

A CRITICAL ANALYSIS

Introduction:

What I have documented on the following pages represents the outline, in chronological order, of a personal history.

The focus of the information relates to the effect over time, of the impact of a functional impairment, in the context of the associated disability and handicap, imposed as a result of environmental incompatibility.

In addition to providing this information, as a means toward creating more understanding of the implications of my particular situation, I have also attempted to provide a perspective on health care, as seen by one who is disabled.

The views which I have expressed are not only the result of personal insights as a result of my own condition, but have been influenced by the attitudes of those I have worked with over the years, while involved in the care of sick and disabled people.

PETER GEOFFREY LINDLEY

1st September 1994

PERSONAL DETAILS:

Male - Caucasian - Age 56 years

Date of Birth - 5th May 1938

Place of Birth - Brisbane, Queensland

Disability - Profound Sensori-neural Hearing Loss since the age of seven (7) years. No residual hearing in left ear - 6% (N.A.L. Scale) in right ear.

Education - Rudimentary - attended "normal" school up to the age of fourteen (14) years.

Rationale

After consultation with relevant Ear, Nose & Throat Specialists of the day, and associated significant others, my parents decided to send me to a "normal" school, rather than to a school for the deaf.

The perception at the time (1945) was that by attending such a school my education would suffer, but I would be more likely to develop appropriate social skills which would enable me to interact within a heterogeneous society.

It was considered that this would be preferable to my obtaining a good formal education, within a homogeneous society, but cut off from normal interaction. I was not required to sit for scholarship. This was due to my inability to benefit academically.

The only benefit I gained from any formal education was at age 9 or 10 when my parents obtained the services of a private tutor for six (6) months.

However, even though they were reasonably well off, the cost of ongoing private education was prohibitive and as a result had to be discontinued.

Family Details

Mother - Housewife

Father - Grazier

Uncle (mother's brother) - Supreme Court Judge, the late
G.A.G. Lucas

Uncle (mother's brother) - Doctor, Gynaecologist

Family Details (Cont)

Grandfather - Doctor, T.B. Specialist
Great Grandfather - Engineer
Cousin - Solicitor
Sister - Businesswoman

Family on Father's Side:

Graziers in Australia from early 1800's.

Sister's hearing normal - went through college and then to University. All members of my family on both sides went to college, except me, most went on to University.

WORK HISTORY:

Left school at age fourteen (14) years worked in a butter factory then held various jobs, erecting blinds, packer and storeman, fruit picker, etc., all menial positions.

In 1960, I obtained a position as a clerk with the then, Main Roads Department, and held this position until 1964.

I then spent two years in New Zealand and on my return to Brisbane, I applied for a position as an orderly with the _____. I have held this position for 28 years:

- (i) 9 years in spinal injuries unit
- (ii) 15 years in geriatrics unit
- (iii) Current - 4 years in head injuries unit

In relation to the changes which have taken place over time, my current employer is

SOCIAL HISTORY:

During my school years, I was consistently at the bottom of my class and my sister was consistently at the top of hers.

This situation was not due to any lack of academic ability but simply because I could not follow what went on. The teachers were unable to devote any time to me personally.

However, as a child, I developed the perception that I was not very bright. This was because I was always at the bottom of my class. The reactions of the other children toward me reinforced this, in that I was treated as something of an oddity, and as one who was dumb.

I was forced to operate on the periphery of what went on at school although I tried to "join in" as much as I could. The teachers' perceptions of my hearing loss were consistent with those of the average person, and the implications were not realised. As a result of this, on a number of occasions, I was punished for misdemeanours involving other children which I had not been guilty of, but had been placed in a situation simply due to my inability to understand what was "going on". Those experiences profoundly affected my trust in adults for many years afterwards.

Although I started to develop good one to one interactive skills, due, I think, to highly developed ability to process sequential information, and good concentration, my self-confidence was always very tenuous.

During my adolescence, I continued to interact with my peers. I developed very good, but inappropriate coping skills which enabled me to be part of the group. I discovered early that if I didn't "cover up" and hide the fact that I couldn't understand, then I was not accepted. Even then I was considered to be something of an oddball. I was called Johnny because my peers felt that I wore my hearing aid more to emulate the current singer of the time, Johnny Ray, who also wore a hearing aid, than any perceived degree of disability.

During those formative years, I did not really understand the implications of my hearing disability and handicap, and at times became very depressed at not being like "normal" people. I sometimes withdrew and shut myself away from contact with others for varying periods of time.

Into my middle twenties, as the realisation of my predicament became more apparent, I became withdrawn and my self-confidence reached a very low ebb. This was particularly as a result of the perception of others who considered me to be a "bit slow". In addition to this was the situation I found myself in, in relation to my family, who were, or had been very high achievers, where as I was not.

I tried to rectify this by reading very extensively, which I have always enjoyed doing. On two occasions, I applied to do mature age entry at Griffith and Queensland Universities. However, due, I presume, to my lack of any formal qualifications, I was turned down. I suspect that my disability may also have been an influencing factor.

This didn't help my self-confidence at all and it wasn't until I became involved with B.H.A. and the Australian Deafness Council, that my self-confidence began to improve, albeit very slowly. My wife's understanding and support has also been a contributing factor in my developing self confidence.

MY WORK SITUATION:

My work is of a very social nature, which involves constant daily interaction with patients, staff and patients' families. I have never found this work easy, even if it involves only basic nursing care.

As indicated under Work History, over the period of 28 years I have only worked in three areas. I became familiar with the work routine, with the staff and with the patients and their families, due to the fact that most of them are long term rehabilitation orientated patients.

This is one reason why I have been able to cope in such an environment. Another is because I have always ensured that I only stick to basic care and do not attempt to become involved in the more complex side of nursing. I use my eyes, I use my head and I read charts. (A measure of predictability is essential for disabled people, especially for those with sensory and perceptual impairment.)

However, this ability to cope in such a social environment results in a price I must pay in terms of stressors imposed. Through the need for intense concentration, through inability to correctly monitor my environment, through having to operate on the periphery of what is transpiring at any given time, these stressors tend to make me very tired, especially since I am no longer as young as I was.

In addition to the stressors outlined previously, is the exclusion from normal social intercourse, either of a work-related or social nature and the implied discrimination involved.

I interact on a one to one relatively well, depending on individual characteristics, however, outside of the one to one situation, I cannot function at all effectively.

Because of my generally good coping skills I am often treated as though my comprehension abilities are much better than they are. (The enclosed letter from my audiologist gives some indication of my position.)

Over the years I have consistently attempted to educate the staff in relation to my inability to function in a particular situation. I have experienced limited success. This may be due to the fact that, unlike other people who have been hearing impaired for a long period of time, my speech has not deteriorated to any marked degree. As I understand it, I have a slight lisp and a tendency to mispronounce words at times, but otherwise it is normal. The reason for this has not been determined by the hearing health care professionals.

I am aware that many patients who have a hearing loss, experience problems similar to my own. For example, most elderly people, who have operated as normal hearing individuals for most of their lives, and who have experienced hearing loss later in life, although they may wear a hearing aid and be diagnosed as having a hearing loss, their speech would not have had sufficient time to deteriorate, with the result that they would present as one without any significant problem.

Over the years, many patients came to me, knowing I would understand the implications of their hearing loss. Many would vent their anger and frustration at the "lack of empathy" displayed by the staff. I recall one gentleman who described them as "cruel and indifferent".

Although my work has been of a relatively menial nature and my status very much at "grass roots" level, I have always managed to establish an excellent rapport with the patients. So much so that over the years, I have experienced a level of understanding and tolerance from the patients, in relation to my disability, that has not been evident from the staff.

Most of these people have suffered from multiple functional, sensorial and behavioural problems of one kind or another. As a result of their own experience, they are well aware of the implications of disability and handicap as it affects their daily lives and the lives of others.

I well remember one young fellow who, as the result of a bashing, was left with multiple functional and behavioural problems, which sorely taxed the tolerance of the staff. However, despite what he himself had to contend with, his tolerance and understanding of my communication difficulties was such that he would manage to control his behaviour to the extent that we could communicate relatively well. He would not accommodate the normal hearing staff to the same extent.

STAFF PERCEPTIONS AND ATTITUDES:

I have learned through experience that the perceptions of the average health care worker toward acquired hearing loss is generally one of indifference. For them hearing disability and handicap seem to represent a condition which does not warrant much attention. It is not considered a problem!!

As I stated earlier, over the years I have consistently attempted to make the staff aware of the implications of my own condition and that of others like me. However, I have discovered that health care workers are not amenable to being told what those implications are and the affects that the persons intrinsic feelings and perceptions can have on their daily functioning. I have also come to the conclusion that these attitudes not only relate to hearing loss but seem to be evident across the whole disability spectrum.

It seems to me that clinical imperatives tend to get in the way of an ability to understand what is intrinsically involved for their patients. Health care workers are in my experience, very good in the diagnosis and treatment of the aetiology associated with conditions.

I believe, through experience and observation, that they are not nearly as good when it comes to understanding the implications that those conditions can have on the daily lives of those they treat. What the person has to say about their own social reality does not seem to have much relevance to the clinical picture.

The very nature of the clinical environment, where objectivity is considered to be the basis for efficient delivery of care, seems to preclude the means toward developing any real degree of introspection in relation to what is involved for those they care for.

Certainly, as a disabled member of the staff working with those who care for sick and disabled people, I can categorically say that as their attitudes relate to me, with some exceptions, this is the case.

As an example of what I consider to be lack of insight, as it affects the patients, I have been told on many occasions that certain patients are lazy because they do not do what is expected of them. When one considers the multiple effects of head injury, where perceptual, emotional and functional problems predominate, or the effects of a stroke, then the term lazy does not even enter the picture.

There has always been a tendency for some patients to indulge in manipulative behaviour. There has also been a tendency to blame the patients for being manipulative. This, without considering the need for people who have lost, to a considerable degree, any control over their lives.

I have frequently been told that a particular patient is being "good". I believe this is a totally inappropriate description in that it is open to wide interpretation. Its use sometimes makes me wonder if the term represents what is involved for the staff member personally, rather than the patient.

Equally, the term "difficult" is often used to describe how a patient is perceived to present at any given time. I believe that an individual will react to certain circumstances in a way that is consistent with individual perceptions, and according to individual characteristics.

In a hospital, I do not believe there is such a thing as a good or bad patient. However, what I do know, as a result of my own experiences, is that these attitudes represent an abrogation of responsibility on the part of the staff member and all the responsibility for a situation is placed on me, as a disabled person, or onto the patient, whichever the case may

be.

In relation to my own experience, the following examples outline what I mean.

- (1) On one occasion, after attempting to explain the implications of my hearing disability and handicap on my ability to function in the ward environment, I was told by a senior person that "I was just feeling sorry for myself".
- (2) On another occasion, when attempting to explain the same thing I was told that "I was always carrying on about it" and to "kindly desist".
- (3) I have been told on a number of occasions that I was expected to be responsible for my communication needs. It was made very clear that this did not apply to the staff.

These examples are a representation of many experiences during my working life. I believe they are also discriminatory in so far as the particular attitudes toward me are concerned.

DISCRIMINATION

Discrimination presents in many forms, either overt or subtle, deliberate or inadvertent. Whichever way it emerges, it is couched as a message of rejection and non-acceptance or even indifference.

In my private life I have the freedom to remove myself from discriminatory practices. In my working life this is not the case. Therefore, during most of that time, I have been the recipient of many forms of discrimination. As an example of a more overt form, I have been told, after requesting written dialogue from an educational video, that it was quite inappropriate of me to make such a request.

Requests for clarification have been ignored. Annoyance has been expressed at my inability to comprehend. On a number of occasions, requests to use my personal audio loop have been ignored. I have also been told that it is my responsibility to provide communication access within the ward environment (i.e. a loop system).

However, the most common form of discrimination occurs everyday in the form of exclusion from any form of group communication, i.e. hand over reports, social chit chat, conferences, work related discussion. I find that I am almost always left out and with a few exceptions, no attempt is made to ensure that I am included.

For example, I attend daily hand over reports, I often pick up a word here, a sentence there. I rarely know who is being discussed. The interactions occur at a rapid rate, and I am unable to assimilate the information. With a few exceptions, staff do not bother to face me and they do not enunciate clearly. To compound the communication problem, the area where hand over reports occurs is acoustically incompatible with constant reverberation which distorts the sound signal even further.

At conferences, hand over reports I have used my personal induction loop system without deriving great benefit from its use. The reasons for this are due to the staff members unwillingness to use it correctly. For example, they do not pass the microphone around, according to each individual speaker. Therefore I can only understand the person who has the microphone.

It doesn't require any great degree of intelligence to realise this and the only conclusion I can come to is that it is too much bother.

Each time I have contact with a new staff member, I always inform them of my hearing loss, explain the problems I experience and I show them the enclosed letter, written by my audiologist. A number of individuals have thanked me for the information, however, the reaction I get from most is "no comment" with body language which seems to say "what has this to do with me".

I frequently encounter a "mental tuning out" when the subject of hearing impairment is mentioned, they just don't seem to want to know!!! I have discovered that as a disabled person, operating within the workforce, that I am forced to exist in a "Catch 22" situation.

If I attempt to assert myself, indicate what my communication needs are and strategies which could be employed to lessen the stressors I experience, then I seem to "rock the boat". I become one who does not conform and the feedback I have received on occasion has been hostile. I have been seen as the bad guy. For a disabled person to elicit hostility or aggression, simply because they attempt to indicate or assert their needs is very difficult to cope with.

These experiences have resulted in a very marked reluctance to draw attention to my communication needs. If I accept my situation (which I am forced to do) and remain quiet, not draw attention to myself, miss out on the normal interactive processes and experience a sense of alienation which manifests as stress through not being able to effectively monitor my environment, then I am accepted, and no adverse reaction eventuates. Either way I find that I cannot win!!!

On one occasion recently I was told by one of two empathetic members of the staff where I work, that the general attitude among the staff is "we didn't ask to work with him!!" I believe that these attitudes reinforce what I have been saying and that what I have experienced is not relegated to the past but continues to exist in these more "enlightened times".

However I must emphasise that even though much of what I have experienced has been through regular contact with the nursing sector, simply because I work with them on a regular basis, these attitudes are by no means confined to that discipline.

I also wish to place emphasis on the fact that not every health care worker shows similar attitudes and I must say that my current charge nurse has tried to be supportive and set by example what should be done to help facilitate communication for me. Unfortunately she has had little success.

Equally, I accept that health care workers are very busy people and cannot always devote the time toward ensuring that I do understand. This I would accept, however, even when the pressure is less and time is not such a critical factor, these attitudes persist, even into the social arena.

As a result of the sense of alienation, I so often feel, and the resentment, frustration and anger I experience at being left out, my behaviour on a number of occasions over the years has been less than acceptable. One such occasion occurred fairly recently.

I have become withdrawn, bad tempered and somewhat aggressive. These behaviours do nothing to help my situation but are not uncommon among hearing impaired people and those with other types of disability.

I was told recently, by a senior person, that since I was aware of my behaviours I should control them. No attempt was made to ascertain why the behaviours occurred in the first place.

If, during the reading of this treatise, certain undertones of bitterness become evident, then the fact that during the past 28 years I can count on the fingers of one hand, the number of times a member of the staff, from any discipline, has said to me, "what can I do to facilitate communication between us?"

CONCLUSION

What I have documented represents material of a highly personal nature and for this reason is not to be disseminated within the public arena. Equally, the material would be considered to be confidential by this organisation, because of its potential for harm. Therefore, due to a sense of loyalty to the institution, because of its magnanimity in seeing fit to employ a disabled person, in a position such as mine for such a length of time, this material will remain confidential.

It is hoped that what I have written is not seen to be an attempt to "rock the boat" or put "peoples noses out of joint". It is also hoped that what I have documented is not viewed in the light of a figment of my imagination or as a result of an overwrought persona.?

What I have had to say merely represents a request for a modicum of understanding, not only for myself but for others who happen, through no fault of their own, to be in a similar predicament.

This predicament, in so far as my hearing impaired contemporaries are concerned, is repeated in other work situations throughout this state. In addition, what I have outlined as a result of my personal experiences is encapsulated within the professional literature for all who wish to read it.

After 28 years as a disabled member of the Queensland workforce and having to "grin and bear" what has been for me a less than altruistic situation, my rights as a disabled person have finally been recognised through the legislative process.

This result was achieved by disabled people through the process of lobbying and consultation with the state and federal governments since 1981, the International Year of The Disabled.

I am proud to say that during that time I have been part of that process. In addition to this I believe that during the past thirteen years I have managed to make a substantial contribution in the area of health care, primarily for those who experience disorders of the ear.

I can say that what has been achieved causes me considerable satisfaction, not only in terms of results, but on a more personal level, where once I was patronised and treated as one who was less than normally intelligent.

For me, the greatest benefit has been that this is no longer the case.

PETER LINDLEY.

DR WILLIAM TONISSON

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16 October 1990

TO WHOM IT MAY CONCERN

Re: Mr Peter G LINDLEY,

I have known Mr Lindley for some years, through his involvement with Better Hearing Australia, and also as a patient.

He has a profound hearing loss, but his ability to cope in a hearing environment as well as he does is quite remarkable. This is probably due to a combination of lip-reading skill and an underlying well-developed "unscrambling" ability.

There is an unappreciated problem in having such highly developed compensating abilities, however. This is that one gets to be regarded as having little or no hearing problem. Even a mild hearing loss puts heavy demands on concentration, a severe or profound hearing loss much, much more so. When this concentration has to be sustained for several hours each day the result is very stressful on the individual concerned.

It is little appreciated by most hearing people that a hearing impaired person's understanding of conversation is critically influenced by the presence of other noise, competing conversation, distance, and visibility of talkers' faces. For instance, what may be a relatively normal, productive conversation conducted face to face can instantly degenerate into unintelligible babble if the talker turns his or her face away. The better the compensating abilities of the hearing impaired person the more likely he is to be treated as a hearing person, with expectations of capacity to cope which ignore the importance of the above factors. These expectations are an extra psychological pressure on the hearing impaired person which inevitably contributes to substantial additional stress.

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William Tonisson, Ph.D.