss tend to generalise and can simplify complex issues. I challenge two extreme views that portray the impact of visual loss as catastrophic or a minor inconvenience.

I argue that the impact of visual loss can lessen with improved interaction. I tested this theory by questioning and modifying my own interaction. My tendency had been to strive for total independence.

I involved friends and two collaborators with visual loss. We explored the themes of –

Limbo status and self acceptance

The common stresses experienced when asking for help.

Our own and society’s discriminatory attitudes.

Our process was action research based. We shared equal power in the themes chosen, action taken and style of reporting.

Appropriate humour was used as an important tool; because blindness is so often feared and the impact is distorted. I emphasised how individuals adjust and adapt to loss, rather than the stresses experienced.
No One Theory.

A childlike passion bounces with this research
And accepts the limbo status of not blind and not sighted,
Then the sense of limbo dissipates.

Passion challenges the theorotyping that argues
Aggregate perceived expectations are ...
Blind people are ...
Blindness is ...
The blind ...

Passion confronts blindness as problem saturated.
It deproblematises by honouring uniqueness –
The individual ways that people adapt to visual loss.

I face my fears and discriminatons,
Discovering what impact visual loss has on my life.
The passion collaborates and sings and designs cartoons,
Shares narratives and writes poems and debates.

This backpack full of methods defies the stigma-theorists who argue that
stigma sticks,
and persists, and creates interaction unease.
With passion.
We can transform unease to ease.
With no one process.
No one theory.
No one solution!

We overflow the backpack with a wholeness,
Appropriate and assertive,
Humour and grieving,
Challenges and acceptance,
Independence and interdependence.
A reciprocal learning toward the satisfaction of interaction ease.