Achieving a place: A communography
of disabled postgraduates

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ABSTRACT

This study is social anthropological insider research of disabled postgraduates, students and staff in tertiary educational institutions.

This is also a study of enabling conditions for inclusion; and ways the participants build relationships between themselves and the wider community.

I consider my participants as kin. This was a joint venture - we were related not by blood, but by the very fact that we share in communities of disabled people. We are connected even if not always interacting with each other; we seldom moved in the same circles on a day-to-day basis.

These are stories of adversity, where the participants have developed successful coping strategies and made achievements, not despite their being "othered", but by living with and acknowledging their differences. These are reflections on our society where we compete in complex emotional relationships within employment and all other social institutions. The university seemed to be a psychologically safer setting probably because it is a place for higher learning and therefore all the people had a more highly developed consciousness. Even though in some cases there were some wider macro barriers, on the whole, the participants' experience was positive.

We found what we as joint participants shared in that feeling of disability was just the same as the feeling of *communitas* as students. Thinking about *communitas* (Turner, 1967), the Latin for community, convinced me that community was the central theme of this whole thesis. There are communities of practice in all organisations and institutions in society and they are used by

the participants in this study not only in developing strategies for inclusion, but also for learning. Because the university is a series of communities of practice a major theorist for this study is Vygotsky and his concept of a culture of learning. We are also indebted to the social anthropologist Lave and her colleagues for bringing his ideas to Western academia.

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Conduct for this research using human participants had the approval of the **Massey University Albany Ethics Committee ... MUAHEC 02**/074

DEDICATION

This research is really dedicated to my parents; my Dad who passed away at the beginning of the study and my Mum towards the end. It was such a shame, I never saw myself as a sufferer, but I could always see my pain in your eyes.

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CHAPTER ONE – INTRODUCTION

Cognition, the self and anthropology

This is my *Turangawaewae,* a Maori word meaning my place to stand. I identify as a Pakeha, which is a New Zealand-born person whose forebears came from "over there", predominantly from Britain. I am a post graduate tertiary student and I live in a world that sees me as disabled. This research deals with both. I have never liked the word disabled or disability; it somehow smacks of a negation of ability. But it is also a construct imposed on some of us by society, usually the medical profession, which interprets my status for the state as an invalid. I am a recipient of a methodology of being dominated. But that state also protects me, acts as a buffer in many ways and is giving me the ability to take responsibility for revalidating myself and making me a regularly participating member of the community.

I make no apology for writing myself into this work; I am an insider researcher. Politically, I identify with the participants in this study as one of them. I see them as kin in many ways: we share a similar history of subjugation, protectionism, paternalism, infantilization and colonialism which all contribute towards a feeling of helplessness. Particularly frustrating is non-disabled persons' (especially validated by scientifically reinforced professionals) interpretation of me, or any of us as disabled people, being less competent and destined for failure - to be invalid and a life-time of dependency. Sennett (2003, p.12-13) talks about a fear of dependency as demeaning, **"welfare dependency is a synonym for humiliation."** This might be an irrational feeling, but for me, in some ways I am protected and in many ways I am helpless, being controlled by the state and forever treated as a child where agency is often denied to me as a competent adult. Very

early on in my studies I read a book by anthropologist Robert Murphy called,
The Body Silent and quoting from it Varenne & McDermott (1999, p. 134)
point out,

> Was Murphy too successful to get a tumour? Was he
> too enabled intellectually by his surroundings to be
> disabled by a disease? Being squeezed into a
> wheelchair was one kind of problem. Being squeezed
> out of full participation from the various institutions
> he had been so successful in was a far greater
> problem (Murphy, 1987).

This thesis is social anthropology I would like to think of it as a sub-discipline
called cognitive anthropology which studies how people make meaning out
of their lives in relation to language. Just as Murphy experienced the
patronisation and helplessness, I wanted to see how language is used to
keep "the other" in their place. There is a way of acting in society and in
many ways one has to play the game. Was a disabled post-graduate a
paradox? Do they have to show they are not capable, and they are in fact
unabled or disabled? One of my co-participants Wayne who has cerebral
palsy, talks about trying to compete in his love of sport when at school. He
says:

> *I was into the football club, inter-school sports, soccer
> and hockey.*
>
> *Regarding the rugby team, I turned out and the school
> principal said I "wasn't allowed to play." He was
> scared of me getting hurt. But my parents didn't stop
> me from doing anything and my father went to see the
> principal to get them to let me have a go. I played
> midget rugby for high school old boys. I remember at
> school swimming sports being left out of the
> programme and was disappointed as hell. In the 25
> metre flutter board I knew I was going to be last, as I
> couldn't doggy walk, but that was just the point of
> being included in something. On the day of the event
> everybody's name was called out and mother went
> over to the organiser and said that Wayne's name
> wasn't called out and was told that the teachers had*

forgotten to include me. So in the end I ended up swimming a width of the pool under water. There was just me and it was really embarrassing. It just wasn't funny at all.

They were feeling sorry for me, that sort of thing, but it showed me up as being different. It seemed to accentuate the fact I was not the same as the other kids. So, I was feeling really low for a couple of days.

At intermediate school I would rate Form One as my best year, I had a great teacher who included me in everything and we are still friends today.

My second form at school I would rate as my worst, because my teacher who had a hip replacement and limped around everywhere just put me back in cotton wool again. I was able, in Form One to play in the inter-house sporting competitions, like rugby and soccer and everything. But in Form Two, when I was practising to do the cross country run and then I got a call to say that I couldn't take part. So I went to see my Form One teacher and he had a word and I took part even though the other teacher thought I would fall over and hurt myself. I hated not being allowed to participate; I think it has scarred me psychologically and yet I was mainstreamed at school. What was it all about, was I destined to be a failure? That is really why I came to university to get away from all that provincial crap. I have achieved the highest academically in my family and that makes me proud. See, I can make it.

This short story gives an illustration of the frustration experienced by disabled people; in many ways others are trying to safeguard that person, but it also has the effect of isolating the individual to be considered by school peers as different. It becomes a barrier to inclusion, a learned helplessness for all parties.

Can there be disabled postgraduates? Yes, disabled in the strict sense of the sociological construct relating to disability, and that it is not in the person, it is in the eye of the observer and the restrictions that society puts on an

individual from full participation in the community. It is relative, it is inappropriately age related - if you are a child you are not expected to have the body capable of functioning as an adult. A child or an aged person may be incapable of some things, but somehow are not usually referred to as disabled. **This is a story about those recognised by "powers" as requiring** rebalancing for equit**y'**s sake. This is about negotiators and manipulators, people who have developed self-efficacy so that they may be able to make their own mark and live respected as contributors to society. Of all the institutions in society, educational establishments seem to be at the forefront of changing the attitudes of the majority.

This PhD research sprang forth from my personal life observations. I found the process of education liberating. I realized the more I learned, the less I knew. It is a bit like that with my understanding of students; we are all students at university, everyone is learning, the higher up in the institution you progress the more you are a student. From the Vice Chancellor down to those seeking a certificate we are all learning, we are all sowing the seeds of knowledge. Similarly my understanding of disability evolves.

I was a boom baby, born in an age not long after WW2. I did not see too many disabled people as a child, they were all incarcerated. I was brought up in an age of prejudice. One profound memory I have is of the depiction of the Victorian figure John Merrick (The Elephant Man) in the film where he was being chased by an unruly crowd eager to get a good view of him and when cornered, exclaiming that he was a man not an animal. Was everyone **curious to observe a "freak"?** I remember as a child, wanting to see the six-legged sheep at the circus. I also had an unclear understanding of what disability was.

I didn't want to study any grand theories on what disability is, and have not studied it as a discipline. But it does require elaboration. I am not sure who disabled people are; I suppose it really depends on who is asking and why they want to know.

What Prompted the Research?

I wanted to be able to tell my story. I had spent a good part of my early adult life on my overseas experience (the big OE). Whilst away I developed some observable symptoms of multiple sclerosis and needed to start dealing with the ways my interactions with society had changed. In the early days, I was more or less able to make my condition unnoticeable, but invisibility is both a blessing and a curse. Quite often there was a dilemma on whether to disclose or conceal. It is often a cat and mouse game we play. To be ordinary and self-reliant we need to be as independent as we can and with it comes anonymity.

I would like to tell you about two articles I've read, one at the beginning of my study. A critical friend of mine pointed out a reference in Russell Bishop's book, *Whakawhanaungatanga: Collaborative research stories* to Lous Heshusius (1992) who gave a keynote paper at a conference on qualitative research and what I thought was quite anthropological regarding the interpretation of meanings. She said something I saw as very profound, which went like this, "Am I my brother's keeper or my keeper's brother?" alluding to the interconnectedness of all living beings. This was very theosophical to me. Well, I researched and found that with Keith Ballard, an educational psychologist from Otago University, in another thesis she had written about Montessori and Khrishnamurti who happened to be past members of the Theosophical Society and the Buddha who many

Theosophists followed and then there was a love of animals, so I emailed her. She replied that although she was involved in special education, she majored in anthropology and studied it at postgraduate level. She became a Montessori teacher in her early career and educated her own children at a Khrishnamurti school. She gave me some good advice along with contacts at the Society for Disability Studies and the journal *Disability Studies Quarterly* which incidentally I was already accessing.

Towards the end of my study I presented a paper at a conference in Auckland, New Zealand for the Australasian Society for the Study of Intellectual Disability (ASSID) in 2005. There was a book launch Patricia O'Brien formerly of Auckland College of Education, now at Trinity College, Dublin, Erie and Martin Sullivan of Disability Studies at Massey University, Palmerston North, New Zealand. Called *Allies in Emancipation: Shifting from providing service to being of support.* In the forward written by Chris Newell **was another profound statement when he said, "Moving disability from other to us."**

This research really grew out of my interest in service to my communities. At the end of my masters study I gave a year to another educational institution, the Theosophical Society, and later in that year I attended a Disability in Education conference at Albany, called Progress through Partnerships. It has been a progression; my studies have metamorphosized. This is no longer just my piece of work, it is my joint participants; it is my father's who passed away in the early part of this study and my mother who passed away towards the end, my friends who are no longer on this plane. I am guided by forces I cannot see through each step I make, each progression towards an understanding, each time I am introduced to a book

or article which makes sense. There is a certain serendipitous quality to study.

The understanding of how the use of language affects the marginalisation of **a group of people considered to be "other" requires deeper ana**lysis, when there is historically little evidence of partnership, participation and representation. The concept of disability is both transcultural and intercultural. It affects all known societies and cultures react differently in treating or dealing with individuals. Even within the same society there are different disability cultures. Disability and impairment is part of the life cycle and it will affect every person at some stage of their lives. Breckenridge & Vogler (2001) in their introduction to the 13th volume of the journal *Public Culture* say that we are only ever in transition, in terms of ability.

Anthropologists spend their lifetime interests in particular communities, where they learn to experience an approximation of what it might be like to be a resident in that group and of the group. But how is their initiation into being considered truly a native viewed by the inhabitants? I intend in this thesis to show that this process is more difficult than it first appears.

Insider researchers have a unique advantage in investigating their own kind. **Of course they have no "God given" right to write and speak with authority** for their own people. There has to be negotiation as to meanings and understanding even in that community. The participant group generally might feel encouraged that the researcher could provide an accurate, more empathic idea of how they live, to provide a balanced commonsense account of how they view the world. One of the advantages of being a member of the **group is that one's** own experience is similar to the experiences of many of

those in the group. The insider researcher has a repertoire of questions and concepts, as he or she already speaks the language.

When looking at the management of discourse, I saw there were issues of ownership over the way language is used. How do people in the group view being named and labelled by another? Even in their own group there is a hierarchy of language spoken, what is appropriate for some is not for others. Of course there is insider and outsider language; there are the subtleties, innuendos, the silences, the similes, the dissention, confusion, pointing the finger.

In **a cultural group like "disabled people", many wa**nt to be known as **"people with disability" or more accurately**, they are peop**le with "diverse abilities" and** they ask why they should be thought of in negative terms. In some way, all these people are interconnected; they share in a culture through signs, symbols, experiences and language. One of the difficulties faced by this group is that it is so immense, it pervades all cultures, it is both intercultural and transcultural.

The health authorities, influenced by the medical profession and welfare authorities, continue to colonise the lives of the disabled other, they universalize the experiences of disability, they reframe people's own understandings and language into scientific descriptions; thus making it easier for society to objectify and dehumanise them. For example a friend who is a parental caregiver was described as a natural human resource.

In effect what is happening is New Zealand continues to construct definitions of social membership by keeping those on the outside, outside. It seems difficult to move beyond anthropology of adversity towards a consciousness

of diversities of ability. There should be recognition that social and cognitive anthropologists have already developed unique skills of cultural competency in the field of human inquiry.

Aims of the Research

I proposed a number of objectives and aims this research should explore as discussed in my university ethics application. In effect many of these aims are interrelated. My intention was to look at access issues, expand the debate on inclusion and ask what an inclusive society is, both structurally and temporally.

The aim is to show that the experience of disability has been framed in a negative light, as loss and deficit, by the majority of the population who do not see the abilities and gifts of the individuals. I wanted to heighten awareness of the diversity and to bring the positives to the fore.

The aim is also to make visible the narratives of people with impairments and to provide encouragement for people to get involved in education.

A further aim is to give more breadth and understanding of the experience of disability, of disability exclusion within the New Zealand cultural context, as much of our information is from offshore communities with a different cultural repertoire.

I also wanted to look at resource issues in New Zealand - with only four million people these issues are very different from other developed countries with much larger populations who have generally implemented disability action plans and codes of practice.

The goal is to encourage disabled people to engage more in education, more in understanding the New Zealand experience of disability, exclusion to resources to empower all people with impairments by sharing these stories of the success of my participants with other students and staff members.

Presentation of the Thesis

I originally wanted to place the participants to the front of this work, to introduce them and then talk about the research methodology. But I chose to describe something about the confusion around disability first, to give the study some historical context. The one factor of concern that the participants had in common was their ability to survive within the community as disabled people. My experiences have been that the medicalised scientific model tended to systemise me. to treat me as an object rather than see my quality of life subjectively. It could be seen that social anthropology is at the qualitative, humanist edge of the social sciences. I use a degree of managed subjectivity when describing some similarities between my participants, to locate them within a group. I am influenced by the social model of disability. I realised people should not be forced to think of themselves as innately inferior because someone has construed them in this way. I refer to us as disabled people or persons, and try to veer away from the singular.

Chapter two is about the evolution in the meanings of disability which is convoluted and lengthy. I show how power relationships have moved from religious and cultural influences to the secular. More recently there has been a developing self-consciousness, where disabled people are able to write and debate issues themselves with recognised authority. The chapter is

complex, as disability means different things to different peoples. This confusion is continuous, as we as people inadvertently confuse the variables in understanding, and have issues with being named and labelled.

Chapter three focuses on my co-participants. I introduce the participants rather clumsily in trying to define and show some similarities as a group. My style of writing is a form of ethnography I call communography where I use my insider research techniques to understand and speak the same language of the participants. I develop a rationale for the stories by giving some structure to illuminate my kin.

I was motivated to do this study by taking part in the "Progress through Partnerships" conference. The methodology in chapter four discusses the journey through the research process. As my reading increased I developed a theoretical position trying to remain focussed mainly on the work of anthropologists. The theory comes from the literature. My anthropologically-based methodology uses the self as an important tool in analysis. I remained a participant observer. I was already participating in many of the groups deemed to be in the disability field beforehand and continued to do so. I attended and presented at conferences, workshops and seminars both at my own campus and other university campuses to help inform this study in both New Zealand and Australia.

I had no specific research questions, but broad brush strokes of themes that may need addressing. In the nature of insider and narrative research, I as researcher, had licence to generate new questions as we co constructed meaning from sharing similar life histories. The dialogical encounters with the participants were face to face, where I took field notes and tape-

recorded what transpired. The follow-ups to the encounters were by telephone or email. These were our stories.

Working from a social anthropological perspective it is important not to be constrained by terminology. Rather, communography is concerned with mapping the understandings of the participants and co-constructing knowledge about people within their communities and how they are operating to adjust and succeed within the academic environment.

Consideration of Research Questions in Communography

In communographic research like other forms of qualitative/ constructivist research, the starting point is to formulate some basic considerations and propositions that can be used to guide the investigation process. Rather than asking precise research questions it is considered more productive to state some general concerns and research issues that can be used to open up the investigation. To construct some understanding of these concerns and issues, focus must be on asking some open-ended questions and listening to the participants, with a view to re-shaping the questions. Thus, rather than beginning with fixed questions, the questions are continuously refined in the process of doing the research, in order to reflect our increasing understanding of the problem (Shkedi, 2005)

Research questions in Communographic research, like other forms of narrative research do not proceed in a linear sequence, but rather emerge from the stories of the narrators (participants). For the purpose of the present study, a number of topics and themes were identified as a starting point for the study. These themes were then organised into clusters and used to generate some over-arching research questions. The research

questions thus provided a framework for conducting the interviews with participants and for analysing and interpreting the results.

Following are the main topics and themes I had developed when submitting my human ethics application, copies of which I had at our encounters and gave to the participants. I was not constrained by them and many times they were necessary, the conversations were free flowing and we co-constructed meanings:

Disclosure Experiences

Disclosure and openness
Family patterns of self-disclosure

"How does family background and patterns of disclosure and self- disclosure impact on the adjustment and well-being of disabled postgraduates?"

Segregation and Exclusion Issues

Disability and culture
Inclusion and exclusion – the language of exclusion
Public domination- observation of others – face to face contacts
Stigma – discrimination – prejudice
Special education

"What experiences do participants have with societal inclusion/exclusion and how have these experiences impacted on their adjustment and achievement in postgraduate studies?

Social and Economic Issues

Public and private issues

Personal welfare – income support

"**What are some impo**rtant social and economic issues and how do these impact on the participation and success of postgraduate students in tertiary education?

Adaptive Behaviours for Acceptance and Survival

Scaffolding – structures for survival

Acceptance – acceptable behaviour from others

Cognition and the learning experience – social construction

Experiences of being disabled educators – learners and teachers

"**What methods and strategies do participants adopt in order to support their** studies and gain acceptance within the **university community?**"

Human Rights and Conceptual Issues

Importation of literature from other cultures and context

Post-colonialism and speaking for the other

Universal nature of human rights and human rights and education

"**What are the main conceptua**l and human rights issues that impact on tertiary education participation and achievement of disabled postgraduate **students?**"

Personal Adjustment/Psychological Factors

Withdrawal − holding back − isolation and aloneness

Self Protection − fatigue

Lack of spontaneity − longer time to plan and do things

Visibility/invisibility − domestic realm − the home − domination − oppression

Frustration due to asking for help − autonomy

Powerlessness- being patient − becoming a patient − lack of command

Diminished world − size of acquaintanceships − support networks

"In what ways and to what extent does the experience of disability impact on the social and emotional adjustment of participants?"

An Explicit Description of the Research Method and an Outline of the Thesis.

The year of registration in the doctoral research school was devoted to an initiation review of the literature and the formulation of a research procedure. An application was made to the Human Ethics Committee at Massey University Albany for approval to investigate participants for this study. In the meantime I started my participant observations. Once approval came through I was able to enter into conversations with those participants.

For approximately 40 years I had participated in the realm of disability awareness. I was somewhat preconditioned for participant observation, an integral component of the research. My participant observation consisted of attending workshops, equity seminars and committee memberships on many disability groups. I attended and presented at conferences on disability in

education in New Zealand and Australia. I was involved at many disability seminars within our own university; presenting to students, staff and the general public on the experience of living with disability.

Field Work

Going into the field was either travelling to visit my co-researchers to wherever they felt most comfortable. Some I saw at their homes, while others preferred to meet me at their own university or they came in to visit me on campus. The study consisted of 18 in-depth encounters, over various time periods, with my co-participants, many of whom I had built up relationships with since first attending university in the mid 1990s.

I presented at the Disability in Education Conference further afield and decided to return later in the summer as I had been approached by three potential participants.

The chapter on exclusion briefly deals with the definition and history of non-participation in society as disabled people, particularly in student interactions in the educational setting. Is exclusion a subjective experience or are disabled persons to blame for being "othered"? The physical environment is not always streamlined even with legislation, where minimalist architectural access is the norm. Everything is in competition for economic resources as opposed to universal design for inclusion. Disabled people are more socially excluded than other groups in society. I intend to highlight where within our university setting many of the problems occur.

In conclusion, an understanding of Vygotsky's *Communities of Practice* is significant for interpreting how disabled people support each other and learn

that the age-old apprenticeship model is an efficient method of including oneself by being of service to other people. I describe the strategies and coping skills of the participants. Here we see that interdependency and cooperation are the ways forward. As we take responsibility for our actions the postgraduate student, already a success story, realises it is not in rights but in service that liberation comes.

Where do we go next and what needs to happen? How important is it to legislate for change or is New Zealand's laid back stance the envy of other nations? An off the cuff statement from a visiting Human Rights Commissioner from Australia commented at a workshop in 2007 that our system seemed neater, many disability rights issues seemed better dealt with through networking than having to revert to the justice system with complicated and unwieldy legislation. But is the reliance on volunteerism enough as it is often difficult in dealing with big business whose primary ethic is the pursuit of profit? As a nation we have led the way in the past as the home of social experimentation.

CHAPTER TWO – DISABILITY

Disability is difficult to define because it is a multi-dimensional concept with both objective and subjective characteristics. When interpreted as an illness or impairment, disability is seen as fixed in an individual's body or mind. When interpreted as a social construct, disability is seen in terms of the socio-economic, cultural and political disadvantages resulting from an individual's exclusion.

(Human Resources and Social Development Canada, 2004, Part I Disability Perspectives)

This chapter is in two parts: the first plots the development of historical paradigm shifts around the naming of the concept of disability. There are interrelationships between all these influences and themes I use: progress from cultural ideas, often called traditional, around health and disability; the influence of religion; the secularisation of religion through science, technology and rehabilitative medicine; and finally a movement towards some disability consciousness. **I'll explain the two maj**or models and give a brief explanation on terminology which is by no means consistent or coherent, but rather like the progression of anthropological understanding as Geertz (1973) indicated, **could be seen as "blurred genre**s**".** But from here we start building a case around disability as a method for exclusion.

In the second section, I look specifically at the word, and explore some alternative usages in the language of disability. Terms like "chronic illness" and "disability" are part of the confusion; to a large extent, people use them interchangeably, but people who are disabled might not necessarily be ill. In the United States an academic/ health professional and mother writing a

chapter in a book on chronic illness, characterised her loved one as **"a physically disabled child… this is a story about an exceptional family—**a family labelled as different because **of the son's chronic disability"** (Curry, 1995, p. 24).

Traditional Society, Health and Disability

Traditional can be a very slippery concept in the literature and often seems to refer to "pre-modern" or "pre-western influences". In fact, people of all societies have been concerned with their health and well-being. All living things before they die will have impairments caused through accidents and illnesses in their lives. At some stage humans are dependent on another person; human babies and older people are reliant on another for their own survival and this is accepted as one of the stages of human development. Humans are social beings; the Irish have a saying that **"it is in the shelter of each other, that the people live."** But societies **were also dependent o**n good health and strength, both men and women being athletic for hunting or farming, protecting young families and reproducing.

Protection of the family unit was vital in harsh agrarian communities, but also in labour-intensive societies. It was necessary to be fit and strong to survive. Human beings are capable of affection and not all traditional societies were harsh. Many had institutions that cared for their ill and infirm (Groce, 2000; Miles, 1995; Sharma & Deppler, 2005). The results of disability affected survival; if it was acute it usually meant death. Those who were ill and diseased were kept away from others in case of infection until cures could be found. The ability to cure was invariably given high status in communities; anthropologists have documented this for many years. Those who looked different from others were kept away and excluded from

participation. Many of these issues pertained to New Zealand and are chronicled in **the history of New Zealand's d**isability, a documentary film called, *Visions and Realities* by (Coates, 1999).

What is traditional? Makins (1993, p. 516) states tradition as being, **"1.**unwritten body of beliefs, customs etc. handed down from generation to generation. 2.c**ustom or practice of long standing". Tradition th**erefore is an amorphous subject and it is probably unclear what traditional relates to, with regard to disability. Anthropologist Dame Joan Metge, in a conversation with the author said**, "one needs to be careful when analysing what people mean** as traditional. Even relating to people of the last generation could be seen as **creating a tradition".** Tricky waters here – there is substantial literature on **the slipperiness of ideas of "tradition".** Tradition is a really unclear and imprecise concept; there are many traditions and it should be noted as such.

Traditional Chinese medicine and acupuncture have been practised for 7,000 years and still has colleges to train practitioners and treat people with ailments. In some cases they do not recognise impairments as necessarily disabling. The Chinese characters for the equivalent of disability are **"broken" and "useless". The Chinese concept of medicine accentuates** wellness rather than illness. But ideas of disability in China have still been problematic – or have they become so in the relatively recent political/ administrative context? Nationally the government only acknowledges 60 million people in the disability category, the same amount as the United States and yet the overall population of China is five times that of the US. Kohrman (2003, p. 109) **says, "Even today, all Chinese universities requ**ire prospective students to take and pass a physical exam (*shenti jiancha*)."** Yet, to show they are part of the international community, the Olympic Games in Beijing in 2008 provided facilities for the Paralympics to a lavish

scale. **Kohrman's** (2003, p. 99) research, a biomythography of a disabled **person's association** with the equivalent of the Chinese disability movement **in China pointed out that disabled people were often, "...called** *fei ren* (social **outcasts, lit., "garbage people")...These outcasts included orphans, the** mentally impaired, the deaf and mute, the chronically ill, and persons with other forms of bodily difference that were viewed locally as highly delegitimized**." Liu informs The United States providers of service on Chine**se culture and disability that,

> The traditional Chinese term for disability is "canfei," meaning "handicap" and "useless," or "canji," meaning "handicap" and "illness." This demonstrates how the Chinese used to view disability. The term "canji ren," meaning "handicapped" and "sick people," is also common. The term "gong neng zhang ai zhe," meaning "individuals with disabilities" is rarely used. In many areas of China disability is viewed as a punishment for the disabled person's parental or past-life sins.
>   (Liu, 2001, chapter IV, 1st and 2nd para. following)

China is often portrayed as having a poor history of human rights, but there is the sheer logistics of modernising a country with such a vast population of 1.3 billion. There are some good examples of change as the country propels itself onto the world stage. Addressing emancipation for disabled people Hallett (2006, para, 8) points out tha**t, "China won an astonishing 63 gold** medals in the 2004 Athens Paralympics. The China Disabled People's Arts Troupe has performed around the world to great acclaim. And the CDPF has helped formulate some of the most impressive disability legislation of any **developing country."**

In Korea, Choi (2001, p. 436) says the wider population referred to impaired **people as those with an, "**Unreasonable body that was objectified and characterized negatively because its bearer was identified as a permanent

burden". **In India**, Dalal expresses an opinion on another country with a huge population. Dalal (n.d., para 5) comments that disabled people are seen as negatively as in other parts of Asia and explained as historical sins of the family. Miles (2001, p.143) takes a much broader view, explaining that there are many dimensions to disability in India. Kaplan-Myrth makes similar points on the experience of disability in Africa (2001, p. 92).

A group of New Zealand researchers, Nikora, Karapu, Hickey, & Te Awekotuku, (2004, p. 16) say on Maori views of disability that, "Little is known about how disabled Maori in traditional society were perceived, treated, or responded to." Perhaps even within pre-industrial Western societies, impairment and serious debilitating illness featured little in **people's life histories**. It was natural. The idea of self in earlier times, even in British literature, indicated that the individual self-concept never laboured on their impairments; it was just a fact of life and the concept of functioning was seldom stated. Many illnesses were very debilitating, caused restriction and therefore handicapped the people who had them. Impairment and restriction was organic and natural.

Hickey (2004, p.1) notes from her research that Maori linguists describe *hunga haua* as meaning disability in traditional times. She also says with Nikora et al (2004, p. 16), that Maori believed illness and disability were either caused by supernatural forces, or believed in an alternative explanation in the existence of a dualistic approach to health and wellbeing - that of holism and pluralism.

A person was seen not as an individual, but as part of the family unit and therefore their treatment considered as a communal responsibility. But the ideals of spiritual healing can still play a part in the fabric of their

community. At Awataha Marae on the North Shore of Auckland the collective approach seems to be a function of their health and wellness clinics and disability is part of a holistic approach.

Perhaps it is this difference that is fundamental between Western and Eastern and indigenous systems of knowing. Do issues of globalisation mean that Maori deal with disability within the concept of a modern scientific understanding? This is a question posited by the Maori researcher, Jo Kingi, who worked with the Beasley Institute at Otago University in New Zealand in the area of disability, particularly with those with intellectual impairments, and became involved in describing Maori concepts of disability. Kingi noted common themes her research participants highlighted, such as that disability was based historically on the loss of land and identity, the process of colonisation and assimilation. **She states, "I have found that Maori concepts** of disabilit**y are defined by colonisation" and further adds, "Is this conception** of disability unique to Maori or do other indigenous and colonised peoples **share this view?"** (Kingi & Bray, 2000, p. 24). Thi**s is only one researcher's** idea and I could ask if all Maori see the relationship as colonisation or did some see it as a liberating encounter that gave them access to modern resources?

Was early Western society that different from other pre-industrial communities? Branson & Miller (2002, p. 8-9) highlight the changes the West went through as wage-labour started to dominate the family environment that in times past,

> was an extended family of more than two generations, linked through complex ties of kinship, affinity, and community. The aged who were no longer productive remained integral to its identity, and the frail, the simple, the crippled, the deformed, and the different were, where poverty or disease did

not threaten the family, cared for and made productive.

In some traditional health systems disability was seen as part of a structure of well-being that was either accommodated or rehabilitated, but in indigenous or traditional, and Eastern societies, the concepts are also complicated. As Groce (2000, p. 4-5) comments,

> ...it is important to understand that belief systems change rapidly when traditional systems change over time, and that often belief systems change rapidly when traditional systems intersect with western ideas and rapidly modernising national and regional trends.

Western society evolved and had a number of traditional concepts in health care and the management of disability themselves. For instance, practices handed down from generations past, faith healing, and homeopathy. Folk medicine and folk healing play a large part in the well-being of present societies. So analysis of disability might be viewed in the light of modern **Western usage, and "disability studies grew during** the 1980s in western **academia"** (Miles, 1995, p. 50).

Branson and Miller (2002, p. 3) illustrate that the process of labelling disabled people happened over time. When Western society had a traditional rural base, it provided for people with impairments within the family unit until it became a liability and an expense that was not well-incorporated into tight nuclear units. This was portrayed by Groce (1985) who gives a biomythography of a historical background to the traditional community at **Martha's Vineyard in the United States in the late 1800s and shows that** hereditary deafness was not so much an impediment that restricted the interaction of Deaf people within the wider community as everybody spoke in sign language. The community had a large population of Deaf, but it

changed to be inclusive. This was a relatively isolated community and emphasised an early form of universal design which accepted people for who they were and made adaptations that benefited not only the Deaf, but also themselves and the whole community. This was an advantage to all people as they could communicate over distances which were considered outside the norm for hearing people. More recently researchers and authors of the Liberated Learning Project in Canada used powerful computers to simultaneously transcribe speech to a multitude of different texts and found that the scope of their development benefited all people much more than they expected. Originally they developed this to help disabled people such as deaf or hearing impaired, it aided non-disabled students by offering alternative formats for understanding.

An internet search shows many links to traditional disability, and relates to disability insurance. This is interesting, and as mentioned earlier by Metge, what do we mean by traditional? In this case it might be a Western ideal for **financial security for people's** old age and infirmity, generally pre-social welfare state. Institutions have their history in tradition. Many of the workers' guilds in pre modern Europe had a benevolence component. Freemasonry is a classic example of another one that has survived to this present day. But there were others like the Ancient Order of Forresters, the Odd Fellows and the Manchester Unity Guild that could have been prototypes for modern insurance companies.

Traditional could mean **"pre-industrial", "pre-modern", "pre**-capitalist,**"** but it is used in modern day vernacular and could refer to old- fashioned or folk. The concepts of disability and chronic illness are complex and many people see the lay discourse on disability for traditional as referring to the previous sentence. Even today some authors think the traditional model is the

medical model as opposed to the social model of disability. In many cultures those who were healers, tended to be respected as members of the community. They generally took over the duties of communicating with the divine. In pre-modern times even in the West many with illness and impairments found support and comfort from members of the clergy who might have been thought of as messengers from God. Witch-doctors were able to invoke spirits and generally exercise control over the people in the communities where they lived. Brown (1991) writes about Voodoo and how it is related to healing and illness prevention in both modern day United States and Haitian communities. It had traces back to African societies. Brown (1991, p. 5) **comments, "It can** be argued that Haitians are more religious than people from many other former slave colonies and also that Haitian Voodou is closer to its African roots than most other forms of New **World African religion."** It is easy to think of traditional as not being of current Western thinking.

Religious Influences

Hevey (1992) stated that one of the three undeclared and historical theories of disability is dominated by religious or magical ways. Miles (1995, p. 49) says Hinduism, Buddhism and Islam have had a huge influence on the **thoughts of half the world's** understanding of disability. Durkheim observed that religion was an anthropomorphic construction not so much for the saving of souls, but more as an instrument in the preservation of society.

The ideas of religion were quite difficult to separate from traditional society as it was a large part of the way of life.

> Durkheim saw it as a critical part of the social system. Religion provides social control, cohesion, and purpose for people, as well as another means of

> communication and gathering for individuals to interact and reaffirm social norms.
>
> Dunman (2003, para. 5-6).

Cohesion in communities was seen in helping one another and the strength is in cooperating with one another. The Christian churches as an example have been noted for their contribution to hospitals; the Roman Catholic Church in particular has world-wide interests in organisations such as Mater Hospitals, and charitable establishments like the St Vincent de Paul Society for the poor, infirm and sick. It is most likely Alms-giving was prevalent in most cultures in both the Western and Eastern worlds. Miles (1995) relates stories of Buddhist, Hindu and Muslim rulers and Emperors in West Asia dating back to the 3rd century and describes how they provided social services to their subjects. Dalal (n.d., p. 4) comments that in some traditional Himalayan societies the people had a healthy view of holism, and it was possible for them to separate and to include all aspects of healing processes from faith to biomedicine.

Judeo/Christian belief systems go back to the Old Testament, Moses was (is said to be?) the author of the book of Leviticus which cements into religious teaching the separation of disabled people and the notion that disability and illness are usually the individual fault of the sinner. The person with disability is recognised as responsible for his or her actions. Disability becomes internalised. Bauer (2005, the biblical stories para 2) notes that anyone with illness and impairment was classed as a sinner **and needed God's** forgiveness. Like those involved with other religions, the sinners were shunned and kept away from the majority. As Hughes (2002, p. 581) comments, "Pity and alms are the stuff of modern bourgeois compassion, the olive branches offered to those who have been deemed unworthy to live **with the blessed and the beautiful." This intimates that society wanted**

separation and was quite intent on **still keeping "The Disabled"** as other. Ungar (n.d.**, p. 11) further elaborates, "Disabled people were seen as tragic, unfortunate individuals who were the victims of their impairments."** Hawkins (1990) presents an argument on the transition from religion to technology in Western individualism. If we want to identify with this as a model, it would be the individualised one, one where that individual was responsible for their own infirmity as being divinely inspired,

> Spiritual autobiography is an eminently suitable genre for a culture that sets a high status of the soul and devalues the body as at best a temporary (and faulty) vessel. Pathography, on the other hand, is appropriate to a more materialistic culture in which the concern with the physician replaces a concern with the spiritual, in which the physical replaces the clergyman as the instrument of the healing process.
>
> (Hawkins, 1990, p. 549)

Industrialisation and modern society carried on the religious taboos and secularised this separating process. The disabled person has for a long time **been thought of as a "stranger" and "outsider". Becker** (1966, p. 16) says, **"To what extent and under what circumstances do people force their rules on others who do not subscribe to them?" The disabled were institutionalised** for all types of medical conditions if they had physical, psychological and mental impairment. This had an effect of separating people and making them dependant.

Hevey (1992, p.**15) says, "In segregating disabled people from a** work-based community to a needs-based institution, the notion of dependence was **put in place". Components of the religious model included accepting** paternalism, altruism and service to humankind. Disability Scholars do talk about the charity/tragedy model in which disabled people were victims and part of the deserving poor. This section presents a double-sided view of how

the ill and infirm were treated by the religions. Through the many histories there were both good and bad treatments.

On one hand the preservation of society seemed paramount and the disabled person was forced to comply: you are included provided you comply with our **exclusionary rules. On the other, compassion and care for one's fellow** creatures is evident by the actions of benevolent individuals or the higher consciousness of some belief systems. In pre-modern societies the Christian influence in the Western world meant the individual was personally responsible for his/her infirmity as a sinner and society had to be protected from these evil doers. In the East, Buddhism and Hinduism believe in reincarnation and it could have been past lives that have influenced the sin. **We enter into the "age of reason" w**here religion can be explained in the name of science and technology where the medical profession takes the mantle of life and death rather, or as well as, Divine intervention.

Science, Technology and Medicine

A combination of social and industrial revolutions in the 17th and 18th century gave credence by rationality in the so-called Western world that would have a huge impact to secularising health and well-being through scientific reasoning. We tend to think of Britain as being enlightened, but prior to 1832 only one sixth of the male population had the right to vote. The process of naming and power were kept in the hands of a minority.

The Industrial/Scientific Revolution; also known for the medical model, added ideas of science, rationally deducing the reasons for illness and disability; finding cures was highly successful. But it also meant communities became homogenised and appeared a more ordered and regular society

which marked an ascension away from seemingly traditional and cultural environments. It cannot be denied that the quality of life and longevity were directly attributable to medical intervention. But this has caused the medical profession to become influential in the healing professions, therefore the administration of dealing with disease, injury and rehabilitation of patients was placed in their hands. Branson & Miller (2002, p. 17) explain that,

> Francis Bacon (1561-1625), passionately set forth the scientific, inductive method, portraying it as a means by which nature could be controlled, harnessed to the services of an explicitly patriarchal **society to generate "progress".**

Research conducted by Dewsbury, Clarke, Randall, Roucefield, & Sommerville (2004, p. 147) are involved within a rehabilitative mindset. They show the benefits of the technological and medical models far out-weigh any perceived social model of disability and place reliance on the individual as being responsible and a central figure in treatment.

As in the former section of this chapter, the idea of personal responsibility was and is still prevalent in the medical model. Whereas before the disabled were just excluded from polluting the majority of the population, scientific reasoning still perpetrated difference and maintained the idea of the status **quo in creating otherness. Davis (2002, p. 14) puts forward, "a central** concept by drawing eugenics into the argument and draws parallels with other perceived minorities or the disempowered and disenfranchised ranging **from women to race and class." Marks** (1999, p. 612) then starts drawing a conclusion on dimensions of oppression by stating that observation through the medical gaze maintained control through subjugation and thus constitutes the patient as a docile and passive body. Very much like **Foucault's** archaeology of institutions (Foucault, 1961) where he unpacks **techniques of observation of patients in hospitals or Bourdieu's analysis of**

power in personal and public relationships as systems of social control. These are extended by ideas of social distance for the ill and disabled, showing this section of the community as different and othered (Ethington, 1997).

Langan (2001) starts his paper with a good analogy about Turkish motorways - restricting traffic in a modernised homogenised society, by excluding those people who lived in a traditional world for not being able to keep "up-to-speed". It is a lot like that for disabled people who are decontextualised from the pace of modern society. He says "Those disqualified from travel on the new highways may soon discover that schools, stores, and other public facilities are more spread out and harder to reach." He uses a further comparison for time and space when talking about the Lawn Mower Man,

> Amplified norms of mobility alter the spatial dimensions of peoples lives... [on the film about the lawnmower marathon] our visual experience of space has been transformed by speed... The deliberately slowed down pace of the film creates the illusion of "real time" and the return to the human scale implied in the title reinforces the film's thematic suggestion that autonomy - figured as escape from the immobility implicit in mass-mediated consumption is still possible.

(2001, p. 460)

An example is the location of the Disability Centre near where I live on the North Shore, which has been relocated from Takapuna to Albany in the northern suburbs of Auckland, New Zealand. It has moved from a centrally placed easily accessible location on a bus route to an out-of-the-way new building. One wonders, who are the beneficiaries? I dare say the decision makers and the staff more so than disabled people. It is like erecting an edifice for the continued institutionalisation of disabled people as charitable cases and those who fundraised and planned have a multimillion dollar

property which implies, "Look, what we have done for these poor
unfortunates. We have kept them in their place, out of the way." Rather
than be inclusive, it just perpetuates the power relationships that business
and the authorities have over disabled people; it allows them to be able to
access all their services from one place. I believe the local city council had
an obligation to keep one fifth of the population not excluded, but active
participators within the centre of society.

The unfortunate scenario is, the building of a new disability centre began its
life in an old paradigm, that of being rooted in a fusion between the medical
model and the religious and charity model or mode. Today this might be
described by many as monopolisation by the scientific positivist fraternity as
they took the power of interpretation of "the other" over how they live their
lives as colonisation. It was not that long ago according to Heshusius (2002)
that an argument was made against the establishment incarcerating people
of difference against their wills. A classic example is the way we kept
intellectually impaired adults and children with physical impairments in
institutions still using acronyms of their names like the IHC and CCS. This is
a pervasive domination in the organisations in the guise of attracting the
charity dollar.

In a not so subtle way, Marks (1999) refers to the medical monopolisation of
order and the disabled person. Or Hughes (2002) talking of the invalidation
of the disabled person in post-modern cultures. It is Hunt who describes the
term disability as a capitalist creation: "Historically one can say that
disability was used to define a category of people unable to work" (2001,
Para. 5). Of course it is much more than that. Another argument (Branson
& Miller, 2002) details the creation of surplus and the transition from an

agrarian based culture to a technology based culture that has its roots in capitalism.

Ungar (n.d., p. 5) identifies a critical period in the modern era: **"Until the second world war, the main response within the medical model was to treat the impairment as far as possible, and to provide institutional care for those who could not be 'cured'." The scientific model, often called the medical** model, has been and still is a necessary part of the process of modernisation, but it has no components that deal adequately with the social consequences of disability and chronic illness. **As Davis (2002, p. 11) said,"** Medical definitions of impairments were developed with no need to create **unity among diverse patient groups."** If disability is in the eye of the other, critical thinking was definitely not in the hands of those who had been affected by it. Throughout this modern period of the industrialised world, attention was placed in the hands of the medical profession. Impairments are the observable natural phenomena that may or may not be treated by the medical profession and to an extent how the person deals with that impairment, may or may not create barriers for the person and they may not feel disadvantages and therefore disabled. These phenomena may well be caused by birth defects in the case of several of the participants. They may be physically observed or be psychological or physical and present at birth and develop later in life or caused by an **accident. Some people don'**t feel disabled, yet they have impairments.

But this methodology is challenged in post-modern analysis as still locked into the binaries of western thinking. A paradigm shift was called for, away from the individual, to placing disability into a social and political context, one where society needed to change towards non-exclusion and acceptance **of people's ability diversity.**

Disability Consciousness and the Social Model

Writing from a point of view of the sociology of disablement Barnes, Oliver, & Barton (2002, p. 3) point out that **"Prior to the 1980s, one or two notable** exceptions aside, academic interest in disability was confined almost exclusively to conventional, individualistic medical explanations and even where others had become involved, they tended to reproduce disability **uncritically within these frameworks." Although their experiences are valued** they are not the same as those living with the effects of disability. Wise & Stanley (2006) explain this when talking about feminist fractured foundationalism, as different standpoints produce different epistemologies.

So now we are entering an age of disability consciousness where disabled people are able to critically debate how disability affects their lives, rather than have others interpret it for them. The formation of the United Nations saw individual freedoms in civil and human rights happen for all people who were marginalised, negated and oppressed. It was the attention given to post-colonialism that saw reformation in the way people were treated when, if you appeared different, you could have easily been incarcerated for offending the eye of the observer. The rights of disabled people are similar to issues faced by women and ethnic identities.

Hunt (2001, Para. 5) relates the hidden history of the Union of the Physically Impaired Against Segregation (UPIAS) movement which combined the self-organisation of disabled people with revolutionary politics, by saying that disability is about not having control over your life. It involved critiquing the social culture that denied people the right of self-determination very much

like the challenging of structures by women and Maori as they tackled the issues of their own colonisation.

This seemed to be the Marxist form of analysis that many British sociologists followed. But not all looked at it as materialism. In citing (Barnes, 1991) Tom Shakespeare (1994, p. 286) noted that,

> Disability stereotypes which medicalise, patronise, criminalise and, dehumanise disabled people abound in books, films and television, and in the press. They form the bedrock on which the attitudes towards, assumptions about and expectations of disabled people are based.

Influenced by sociologists in disability like himself, Sullivan (2000) agrees that people do not have disabilities, they have impairments. Disability is what happens to people, and it is a tangible construct, like the concept of community or culture. He has been more instrumental than anyone else in New Zealand for influencing critical thinking on the social model of disability. Sullivan cites the UPIAS saying that disability is something imposed on top of our impairments. It should be noted that Sullivan was very influential in discussing language with the drafting of the founding document of New **Zealand's relationship between the government and disable**d people, the New Zealand Disability Strategy (NZDS).

Momm & Geiecker (1998, Para. 5) discuss this topic saying there have been many debates as to what to call people affected by disability. In Britain the idea of the social model has been advanced by sociologists. Barnes, Oliver, & Barton (2002, p. 3) **have said, "Rather than ide**ntifying disability as an individual limitation, the social model identifies society as the problem, and **looks to fundamental political and cultural changes to generate solutions."**

Bickenbach (2002, p. 2) a Canadian lawyer confirms,

> When disability is a burden, they argued, it is a burden created by the world in which the person with impairments lives. That burden ceases, or is **reduced, when the person's environment is** accommodating and accessible. In short, when disability is a disadvantage, it is so because of the socially created, maintained or sanctioned environment. Socially created disadvantage, moreover, is discrimination that violates the fundamental human rights of people with disabilities.

Davis (2002, p. 11) made an important point that in th**e United States, "With** the return of veterans from the Vietnam war, a movement grew up around **civil rights for people with disabilities." Coincidentally about the same time** other western societies were reacting to the United Nations declaration on Human Rights. On the other hand some consider that minority rights defuse the meaning of the social model. As Ungar (n.d.**, p. 6) says, "Proponents of social models of disability reject the 'personal tragedy' notion of random** affliction by highlighting the non-ran**dom nature of disability."**

Within groups of people that have to face these issues in their lives there is confusion. American anthropologists involved in disability studies as educators Kasnitz, Switzer, & Shuttleworth (2001) say disability scholars use several social or socio-political models of impairment and disability. Bickenbach (2002, p. 1) was a consultant in the drafting of the International Classification of Diseases and Functioning & Disability (ICF) for the World Health Organisation and said at a conference I attended that,

> The debate over models or definitions of disability has led to the consensus view that the lived experience of impairment – that is, disability – is a complex interaction between intrinsic functional and structural features of the person and features of the **person's physical, social and attitudinal** environment.

A group representing those involved in tertiary education in New Zealand called ACHIEVE (2005) indicates **our own government's confusion on** definitions of disability: various definitions of disability exist. The definition used in *The New Zealand Disability Strategy* is different from that used by Statistics New Zealand for the 2001 Disability Survey and in the Human Rights Act, 1993. (Achieve, 2005, p. 11). Branson & Miller (2002, p. xiii) indicate there is some complexity in the term **"the disabled" saying it should** be underscored as functioning on a number of different levels. Neilson is a New Zealand researcher and teaches at university on disability issues in education; identifies herself as a disabled person and comments in the first chapter in a book on special needs.

> It might be useful to know that this chapter is written by a woman who was born with a physical **disability that affects her joints" (2005, p. 9)**. It is particularly difficult writing as an insider, and writing pragmatically about oneself and trying not to sound as if one adheres to the medical model as **she describes attempts to define 'disability' raise** many conflicting political issues.

> (Neilson, 2005, p. 11).

Marks (1999) points out there are problems associated with the social model, and thinks the social model contributes to the maintenance of the individual model of disability. By saying that, excluding the personal experience from the analysis of disability, it leaves a theoretical vacuum, only to be filled by people who wish to continue the individualistic model or perspective. **Shakespeare (1994, p. 296) agrees that, "The social model** needs to be reconceptualised: people with impairment are disabled, not just **material discrimination, but also by prejudice."** Complications are further identified by, Hacking (2001, p.39) who writes on Harlan Lane, a distinguished deaf rights advocate who compiled an essay titled *The Social*

Construction of Deafness. He mentioned there was more than one construction of deafness, some were dominant and there was competition within their communities.

Perhaps the Deaf community has a sense of identity and shared histories and excels as a culture within a minority group where their impairments are seen with pride. Of course the hearing-impaired overall might be fractured; they have five distinct cultures and as mentioned earlier different standpoints produce different epistemologies. But is this argument fudging the problems of finding meaning towards disability? Perhaps yes and no? This discussion is highlighted by Kasnitz & Shuttleworth (2001, p. 31) mentioning,

> Reconceptualizing the disability/ impairment distinction and reclaiming the impaired body from medical discourse and embodying it as a subject in its own right is viewed by Hughes and Patterson as vital to the identity politics of the disability movement.

This is not surprising; even the Ministry of Social Development in New Zealand that is the parent body of the Office of Disability Issues (ODI) call **their client group, "people with disabilities" a**nd yet ODI call the same, **"disabled people."** (Ministry of Social Development, 2005). Confusion has even filtered down to the DPA which was once known as Disabled Persons Assembly that has retained the brand name DPA, but is known as the Assembly of People with Disabilities. When I mentioned this in 2005 to their National President, he said they are interchangeable. I am not sure whether Mike Oliver, one of the chief architects of the social model would be delighted with the whimsical fudging of a highly significant marker of identity for those in the disability movement. Heshusius (2002, p. 106) by using a

post-colonialist standpoint illustrates this perspective, "As scholars in Black studies have known for ever, the problem in the Black/White divide has been that "White" was never seen as a construct, but as a given, a sign of the normal, the desired, the standard." This idea of naming is confirmed by Snyder and Mitchell (2001), Davis (2002) and many other disability scholars.

Davis (2002, p. 50) says he defines "physical disability as a disruption in the sensory field of the observer. Disability, in this sense, is located in the observer, not the observed, and is therefore more about the viewer than the person using a cane or a wheelchair." The idea of power relationships in disability consciousness will not go away and it was noted by Barnes et al (2002, p. 7).

> However over the last few years, a contrary and more radical perspective has emerged, championed by a small but vocal band of predominantly disabled scholars, many of whom are based in the humanities and cultural studies fields, in universities in North America and Australasia. This has led to a growing demand for the development of a more critical, interdisciplinary field of enquiry more in keeping with the socio-political position associated with the social model approach…

The Word Disability

As a word, disability is relatively simple; it is fashioned from the Latin term *habilis* for ability, and literally means; to lack ability. To disable, according to Makins (1993, p. 140) is 'to make ineffective, unfit or incapable by crippling'. Linton (1998, p. 30) however says, "The Latin root of disability means apart, asunder." According to Pearsall (1999, p. 3) the word able means having power, skill or the means to do something. She states also the origin of it is from the Latin word *habilis* which means handy, (to hold). Makins (1991, p. 2) says that, from the words, '-ability and -ibility, [she derives] -ible and –

able are used to form adjectives from transitive verbs…Many of the adjectives formed can become abstract nouns by the addition of **–ity.'** Makins further goes on to address **–**able, eable, and **–ible [are the] '**most common ending for an adjective formed from the transitive verb and some nouns is **–**able…**A number of w**ords take the ending –ible because they come from Latin stems. From these dictionaries we may take that iblity is the same as ability. The Microsoft Windows XP (2002) thesaurus says it is both the noun and verb state to give some idea of how we use the word in our everyday language.

Throughout this thesis one will determine the importance of the language we use. Although we are discussing disability it should be noted some of the participants in the study would describe themselves as living with the effects of chronic illness.

In her book on medical sociology, Cockerham (2003, p. 20) has no section on disability or illness. But she has sections on chronic disease and says, **"Several** important analytical concepts assist the epidemiologist in describing the health problems of human groups. One of these concepts explains the definition of a case. A case in epidemiological terms, refers to an episode of a disorder, illness, or injury inv**olving a person." The renowned sociologist** Giddens (1989) refers to mental illness in the chapter on deviance when talking about crime. However Giddens (2001) by the 4th edition gives illness its own chapter in the sociology of the body: health, illness and aging.

English language is also dynamic and evolving; we change words and develop them, assign meanings that might never have been intended. For instance disability, was used in answer to, and in conjunction with, the word handicap. In fact, Makins (1993**, p. 229) described handicap as, "**any

physical or mental disability, something that makes progress difficult, **disadvantage or advantage given." At the Pathways 6 Conference in Sydney** Australia, a disabled student raised a question in a student forum about language and proposed we change the word disability to diffabilities, explaining it was a concoction of the words different and ability. Gordon & Rosenblum (2001, p. 6) calls for a change of name signalling a new identity, as is a case for the disability rights movement which specifically called for a rejection of the term "handicapped" based on the assertion by some that the term originated in disabled people having to beg**—"cap in hand"**--for their subsistence (Biklen & Bogden, 1997). Handicap is also a complex word; and in the definition by WHO, has been dropped as a heading from the category on disability and impairment and functioning. It had connotations of imposition on people by the medical fraternity and is now being used much less as a descriptor of disabled people. According to Pearsall (1999, p. 645) **Handicap is, "a condition that markedly restricts a person's ability to function** physically, mentally or socially. 2 a disadvantage imposed on a superior competitor in sports such as golf and horse racing in order to make the **chances more equal."**

In North America according to an online dictionary (Lexico Publishing Group, 2005) handicap is still in wide use, but has been seen as offensive to some. Disabled people were once and still are known as handicapped, to many insinuating cap-in-hand, as if they request alms, as if they cannot survive without charity. Lexico further state that there is a clear choice there to put the person before saying they are disabled.

For a number of years including the start of this research, I had always disliked the meaning conjured by the word disability, the negating of ability.

Confusion and Controversy

The confusion and controversy comes from the fact the two major camps influencing disability studies come from either the European, mainly British model (social model of disability), or the American model.

Davis (2002, p. 23) says that he wanted to make the point that disability is in itself an unstable category. Albrecht (2002, p. 18) has indicated that, **"Disability studies developed as a field in response to the perceived universality of the problem." G**ordon & Rosenblum (2001, p. 1) stress the importance of the social constructionist perspective, denote the difference between the British and American models; and they note the same as Tregaskis (2002, p. 458) that people with impairments are disabled/excluded by a society which is the social model in Britain and both mention the dominance of sociology in the field of disability studies. **Bickenbach (2002, p. 4) says "Disability advocates have consistently** conflated health, and health professionals, with medicine and physicians. If nothing else, this devalues, or rather makes invisible, the health contributions of the various, non-medical, allied health professions, such as **the therapists."** The situation is changing and Davis (2002, p. 10) adds a dimension indicating there is a two phase struggle. The first phase is identity and proud-to-be-disabled types and phase two is the redefining of the struggle, diversity within the disability movement. He notes there is much more conflict between groups of impaired people.

Sullivan (2000) believes it is **"**[t]he Language debate where the imprecision starts. It is my firm belief that the seeds of this confusion lie in the outcome of the debate within the disability community over what we will call ourselves**"** (1999, para. 17). The Union of the physically impaired against

segregation (1976, para. 10) **comments," The Union maintains that, far from** being too concerned with the cause of disability, the "experts" in the field **have never concerned themselves with the real cause at all."** Although Gordon & Rosenblum (2001, p. 14) have an important point to make about bringing a comparison with disability between other ways of being, there is still some confusion with language when they continue to talk about people as if disability is part of their **problem by stating such things as "those with physical disabilities".** Heshusius (2002) view is,

> … **that disability and ability diversity is invisible in** them but not absent. For the view that a human being at her/his normal core is able, understanding-capable, a partaker in public discourse, an equal participator, and so forth, can only have currency against that dark other possibility: that said in-ability, that hideous dis-ability and dependency, that unsaid lack of competent language, that hidden slowness, that lack of rational knowing, that lack of capability.
>
> (2002, p. 107)

Breckinridge & Vogler (2001, p. 351) call for a capabilities approach and **have indicated that, "If the difference that we name *disability* promises to** turn some intellectual work upside down, a special challenge for *Public Culture* is to unsettle the tendency in disability studies to universalize **various Western values and assumptions." The notion in society that people** with impairments are treated as something different compromises the **language debate. Heshusius (2002) reminds us that, "If theoreticians** consider disabled people as innately deficient **…** the next step, she says, too easily becomes thinking of their marginalization as warranted, or at least as unquestioned**"** (p. 99). Momm & Geiecker (1998, para. 14) state however, **"Nevertheless, this points to an ambiguit**y in the concept of disability that gives rise to so much confusion and that could be a main reason for the **social exclusion of disabled people."**

Disability Summarized

There is much debate over the concept and language of disability. Since coming to the fore as a serious topic of conversation there is still a lot of confusion as to what the group calls itself. It is obvious that there are people who subscribe to the disability movement as there are so many that are affected by it. Maori when approached by Europeans in the 1700s asked by **Captain Cook, "who are you" just said** "we are Maori" which meant "ordinary". Perhaps that is what disabled people are seeking, just to be ordinary. Disability encompasses people who associate with bodily differences; they may or may not have illnesses. Many chronically ill people would associate or identify with being disabled. They may be people with loved ones that are impaired and so they are restricted from full participation in society themselves as carers.

It wasn't that long ago that some men were granted human rights in the Western world, then followed women and racial minorities. Even in the disability movements today, disabled people are disenfranchised by the majority of the population and they in turn see that women and minorities are still, in some ways, disenfranchised. There is still confusion over language and that disempowers disabled people. There is a lot of political rhetoric coming from the government who are only shamed into providing legislation by the international human rights bodies in the United Nations. But even this is changing, as Barnes et al., (2002) **elaborate, "Since its** politicization in the 1960s by disability activists and disability organizations across the world, disability has become an increasingly important issue for **politicians and policy makers at both national and international levels."**

We have to be careful over the language we use, disability is a concept, and it is not in the individual, it is something that happens to us. Many now say they are people with a disability or they have disabilities or they say this is my disability. Which can be misleading and confusing. I went through the stage of thinking I was a person first and that disability was secondary, when I was really meaning my impairment (even though it is not all encompassing) was secondary. This adds to the confusion as in most western societies, the majority both inside and outside the disability movement, transpose impairment and disability and consider them interchangeable as much as they do with putting people before disability.

The "people first" issue was and is a knee-jerk reaction to being labelled disabled and colonised by the administrative establishments and medical professionals. I just wonder how many people bother to critically analyse and reflect on the meaning of disability. In many cases, the anger of seeing others are trying to reframe the naming process means this is not being discussed adequately. We try to find words that are more politically correct, like ability diversity, but it never seems to matter much which of the terms are used. It seems to be the concept and construct itself that attracts the unwanted dehumanising negatives.

It should be simple if we think of disability as a concept, it is not personal, and if we treat it as that, why try and change the language? In fact, I am a person first and I try not to use the terms **"disabled person"** or a person with **"impairment" as** these are all encompassing categories. I tend to say I am a **person and try to underplay the "with multiple sclerosis" part as I want to be** able to display the levels of incapacitation, or temporarily hold back from participation in community.

A matter of fact and pragmatic usage is called for where subjective and objective are not differentiated. This is in line with many feminist reasonings like Heshusius (1994, p. 15) **who indicates, "For a number of researchers,** anxiety about how to be as objective as possible has been translated into anxiety about how to manage subjectivity as **rigorously as possible."**

This is also in keeping with Davis (2002) who presents the argument that many critical theorists now view as existentialist:

> Indeed the postmodern period is one that saw the proliferation of multiculturality. One could attack the shibololeths of any ground of knowledge, but could never attack the notion of being, for example, African American, a woman, or gay. To do so would be tantamount to being part of the oppressive system that created categories of oppressed others.
>
> (Davis, 2002, p. 12-13)

All in all, the discussion on disability has only just been tabled. Disability means different things to different people. We have different languages even in English that we all use and they have different meanings to the different players of the game. In disability consciousness the debates were instigated by the social model of disability in Britain and as Davis (2002) said, there is conflict between the different factions in the movement. This is similar to the major arguments in racial studies and feminist critiques insist that there is more than one kind of experience. This thesis looks at particular experiences within disability not disabilitisms.

CHAPTER THREE - PARTICIPANTS

Introducing the Participants

In this chapter I describe my kin. This is a joint venture - we are related not by blood, but by the very fact that we share in a community of otherness. We are vicariously connected and do not always interact with each other on a regular basis. This is a community of shared experiences and practice; there is camaraderie between group members because of this. On communities of practice Wenger, McDermott and Snyder(2002, p. 4) say that, "Communities of Practice are groups of people who share a concern, a set of problems, or a passion about a topic, and to deepen their knowledge and expertise in this area by interacting on an ongoing basis." Many of my participants know each other. It may be that we share similar impairments and are associated in the same support organisations and all of us share in the constructions of society's concept of disability. This area of kinship is advanced by other anthropological authors who say connectedness and kinship can be either familial or conceptual. Rapp & Ginsberg (2001, p. 535) have been noted as saying, "We stress the cultural work performed by the circulation of kinship narratives through various public media, as an essential element in the refiguring of the body politic as envisaged by the advocates of both disability and reproductive rights".

Initially it was my intention to write ethnography, but I find I meet somewhere between a biomythography and communography. A biomythography is something the medical anthropologist Kohrman (2003) describes as he pieces together a documentary on articles written by other members of the same community, sometimes retrospectively, of a person's life. "Bio" alludes to the shortening of biography, which in some cultures

they abbreviate to bio and add data to create the word "bio data", which is **the same as a resume of one's life. Whereas the educational psychologist** Sobrun-Maharaj (2002, p. 110) illustrates communography thus,

> This label will describe research undertaken by a researcher who was a member of the community being described. As an insider, the researcher does not need to negotiate her position with the subjects and spend prolonged periods of time with them within an artificially created situation. As a member of the community, she has first hand knowledge of the perceptions of this group, which constitute their social 'reality'.

This later description could be a somewhat problematic assumption. There is an issue in that the researcher is more often than not in a power relationship over the research participants. The a**uthor's experience,** was aa a teacher and an elder researching a community of students, although she happened to be ethnically similar to her research participants. Structurally it is still a top down study; she is doing it to those who are less powerful than her. The anthropologist Cohen (1995) has maintained this stance:

> How do you know what the other person is thinking? How do you know that the other person is thinking? How can you discriminate between the other person's consciousnesses? The answer to the first and second questions, I cannot know for certain, leads inexorably to the answer to the third: I cannot. What we can do, what anthropologist's customarily have done, as recent work has shown us, is to use literary devices of one kind or another to convey in our authored texts the impression of such a discrimination. But it is one which we as authors have engineered.
>
> (Cohen 1995, p. 3)

What we can understand from this is that you cannot assume you are on the **same "wave length" of any individual.** Even if we do have similar experiences.

Another critical friend of mine has reminded me I need to
define what my group is? Who are included and who are excluded? What
makes them members? What do they have in common and how can I
describe them as a group I can only allude to the fact the study identified
what the participants sought, were disabled people and members of this
research group have significant impairments and have been involved in the
environment of tertiary education, for a longer period than other students.
In other words there is an element of long length of time in both.

These vignettes or portraits of my participants are intended to set the scene,
to show we are dealing with real people. Although their names have been
changed and many are known to each other, it has been a logistical
nightmare to make sure **each person's** confidentiality is protected. Of course
it is not possible to say your anonymity will not be identified by another
member of the group, as there is a good chance their peers have a more
intimate relationship than I and may be able to piece together their life
experiences or match impairments with individuals. I needed to be a bit
matter-of-fact and sort-of picked several areas to explain descriptions of
these individuals like their impairment, how they live, a little historical
background, my interaction with the participants, something on what they
did at university and an attribute I think they have. Impairment is a
problematic term; I was troubled, in that one might associate the study as
aligned with the medical model. But the social model of disability has some
roots in scientific study. Feminist Crow (1996, p. 225) says in her Notes 1
that, "Along with many disabled people I feel some discomfort at the word
impairment because it has become so imbued with offensive interpretation.
Perhaps we need to replace impairment with an alternative term". When
trying to find the social model of impairment Hughes (1999, p. 328) cites

the UPIAS when it comes to the distinction between disability and impairment by stating,

> Impairment: Lacking part of all of a limb, or having a defective limb, organism or mechanism of the body; Disability: The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities.

This points to a much medicalised definition. Brunt & Chronis (2005) present a really powerful and inspiring book on the positive aspects on the lives of New Zealanders with disability without dwelling on aspects of their medicalisation; the text is peppered with pictorials and a picture paints a thousand words. This strongly acknowledges that disabled people do attain high levels of efficacy and self worth.

Being an insider researcher has advantages, I wanted to tell the stories of the participants much the way they may want them related. Within insider research (personal accounts) and auto-ethnography identification with my peers, showed I was really just one of them. This lead to my writing an auto-ethnography. O'Reilly (2009, p. 171) **elucidates by showing , "Auto**-ethnographers challenge the absent authorial voice of much realist ethnography by front-**staging their own character and experiences". She** further extends this theme by saying that in contemporary ethnography is legitimised O'Reilly (2009, p. 189) s**ays, "That is, an awareness** ethnographies are constructed by human beings who make choices about what to research, interpret what they see and hear, decide what to write and how, and they do this all in the context of their own personal biographies **and often ensconced in scientific and disciplinary environments".**

Being an insider researcher has advantages, I wanted to tell the stories of the participants much the way they may want them related.

Somehow there appears to be a tenacious spirit in all members of the group. There is all too much negativity out there portrayed about people with **disability. Of course the word "disability" in itself negates the ability of** individuals. I wanted to draw this study out of the colonialist interpretation of other. I sent these stories back to my participants and waited. For my Masters research I had transcribed interactions between myself and participants saying to them, of course these are confidential, but in two **cases "loved ones"** telephoned me flabbergasted they had been portrayed in that way. In the end no other person had access to my data and it really **wasn't an issue for the transcriptions to b**e verbatim. Only the quotes I used needed to be accurate, the idea was for me to use the transcriptions only as raw data. I sent the vignettes back to my joint participants, not so much that I wanted them to massage and manage my perceptions of them, but out of respect. To make them feel included in this emancipatory and collaborative research process. In my introductory letter to the participants I mentioned that in return for their consent I would keep informing them.

Rationale to the Vignettes

It should be noted I do not have a medical qualification. This is not medical discourse, it is observational and I can only lay claim to being a keen observer of people. As a social anthropologist, I have been taught that participant observation is an important tool in our professional arsenal of inquiry. All the members of the group are affected; we assume by disability, but this is subjective and different people react differently to its effects. To

be pedantic, the things my participants have in common are that they are affected by impairments; they are graduates and are probably pragmatic.

The vignettes will describe the major impairment or impairments the participant had. It is by no means conclusive, but gives an indication of the challenges faced. I described their living situation and location. Then I would give a portion of their life history or something from the past. I might also describe where our paths crossed and something about how our relationships with the disability movement still continued. I would find a defining quote that helped to locate the participant within my research.

Angela

Angela is woman in her 40s and is significantly challenged with sensory impairments. She has considerable chronic fatigue which necessitates her permanently using a motorised wheelchair. Using a motorised wheelchair is a signal to society that her assessors consider her condition to be permanent enough to warrant this expensive apparatus for both interior and exterior use.

Angela rents a house close to the university and is able to access it by means of her motorised wheelchair. She has her own room on campus, but says it is a distance from the sick0room if she needs to rest. She spends a considerable amount of time at home where she is able to interact with her considerable networks via the telephone and email. She is a solo parent, and manages the household of three with her teenage son, who has some cognitive impairments. At the time of my visiting her she also had a resident boarder.

We met in the early stages of my PhD study at an Annual General meeting in the South Island of a disability political movement of which we were both members. I mentioned my research, asked if she might like to share her life story. We have contacted each other by email and I introduced her to an email list-server for people who support each other and discuss current issues relating to disability.

Angela is a tutor at her university; and has attained a high level of distinction with her post-graduate studies. She is currently researching for her PhD in the Social Sciences. Angela says the topics of her study are about invisibility and identity. She says,

> *What I am curious about with identity; why is it, that we used the word dis ability, that is the opposite of able so does dis, when you break it down, that is the opposite of able. So dis means something defective*.

Angela is on an Invalids Benefit so is supported by the state for her living costs. Being a good student she is supported by her university with a Vice-Chancellors Scholarship for her PhD Studies and she is currently a full-time student. She also benefits by having equipment provided through Workbridge[1] and has the use of voice-activated speech recognition software to combat her fatigue episodes.

Angela, like the majority of the research participants, is a servant to her communities. Apart from her huge academic workload she is involved in helping people whom she considers less fortunate than her. She assists as an advocate for intellectually disabled people and offers her services freely

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[1] Workbridge. An incorporated society, is a professional employment service for disabled people, it also provides support funding for people seeking employment or are in fulltime education and wanting to work.

to other marginalised groups. She is a clear thinker and a political activist. She has strong convictions for helping oppressed peoples.

Angela says,

> *The minute you identify with something weak, you are seen as weak, you are seen as being unable to be part of the community.*

Arthur

Arthur is a man in his late 30s and lives with a debilitating, potentially fatal and extremely painful medical condition; in fact he has often been critically ill and has been so since he was in his teens. He needs to be constantly vigilant of what he eats and drinks and says in the past he did not take enough care and attention. He has a love/hate relationship with his impairment. He said,

> *I could be in hospital tomorrow. That's how quick this thing is, it has ruptured in the past.*

He was putting himself into high stress situations like employment, family stress and living life in the 'fast lane'. From 16-30 he didn't deal very well with his health and lived as though he was OK. In fact, he needed an operation and to live in a less stressful environment. He even made a point of going overseas on "His Big O.E."

When he came back to New Zealand he went into a corporate job with big money and high pressure and went downhill physically and within a year had an operation. He said:

> *Within six months they opened me up again, and this time it was right throughout my bowel and it has taken 15 to 16 years of stuffing a tiny piece up and took six months to finish the rest of it.*

Arthur is separated, (estranged from a wife and two children) and rents a property which he shares with his sister.

Arthur doesn't see himself as disabled.

> *I wouldn't even refer to it as that. The word my father would use, oh, you are crook, you are sick. Crook used to refer as temporary, he couldn't conceive of it beyond the temporary thing. Oh you feel sick and as a boy he would say he can't play rugby this weekend because he is crook. But it was not the flu, or a bug or something. And that is the way I grew up thinking about. That I was just crook and had to get over it.*

An introduction was arranged for me by one of my informants and we arranged to meet for lunch where I could explain the purpose of my research and get his written consent for him to be a participant in the study. The first meeting took place over lunch in a café, this was too noisy to be to tape recorded and we later arranged to meet in a quiet location.

Arthur had a first class honours degree and approached a university close to his home. Once he enrolled and notified the university he had an impairment, he was informed by the disability coordinator of any necessary assistance he might get from the state to complete his studies. He is a full-time PhD student on a scholarship, and has computing equipment made available through Workbridge.

Arthur was inspired by his neighbour who, at 70 years of age, was diagnosed with cancer.

> *He was diagnosed as dying of cancer and advised by his doctors to go home and take it easy. He went out, and bought a lawn mowing business and at 85 he still mows 30 lawns a week. He fixes my car, my washing machine, my lawnmower.*

Arthur has a philosophy about his life and wellness and said,

> *It is a foreign invader you just have to live with it but don't let it become you. So that has changed a lot, and I think where your focus is. And if you focus on that then I will become who you are and I have got other things I can focus on really. The PhD has given me focus. That was another reason why I came and did my PhD. I can sit there and focus on the four walls or I can say I'm going to go and do a PhD.*

Daphne

Daphne is a woman in her 40s and was born in Britain totally blind. She had an operation as a young child and gained some partial vision growth. She is still appreciably impaired enough to be legally blind and has a constant guide dog companion. Several years ago she was involved in a major car accident where she sustained serious head injury along with liver damage. Because of this accident, she has difficulty with her highly developed cognitive skills that had been necessary to function adequately as a blind person. Now she is challenged with recalibrating perception and memory functions.

Daphne is married and lives with her partner in their own comfortable modern suburban home close to amenities and with easy access to her university.

Daphne says that on her life experiences, a lot depended on her background (social historical) and her parents were great support and great fighters for her independence although her mother died when she was very young. She had gone to a good school in Britain, but her experience at university there was**n't that successful**, **as accommodations for her blindness weren't catered** inclusively enough. She commenced her tertiary qualifications in New Zealand and has practised law and worked for government departments and a labour union.

She said:

> *The blindness doesn't worry me; the things I miss most, is picking up a book and not being able to read it or driving because of lack of independence.*

I had attended an A.G.M. for a disability organisation of which she was a board member and thinking at the time she might be an excellent participant for my study. A few years later I met Daphne at a conference on disability and education issues and had a chance to dialogue. Our contact has been quite minimal, apart from spending some delightful time together for an interview and I was her guest for lunch. My interview with her was marred by my not feeling well.

Daphne completed her LLB and a Masters doing research papers and a dissertation in New Zealand. When she had the head injury she convinced her university to make adequate modifications for assessment which became more assignment rather than examination based. She is currently completing PhD research. She has developed good support networks and because she is blind requires researchers and personal assistants to gather information for her requirements in her research. She also has equipment to

help her convert text to audio to assist her in interacting and give the ability to compete in the education environment.

Daphne **has many attributes and is involved in her "love of community"**; she **offers her life skills and solicitor's background**. She is an executive board member of many national committees and advocacy groups and yet doesn't admit to being altruistic.

Daphne just gets on with her life despite the cognitive problems and says,

> *I don't think about problems. I don't have problems, it is too negative. I do get fed up with pain... I am not fussed on the word disability, but it is better than impairment but I still don't like it, I think disabled is worse than disability. Some of these terms are quite irritating and negative.*

Fran

Fran is a woman of about 40 whose life is significantly affected by major sight loss. She lives independently and her most constant companion is her guide dog. She has been an insulin dependant diabetic since childhood, and also has an under-active thyroid and chronic anaemia which leaves her particularly prone to fatigue. Her regime for maintaining good health involves frequent blood tests, multiple daily injections, eating sensibly and regular exercise. Her daily routine is thus always affected by her diligence to prolonging her life and the quality of that life. There is a caveat here: **Fran's blindness is not because of her diabetes, rather it was more a series** of medical mishaps that caused her to lose sight.

Fran is the owner and sole occupant of a recently built, detached suburban bungalow which is easily accessible to all services, including being within short walking distance of shops and good bus services.

Our interaction began with our meeting at a conference and contact continued via email. This was followed by an in-depth, audio taped conversation at her home on the lounge floor on a very pleasant, sunny, late **summer's day. My one regret was that I ran out of time** in our interview as the time allocated to visiting was marred by my being unwell. Our friendship has continued over a number of lengthy telephone calls. We also keep abreast of issues aired on an email list-serve we are both members of.

Fran is a part-time Honours student in the Social Sciences. Being blind means she does not drive a motor vehicle but travels to University by bus, taxi or, has in the past, with student friends. One of her main obstacles is getting access to usable reading materials, and she has to constantly remind the University services co-ordinating this for her, of the need to do this in appropriate time-frames for the beginning of course papers. She requires skilled assistants to skim-read literature pertinent for her topic interests so the material can be made accessible for her.

Fran has had assistance with study-related costs from Workbridge and Work and Income[2] in the past. She has relatively up-to-date Work and computer facilities, including software which converts text to speech to assist with communication and give her access to the written word, rather than relying

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[2] Work & Income is part of the Ministry of Social Development, a government department which admisters the day to day benefits for New Zealanders not earning an adequate living through employment.

on another human to recite what they read. She also interacts with many at the Foundation for the Blind.

What appears, on the surface, to be a rather robust, determined individual has been a very sick person in the past, having spent months in hospital while dangerously ill. Referring to that time, she said:

> *I was in pain, bearable pain, and it helped sometimes at night to walk around the ward, through the day room and back to my room. I would fix the nurses' knitting and take the little old lady in my room to the toilet... But one weekend there were three people who died. I don't know whether it was two on Friday and one on Saturday or the other way around. Whichever, I decided I wasn't going to go out on that green body trolley (my saying, not theirs). When the specialist came around on Monday morning, he said, 'Are you in love or something?' I said, 'what do you mean?' He said, 'something has happened to you.' I said, 'Well I am not going to die.' He said he thought I had turned the corner. Not that I was sick because I wanted to be sick, but at that point I was quite determined that I would leave the hospital alive, and if I could, when I got out of hospital, that I would live my life, not just exist. I didn't want to wake up one day when I was 50 or 70 and wonder where my life had gone. I wanted every single day to have something in it to make me think it's good to be alive.*

Joan

Joan is a woman of about 50 who had a serious accident in 1990 in which she ruptured vertebrae in her lower back. She is in constant and chronic pain. Sometimes this can be severe, even twisting in bed can see her spend many weeks on treatment including relief which needs to be alleviated through morphine. Because of her impairment, she has many associated sensory complications which range from numbness, to fatigue, to loss of dexterity making mobility extremely arduous. Because of the progression of

the ongoing damage to her nerve supply she has a high-sided automatic motor vehicle so she will not have to stoop down to get into her car and at times needs to use a walking stick.

Joan is a young grandmother and she and her partner live in a tranquil rural setting surrounded by farmland, but is within easy driving distance to her university and local city. She spends one day at home during the week looking after family, and four days a week as a social worker and counsellor.

Joan was a qualified practising nurse, and worked for many years in that profession. She said she had to go into hospital and disclose all her medical history because,

> *It gave them a foretelling of what might be the problem. And even if I didn't want to disclose it, we had to and even then I had to remind the staff to be very careful and aware of transporting me to surgery on trolleys as I had back injury. Nowadays I prefer alternative treatments, an herbalist and cranial treatment with osteopathy to alleviate pain and maintain if not increase mobility so that I may function as well a possible in society.*

I first met Joan at a luncheon where I was given an opportunity to tell of my research. She agreed to take part after I informed her the benefit of the research was to tell the stories of the participants in an empathetic way and that the study would be ultimately beneficial to those being researched. She did indicate that she didn't feel comfortable in the disability support gathering at university - being grouped together could be restrictive.

Joan is a part time Masters Student. She is able to attend to her honours classes at university and working part-time allows her to multi-task by minding her granddaughter for her daughter and has some extra study time.

Because she has been, and is, in the helping professions Joan benefits the wider community through service to support groups. By looking after her **daughter's baby she enables** her daughter to attend to her own health support needs.

On giving interviews about her health status for the medical profession, she prefers in many cases not to be involved. Joan said,

> *Thank you but no thanks. Not because I have any stigma of myself, I just think that you don't have to talk to every Tom Dick or Patricia.*

Josh

Josh is male and was born in 1965. He has a cocktail of different impairments resulting mainly from long term health challenges like cellulitis, a skin infection that suppresses his immune system. Normally it is very treatable, but he is allergic to all forms of antibiotics especially penicillin. For him it has become a chronic condition which has often seen him hospitalised. He has a dangerous weight problem and has for a number of years lived with type two diabetes. It is little wonder that all of these impact on his health status necessitating treatment for severe depression.

He is married and they live in their own home and have no children although he talked about a recent miscarriage. He is able to drive to university and does work part time.

Josh attained university entrance at school and entered the workforce rising to management positions in a number of different companies. He maintained

a relationship with academia primarily to enhance his employment prospects and completed a couple of tertiary qualifications both in this country and when working abroad. After a bout of illness and while on sabbatical he was persuaded to pursue further study for a Masters of business administration. He approached a university offering a course extramurally and on consultation with an official decided it might be too restrictive intellectually for him as he was an independent critical thinker ideal for the arts in either social sciences or humanities.

Josh was a board member of a committee that I was also a member of and our interaction began from meetings and functions we both attended. Contact has been quite minimal, we had a number of short interviews and keep in touch from time to time in passing.

Josh is a full time student and is in the process of completing a Masters degree. Being a bright scholar it is likely that he will progress to a PhD as he indicated that he enjoys the university environment and would have access **to scholarships. He doesn't seem to have an affiliation with Workbridge and** is able to work part time and owns his own computer.

Josh is articulate and believes he got his fair-mindedness from his parents and said,

> *A sense of dealing with authority and not taking no for an answer. Being very self-conscious that when you are in a sense of your moral obligation to do your best. I am very good, that is why I think I am one of these people who do very well on committees and things. I can sit there and look at things and ask the questions like. Why are you spending this money? Why are you doing this?*

He has been a great servant to his fellows and has been involved in student politics and offering academic mentorship to other students.

Josh had an unpleasant time in hospital recently, probably unintentionally poisoned on the drugs that were supposed to save his life. He said:

> *I got up on a Friday morning, didn't feel too well, by 9 a.m. I had high fever and was delirious and by lunchtime I was walking around Accident and Emergency quite deliriously, I was so gone, I was about 39 degrees so you can imagine, that night I was watching television and the nurse said, "we are bit worried about you, your heart beat is about 190 per minute," and I am sitting still in a chair. And I said to them, why don't you take the antibiotic drip out of my arm and I suggested it might come down.*

Karla

Karla is a woman of about 70. From the early 1970s she has been hospitalized and requires full-time nursing care because of a fall causing her to have a high-level spinal injury.

> *Initially I had no movement at all but was expected to operate at the "normal" level of ability for the presumed level of my break, i.e. feed myself, push my wheelchair, and other things. In fact, haemorrhaging in the spine had damaged me to a much higher level of impairment- and 30 years later I need someone to do the simplest of things like feed me.*

Our meeting took place in Karla's home; her own hospital room. She had a computer workstation and types with the aid of a mouthpiece, uses internet facilities and a telephone in her room. She said that in the early days after her accident there were no facilities for people with spinal injuries. They were just placed in some geriatric ward. Her social worker, a fellow

Englishwoman, arranged a transfer to a private hospital that had a spinal unit. She said:

> *The first two years there were hell, due to the combined influence of the male doctor, a physiotherapist who ruled the roost and a registered nurse who was the prototype for nurse Ratchet from "One Flew Over The Cuckoo's Nest".*

The problem was that Karla wasn't sick, **she just couldn't mov**e. Karla tried to keep some sense of ordinariness in her life.

> *My kids were six and eight years old at the time of my accident and for 10 years we kept our family atmosphere intact. My husband was amazing; I went home every week end. Although we parted in the official sense many years ago, we still have a good relationship and Christmas Day and similar events are shared with the grandkids. The break-up has allowed us to each follow our own path. I went to university; he is 'a doer' and a self-taught musician.*

After passing a few papers extramurally, she worked voluntarily with a local school and the WEA on reading programmes.

> *One young man couldn't even spell his own name. He came to me three mornings a week and went to a garage for work experience - twenty years later he still keeps my van in order.*

Karla came up to me after a presentation I had given at a conference because she really appreciated the argument offered and volunteered to be interviewed for my study. I arranged to see her when I was next in her area. We had a pleasant chat and she arranged afternoon tea. We have maintained contact by email.

Karla said:

> *I started in academia mainly to get the hospital staff off my back. As long as I could be seen to be 'doing*

something' then they would stop trying to get me to push my chair. When the occupational therapist put me in front of a typewriter with weights and pulleys attached to my hands I could spend the whole day typing my Christian name, I thought, what is the point? Finally, the occupational therapist said, 'I suppose you could try by mouth' as though it would be giving in. I have never looked back. I have just completed 22 chapters of a book.

Karla initially enrolled in a degree on political science finishing with a joint major in education. Eight years after three papers as an extramural student, it became possible to enrol as an internal student.

I remember my first day as an internal student and loved the total acceptance by the other students and staff. I was just one of the crowd. I remember enjoying the very first lecture and I would say now, university is the only place I have never been patronised or treated as being 'different'. Rather, I have always been treated on equal terms.

She felt no wish to continue formally in post graduate studies, but offered her services as a voluntary researcher. The head of the Department rang her and offered her a job as tutor. She accepted and did it for 14 years. She appreciated a little money and thoroughly enjoyed university life.

Karla has a life outside hospital which is full of variety. She has friends from several different worlds including university and a great family. She has been one of a group of militant disabled people since the 1970s, a major achievement of the group being obtaining the use of an old school for disabled students for a different purpose as a Centre for Disability.

Karla is still involved in talking to groups about disability. In the last 30 years she has been an advocate for others marginalised by society and tries to put disability in its place - she believes **it is 'purely a problem' i.e. not a situation** where the emphasis is upon sickness. She said,

When I open a discussion I ask if anybody has a disability, probably one person from the whole group might indicate yes, then I say, everyone has a disability, perhaps you have smelly feet or an overdrawn bank account, and I go on from there.

Kathy

Kathy is a woman of about 50 and is hearing impaired, her audio field is such that she has to wear hearing aids in both ears as without them she is deaf. She manages concealment of her impairment and interacts very well in one-to-one conversations. The hearing loss is congenital, her brother is also hearing impaired and her loss became pronounced when she was an adult. Because she has profound difficulties in filtering many background noises, she finds it easier to complete her studies extramurally.

Kathy is married and lives with her husband in a delightful comfortable contemporary home on the outskirts of a city. She has three young adult children, her youngest is going to university and returns home in semester breaks. Another, separated from his partner is the father of a young girl, and Kathy often has her granddaughter staying for weekends.

Kathy is an independent critical thinker and has issues with what she sees as inequitable power relations over people who are marginalised by society. She has often advocated for other students and members of her communities; she is not afraid to stand up for others and motivate them to be counted for their convictions. She does feel disadvantaged herself at times by working from home as she feels invisible. She commented:

> *I feel really out on a limb out here. Completely divorced from that whole academic scene, there's no two ways about it.*

I first heard of Kathy when she called for interest in a conference she was attending on behalf of disabled students. I contacted her by email and a relationship developed. I have visited at her home a couple of times.

Kathy has a number of different qualifications including teaching and has quite an eclectic view of her education. At present she is completing two post-graduate degrees. She feels she has probably developed a multi disciplinary style and is aware that her post-graduate degrees are in different fields from her undergraduate studies. She is now in the process of completing a PhD.

Kathy said:

> *I did my secondary teaching training and I realised when I got out into the classroom, I actually hate this. I think it is artificial to have all these adolescents herded into one place, you are going to buy yourself trouble doing that aren't you, just by having all these people of the same age. As I say, to me schooling is about creating obedient souls as in docile bodies.'*

She has a great sense of purpose to know and do what is right.

> *I am for instance not opposed to alternatives to "scientific", medical interventions, given this latest little stuff up with Pan Pharmaceuticals, natural products turned out probably to be killing you more than the other stuff. Now having said that, you just need to read the papers. One in four admissions to hospital results in an error or something. The statistics are actually hellish. You'd never end up going near a hospital.*

Lesley

Lesley is a woman of about 50 who was born with distinct physical impairment. She undertook a large number of surgeries to help correct and"normalise" her limbs while she was a young child. This was to help her function as ordinarily as possible in adult life. She has lived with disability all her life and her early childhood was affected by hospitalisation.

Lesley was cherished as a child and her parents did not want her to be institutionalised, against the advice of the medical profession. She was bought up in a solid family background. As a child she understood she was different from other children. She related how her mother coached her to overcome the taunts of others and always made her partake in communal events and socialise through the ordinary rites of passage that others did. At times she felt ostracized and uncomfortable but, she said,

> *Yes I have had lots of knock backs. But my Mum always said to me it is character building stuff. She said the patches and scratches and things like that is going to make you a fine strong adult and now I believe that is very much what has made me what I am.*

Lesley has led a fairly ordinary life. She was married in her early twenties and now revels in the fact that she is a doting grandmother. She was divorced and since remarried, lives by the sea and commutes inland to teach at a university. She comments:

> *I'd always thought I'd never get married. I just didn't expect that, I just thought I would grow up, be left to earn my living and be independent. I married at 23, which was ordinary for my cohort. I met my first husband at university in Auckland at a party. I just did things like that, just like other people.*

I became aware of her research interests and work on disability issues when I read her Masters thesis on disabled women, when preparing for my own. I finally managed to meet her in person at a book launch and workshop she helped organise where she presented some of her research findings. We have since exchanged information via the email.

Lesley is a University Lecturer and a published academic on disability issues. She says:

> *I strongly challenge the university when they are talking about disability and not using our lived experience. We should value our lived experience; there are not enough people with disability in this academic setting.*

She offers her expertise to organisations such as Workbridge, DPA and has been involved in other disability politics. She is a recognised member of the community not just in disability issues as she has been a long time member of women's groups and is a J.P. Lesley is tenacious.

> *Yes I do think you have to come out fighting. We have to almost become desensitised, because we are the role models. We have to show that our life is not over.*

Lesley's outlook on life is positive. She inspires her students by saying:

> *There are so many different ranges of people. We must help children in the classroom to see that everyone had a little bit of a difference in the way they see life that impacts very much on how they go about things. And you don't realise until you get inside and bring it out into a classroom. You have got to see everyone's strengths and challenges. This emphasises that we have to celebrate our diversity and that is something that I keep trying to emphasize. We are all different and we should celebrate that, rather than trying to hide our differences. This is what makes us as people.*

Lynette

Lynette is a woman of about 50 and lives with a major mental heath issue, often living in a state of unwellness which complicates her post-graduate study. She informed me she recently had problems with her medication where the health authorities changed her prescription. This caused her a **period of great distress and disequilibrium and it wasn't until she convinced** her doctors to return to her former medication she was able to get any form of ordinariness into her life.

Lynette owns a cottage on the fringe of the city and attended her taught papers at university. She shares her home with a boarder, and as her property is in quite a remote location she accesses her amenities by car. She had major traumatic abuse in her childhood and this has really affected her adulthood. As a mature student she managed to study at her local university. She started her undergraduate studies as an ordinary student and paid for her education on a student loan. A**t that stage she wasn't** diagnosed as having bipolar disorder. Then she applied to get assistance for her studies and found that the Training Opportunities Scheme was only for individuals up to degree status. She then enrolled in a Masters programme and the degree was conferred.

I have known Lynette since 1994 when we started our studies as undergraduates. I met her at a number of functions at post-graduate level at the university and kept in contact by either email or by telephone. She arranged to come in to see me for a taped conversation and eventually we had a chat at her home.

Lynette started a PhD and when we had our in-depth conversation she had suspended it temporarily on health grounds. At that stage she indicated she would complete her studies on a part-time basis as she was arranging consultancy work and setting up her own business in staff development training. She had even arranged a couple of sessions to teach on post-traumatic stress disorder and another on bipolar disorder and how to live successfully with it in the community. She commented on her being assisted into the workplace:

> *I want to get back into working where I can use the qualifications that I have worked hard to get, and that I know I can do it.*

One of Lynette's enduring qualities is her resilience. Above all the hurdles with the intermittency of her health issues, she still perseveres and completes her studies. For quite a while at university she was an academic mentor and she says in that role she would liaise with the teaching staff and her students for accommodations to be made in the learning process between the University and the student. Lynette said:

> *Nobody knows me really. Other than they know I have the qualifications, I have the skills, I have the tools, and I do what I need to assess a child for literacy or attention deficit or what ever it is. I have the remediation ability with the remediation software. And that makes me free as far as my disability is concerned, because I really don't have disability.*

Marg

Marg is a woman in her early 50s and has vision impairment, but it wasn't till her early 30s that it severely affected her life. She has partial vision and can read very large print with good lighting. She explained:

> *I think it is macular degeneration which was age related which is a horrible expression. He [the eye*

> *specialist] said you are the youngest person I ever had with that. A few years later they gave me four or five years… well within five years… you are going to be blind. Whether that it is a self-fulfilling prophecy or not, I do not know.*

She related some more experiences.

> *And we had counted…every time something bad happened and I was under a lot of stress or something emotional or whatever and it would affect my eyesight and no one could explain that. I think I was about 35 when I noticed there was something different than being just short-sighted. It is called bilateral degenerative myopia now. When it started, nobody knows. I only use my right eye and the only thing is that my retinas could detach at any time in the next 10 years. Or it might last a month, mainly for sensory awareness of where I am, to a degree… I don't realise I have a pair of prescription special sunglasses.*

Now she is legally blind and has a guide dog. When I visited her it was only a puppy she arranged to train for the foundation as she lived on a farm.

Marg successfully lived in a household family partnership on a dairy farm and she was comfortable with her surroundings. She subsequently moved out of the marital home, went looking for residential accommodation, and now is in a property in the city.

Marg had noticed in dealing with non-disabled people, whether friends or the public, **that they didn't think of her challenges in negotiati**ng or existing in the community. She said:

> *I have had people be extremely rude to me. Some people say to me "Put your head up and why don't you look where you are going?" "That's why I looked down" I say "to see where I am going". People don't understand.*

I saw Marg advertise for research participants on Discus email list server and took the opportunity to flick an email and ask if she would be a member of my study as she lived within my target area.

Marg is completing a Masters in the social sciences extramurally. Some of the difficulties she relates are in reading the literature, and technology for enlarging fonts. She said:

> *Oh I know… it is so frustrating. Have you ever seen this closed circuit television (CCTV) you can put the book under and look at it on a screen? I know people that had to take seasick pills to use one of those, because as you move the words are going all over the place. I borrowed one for a weekend, I was only able to use it for about half an hour and I was nauseous. I was ill and I doubt this was how people use them.*

Marg gave much to the community. She used to be president of SPELD and says she has become more insular since her eyesight deteriorated. She has recently joined the organisation of graduate women. She said,

> *When I go into public I was never going to admit that I can't see very well, when I first started I would never let on that I didn't see very well. When people find out, you see their attitudes change, sometimes it is positive and sometimes it is negative. And sometimes I just wonder if people should wake up the poor girl might not be able to see too well but she can certainly do it. In fact there was a man on TV this morning, this guy who lives in Matamata and goes fishing, and he says people often say to him, you shouldn't be putting your bait on your hook, you shouldn't be out here fishing. They might as well catch the fish and I could go to the front of the boat and have a feed. I thought that was a way of working, we can all do these things.*

Marina

Marina, a woman of about 50, has had to live with episodes of major **depression since she was a teenager. She seems to manage people's** perception of her very well and is able to rationalise and withdraw from major societal involvement when she is having a troublesome period. She did say, in her later life:

> *My depression again became really bad after I had my kids. I was working and then I had the kids, I was really quite ill. And I found that really hard; again it was a different depression, for me there are two forms of depression, there is that chronic depression the on-going stuff.*

Marina is married and lives with her partner and children in a suburban area close to her university; she is a full-time student and completed some part time study for her honours papers. Being the mother of teenagers she is an apt multi-tasker, and even manages the household and drives to university where she studies.

Her impairment is invisible to other people and often she is faced with the dilemma of when to publicise she is having problems.

> *It has always been on the back of my mind. How much do you disclose, it's always a problem of disclosure … Sometimes you disclose too much, many times you wish you hadn't disclosed.*

She further commented when reflecting on her life,

> *You need to pull yourself together, and I often had thought since… I have often wondered since whether my mother was the same. Depression according to the research is supposed to affect one in four people…. Some say one in 10, but I think major clinical depression at the very lower end, general melancholy, is probably quite rampant.*

Marina in her working career has been very proactive, and in past employment was involved with staff training, holding views on equal opportunities, before they become fashionable on, aspects pertaining to marginalised groups. Although commenting on disabled people in her establishment, they recognised mainly three sorts of impairment: those associated with vision, audio, and wheelchair users. There was little tolerance for people with mental health issues who were often institutionalised and hospitalised. She mentioned one of her colleagues who disclosed he had a mental health issue and said:

> *He took about three months off without pay, and he outed himself as a depressive and I can remember it rippled around the place. Because I got to hear about it, he went and told all his team. So there's stigma there, you do not know how people are going to react. I sort of feel that maybe they see people with mental health* [issues] *as weak.*

I had met Marina long before this study commenced; it was fortunate she happened to be studying for her masters in the social sciences. She has considerable experience in teaching and has worked in a university setting. I had no idea she had an impairment that affected her studies and she had heard of this research and approached me and asked if I would be interested in what she might offer.

Marina has developed many skills and is an effective communicator saying,

> *You know I can rationalise things out to a certain extent, but there are times, a lot of the time, I am very impulsive. When I get myself into something before I've rationalised that out, right through. So sometimes I am quite effective, but I am a great contingency planner, I think that's another coping strategy that I have.*

Melanie

Melanie is a woman in her 40s and lives with mental illness. She says:

> *It has taken me a long time to realise that I have had illness and I have struggled with inclusion and exclusion all my life.*

Her issues probably started in her teenage years and she indicated she **couldn't r**esolve problems with her parents' marriage break-up and this saw her involved in another relationship. She said of it:

> *I was there three years – physical, psychological and sexual abuse and she* [this other women] *just controlled me and took away my identity in the years that it was forming. I struggle with anti-depressants, but they don't help with my main problem, which is anxiety, and finally my doctors have got to know me, and I used to use tranquillisers. Now I don't do that any more, because I needed them at one stage to survive. And I take anti-depressants and sleeping tablets now in case I get a panic attack.*

When she arrived in the country Melanie worked for the Probation Service. She is now a State Beneficiary and rents an apartment in a home and lives independently. She cycles to university, and accesses all local services. She appears physically well and is a fitness fanatic. She uses her strict exercise regime to help maintain an optimum mental equilibrium.

Her parents are dead and she is an immigrant to New Zealand. She has a sister overseas and a married brother here. She said because of a misunderstanding in her personality she didn't get on with him and his wife and now **she doesn't see them a**ny more. She said:

> *I always do things that are inappropriate and it has just been a long process for me to accept that I have a mental illness.*

Consequently she has no close family contact.

I have known Melanie for a couple of years and was introduced to her when she needed to interview a participant for a research project she was involved in. I was glad to offer my services and I suppose her involvement in this study is reciprocal. We had a series of interviews, keep in contact by email and have attended conferences.

Melanie's qualifications and degrees are in social work and she obtained her Masters degree overseas. When I met her she was doing preparatory work for PhD research in New Zealand.

Melanie is a solitary person and tries to improve her situation. She says,

> *I know, and I did, and I fought and I fought, that is the thing with me, I find I get up and try to improve myself, and in the process I have worn myself down. I had a mental and physical breakdown, I am recovering slowly and I think it has damaged me. I was fragile to begin with… I find more acceptance at university. I was working in the probation service, and when I think back to those few years I struggled and I didn't know what could be like in New Zealand. In the prison service when I think back, I got the feeling of utter terror; I don't know how I survived.*

Roger

Roger is a man in his 40s; he has no eyesight, being born blind. This was complicated as he has been unwell for a number of years. He is ambulant and has a guide dog. He now lives in the city and is able to access amenities by bus, and taxi.

When I first met Roger he was living independently in a university flat where he could take either the university shuttle bus or walk to classes for his

honours papers. The flat seemed to be unsatisfactory as it was built for and intended to be shared accommodation. This proved difficult with the dog and the uncertainty that he might have to share with another student. When we met for our interviews he rented a town house some distance away from the university, where he might get access to his employment to complete his studies part-time.

He has home-**based support from the state, but he commented that it wasn't** easy to get and is difficult to retain consistent service. He mentioned that some of the challenges he faced that the assessors and providers of home help service are non-disabled people who manage to interpret and determine what his needs are and how they are satisfied, and not always empathetically. But for them quality of life, **doesn't enter into the equation.** He says,

> *I have a big living area and I have a dog, it is a pretty demanding exercise to keep the floors clean when you have a dog and then they came back and said you have two hours cleaning and two hours shopping. I didn't want any shopping so take it off. But we always have two hours shopping and in the end we argued over the telephone for a bit.*

Roger is articulate; he managed his undergraduate degree living on campus back in the 1970s when t**he University's policies were more exclusive than** they are today. He told me he had an argument with the Dean of the Social Sciences who said he could not enter into a psychology paper because of his blindness. These were in the days before Human Rights legislation were enacted by the government.

I met Roger when I was studying for my Masters back in the late 90s. We attended some university committee meetings relating to issues around

disability. We also attended the same conferences. I have infrequently spoken to him by email.

Roger was completing a Masters degree in the social sciences. The university obviously had a good disability coordinator and made some accommodations for disabled students. He had use of comprehensive disability services, got his books delivered as if he was an extramural student and was able to get into a university flat.

Roger indicated that for him his university hadn't developed any comprehensive strategies that eliminated institutionalised discrimination and where disablism was minimised. He found that other students who had minority status, including women, had clout from the students' association.

Roger is an advocate for disabled people and continually believes we should be crusaders for our own kind. He is a leader and has been involved at the forefront of the governance in organisations whose interests have been to aid and better the lives of blind or disabled people. Roger says:

> *It is also a very austere form of existence and one of the things I got very disillusioned about in continuing post graduate studies, there are so many good things in life you simply cannot have access to by living this kind of life. It can be very lonely, as I said it is austere, it is restricting and some very inflexible disciplines are imposed upon you, in order to get things done as a student.*

Ross

Ross is a man in his late 40s and was born with a pronounced physical impairment making ordinary daily tasks of holding anything extremely difficult, but he manages successfully by making adaptations to his

environment. He did say he needs to be vigilant in crowds of people as he cannot balance effectively and cannot afford to be knocked over.

Ross lives in a self-contained one-bedroom flat with an accessible mobility car park right outside as **part of the university's student accommodation. He** drives a modified motor vehicle and is able to access his taught papers at his nearby campus.

Ross says,

> *We grew up the hard way especially the ones that grew up in schools (talking about establishments for segregating disabled like children's homes) we got all the knocks.*

He left school and got a job in the primary industries, then eventually as a disability coordinator in a tertiary educational establishment. He disliked the hypocrisy and was hit b**y 1997 changes in the invalid's ben**efit and the right to work.   Capacity tests for disabled people meant you should work no more than 15 hours a week. He said:

> *I got hit for being good. A blind person can work and not be penalised as much, they can work more hours. I decided I needed a stronger theoretical base so that I might be able to help the disabled community more effectively.*

I visited him at his flat and have kept in contact via telephone and email. He was a member of the discuss list-serve for people who are disabled.

Ross is conducting undergraduate study and has had a relationship with tertiary education for a number of years. He says:

> *My degree is in life - I have been in the environment all my life. I am already a teacher and I am here to teach others in academia. I have a working record of over 20 years and was employed by a non-*

> *governmental organisation and have been a trade unionist. I was raised from Scottish stock. In the sixties I was raised (in the history of impairment) with hospitals and rehabilitation units and Crippled Children Society homes. …there are other species that are also disabled, most of them do not survive.*

Ross is an activist in the disability movement, he doesn't always see eye to eye with his peers and he tends to ruffle a few feathers in his plight for ability diversity and holds strong convictions for the equality of opportunity for all people. He says:

> *I am not doing this for myself. I am doing it for everybody else.*

Ross has a strong conviction for a disability culture pointing out there are 744,000 disabled people in New Zealand, yet how many of them are represented in parliament. We come from an oppressive background and he sees us as a stateless people.

Ross is dogged in his convictions:

> *I stay focused on the way I walk; I can't afford to be knocked over. That is part of our history.*

Shaun

Shaun is a man in his late 30s and was starved of oxygen for 18 minutes at birth causing brain damage which affects his sensory/spatial/motor coordination. He told a story of his early years of when he used to do weight training and was more physically firm as he was able to control some bodily functions. Now he says he drinks liquids with the aid of straw and has difficulty with mobility. He is intelligent, very witty and humorous.

Shaun lives with his partner and commutes daily to his university.
Shaun attributes much of his drive to his stable family environment from his grandparents to his parents, who taught him to how to react and live within a disabling society. He said,

> *My mother and father were very wise people, my father said "son, you are an ambassador of a foreign country, as an ambassador you should hold that role and also be a diplomat". Well, being an ambassador and diplomat you should never forget your principles and always hold true to it, speak that character and speak that truth.*

His mother has had a creative influence. She had experiences of instiualisation as a child. She also was labelled by society as being impaired, and is a teacher and international artist. His father is a successful engineer who engendered a pragmatic approach to solving problems. He comments:

> *My mother and father saw my impairment as natural. I was in a foreign society where they* [society] *saw it as abnormal…my parents didn't want me to have a special education. And I'd like to suggest that the word special means exclusion. I was able to attend a quality private school.*

Shaun is the person I have known the longest out of my participants. He was introduced to a group I was a member of through one of my friends who happened to be his physical instructor at the Y.M.C.A. in earlier years. I attended one of his presentations at the Disability in Education Seminar that helped me start this research project. I have attended presentations and workshops he has also attended.

In 1996 he went back to university to complete a post-graduate qualification. Shaun is a critical thinker and is now an academic and administrative professional at a university. Initially he sought employment

through the mainstream scheme and has now been accepted as a full-time member of staff.

Shaun is an activist for the rights of people disabled by society and informed many through his interests in community radio. He says:

> *So that is kind of what I am about. Creating different paradigms for people, not to say this is the right one, or this is the wrong one. But to say for "Christ's sake" if we are to mean diversity that also means it is about liberty. Diversity of libertarian actions. And that diversity will naturally incorporate different ways of operating for different people with impairments.*

Shaun wanted people to know he was a total person, complete the way he was, with his impairments and in those days it was a radical statement. He **thought he didn'**t want to be cured; he does not want some medical colonisation. That he was OK, but it was society that does not see that.

Shaun said:

> *I was thinking I would like to teach, I want to be an activist, an orator, a speaker, and I want to learn. I am sort of putting it all together. University is the first environment, outside my family where I was kind of valued. And to be devalued most of your life outside family, which is a hell of a reinforcer. I don't want to go off campus, why would I, it is like Monte Carlo, my own bar, my own library, why would I? I almost wanted to live here; I wanted to deprogramme the stuff that I had and sort of try and capture some education. So it was my intro into education, I went on. My girl friend said I think you can teach, you taught me how to read, and she was non-disabled.*

Terry

Terry is a man in his 40s and was born with a cleft palette that was successfully attended to when he was a child. He says:

> *I have had early experiences of hospitalisation and plastic surgery and ideas of self-consciousness. I do not describe myself as a disabled person. My mother and grandmother and two brothers have the same impairment; as do aunts and uncles and nephews.* [His two children do not.]

He believes he has allied status and has been a member of the DPA for a number of years and has taken on many causes as an advocate for disabled people. As one of the primary focuses of this thesis was looking at the ideas of inclusion and exclusion, it would be very unfortunate not to use the experiences of this strong ally and supporter in the movement. He offered **value and has contributed to the cause. The fact that he doesn't feel he is** disabled is not unusual in this study. He may no longer be impaired, but he can feel empathy.

We never did really talk about his living situation, I visited him at his university and all I know from our conversation is that he is married and lives with his wife and has two children.

Terry is concerned about people living in the margins of society, but he had never taken a position of being an activist and he sees many shades of grey: Maori, the poor and disabled people. He attributes this to his early influences:

> *My grandmother had polio and her son, my uncle, who was about 10 years older than me, also had polio. He was in a wheelchair, attended Wilson Home, but died in his teens.*

He often stayed with his grandparents in their state home which was completely unadapted for a wheelchair, so he learned at firsthand the **dependency created by inaccessibility. Terry's** tertiary education is atypical, he left school in the sixth form and after a few years went on his overseas experience. In London he flatted with a couple of Kiwis who had higher education qualifications so when he returned to New Zealand he decided on tertiary studies part-time while he worked. After the firm he was working for closed, he went on a six-month social work course. He had a placement at the Royal New Zealand Foundation for the Blind, partly as he had an uncle who was blind. The course helped him to get employment in a student support role in a university. He has stayed in the field since.

When I met Terry I knew he was involved in disability research. I had been in contact with him over the years and was involved as a research participant in one of his studies. He is a member of the discuss list-serve I am involved in.

He is a post-graduate, and his interests are concerned with education and sociology. He had completed diploma papers at postgraduate level at the time of my interview. He was in a Masters programme. Terry is a published academic on disability issues and is a technical support person at one of the universities.

He sees disability as a process of exclusion from opportunities.
He knows, because he works in the disability field, about marginalisation. He says this marginalisation extends to able-bodied support workers too, with pay scales less than what the market pays other groups. He has rapport with the people he comes across whether in student services or in disability issues.

Wayne

Wayne is in his early 30s; he was starved of oxygen at birth and has minor brain damage which appears mainly as physical and sensory impairments more than intellectual issues. He has severe mobility problems and although he is ambulant, he doesn't use walking aids and has a very pronounced gait. He says he can wear out a pair of shoes in a week. His associated sensory concerns at tertiary education have been maintaining long periods of concentration especially with computer overuse and sensory reactions to visual display unit sensation.

He now rents a pleasant two bedroom basement flat in a seaside suburb. When I first met Wayne he flatted in student accommodation close to his university. He started having episodes with relating to his flatmates and eventually spiralling towards some minor mental health issues which impacted on his studies. Wayne then went boarding, hoping that a stable family arrangement could mean that he would focus on his studies. This obviously worked as he finished his papers eventually, attaining a degree in business studies.

Wayne has overcome some serious limitations because of society's low expectations of his physical impairments for him to be successful. He related a story from his primary school years of a swimming sports day. On the day of the event everybody's name was called except his, so his mother went over to the teacher, and she said what about Wayne. The teacher said he had forgotten to include him. So in the end Wayne swam a width of the pool underwater all by himself. He said:

It was just me. It was really embarrassing. It wasn't funny. They were feeling sorry for me, that sort of thing, so I was feeling low for a couple of days.

At school he was held back from progressing for three years and said the other school children were at leaving-age by the time he made it to secondary school. He is young enough to experience society in New Zealand that no longer had compulsory segregation in education and he was mainstreamed in his schooling. In his view many of the schools still treated him inappropriately and it was a struggle to get inclusion in sports teams. He had many knock-backs: his father had to convince one school to allow Wayne to have a go on a cross country run and he was refused permission to accompany a rugby team to Australia after having been heavily involved in helping with fund raising.

The education system taught him not to set his sights on being a high achiever and he was conditioned in life for charity handouts and learning the art of helplessness. But Wayne has remained committed to attaining his desired goals to becoming a high achiever. In reality this unassuming **individual, has strived against all the odds of being one of life's little failures.** He moved from the country to the city as an adult and is following his dream of becoming a sports manager. He is proud that in his immediate family he has attained the highest academic achievement against all his temporary setbacks.

I first met him at the Disability in Education Conference in 2001. I found him a very affable and friendly person with good social skills. We have met many times for coffee and interacted more than any of the participants in this study. He has been my greatest teacher. We met at his home for an in-depth taped conversation. For many years we participated on the same

committees. I was fortunate enough to be invited to his graduation and often still meet for dialogue over coffees.

Wayne is not proceeding in post-graduate studies at present. Until he secures some sports management position he uses his communication skills working as a telemarketer and assists with an organisation as a storyteller for young primary school children about disability issues.
Wayne says,

> *We have developed strategies to survive because the benefit only gives enough to live and that is all, but there are things we want to achieve and do. We need to develop strategies to get over that wall or smash down that gate or whatever.*

CHAPTER FOUR –THE RESEARCH JOURNEY

Introduction

This chapter is about my journey through the research process. The study is in social and cognitive anthropology and this route is marked by the development of theories based on a review of the literature in anthropology on issues that can relate to disability. Rather than have separate sections for methodology, literature and theory I think they are intertwined.

The position I take in this thesis is that I align with a social anthropological ethnographic research approach rather than saying the study is rooted in disability studies. I quoted Linton in my introductory letter to my participants who commented thus in the same article:

> Anthropology and history are two areas of scholarship that could paint a broader picture of disability. Scheer and Laborsky (1991) define anthropology as the cross-cultural and holistic social science [which] analyzes how the interaction between cultural values and beliefs, social relations, and historical changes affect patterns of daily life and personal experience.

(Linton, 1998, p. 102)

Disability studies seemed to me to be particularly dominated by traditional sociologists, with exceptions when I found that some anthropologists were involved with disability as lived experience. On traditional sociology and social research Walby brings to our attention there are other methods of enquiry that traditional sociologists do not use when he said, "Institutional ethnography (IE) is a method of inquiry that problematizes social relations at the local site of lived experience and examines how textual sequences coordinate consciousness and ruling relations" (Walby, 2007, p. 1008). Or Madison who says that critical ethnography is always complicated when it

comes to representation and requires critical reflection and positionality. Madison (2005, p. 5) **indicates, "Because the critical ethnographer is** committed to the art and craft of field work, empirical methodologies **become the foundation for enquiry". She rightly notes that knowledge is** power and describes that the ethnographer must take a position as we attend to our own subjectivity in relation to another person, which both informs and is informed by our engagement and their representation. This is similar in many ways to Heshusius as she describes her concept of participatory knowing stating,

> The 400 years of disenchanted knowing has left us alienated from each other, from nature, and from ourselves. The move from objectivity to subjectivity has been very important indeed in that it has started to upset the false stability inherent in the idea of objectivity, and has focused on values and emotions as related to the act of knowing. I fear however, it has not eliminated the forced distance between ourselves and other, created by the idea of objectivity. The real shift it seems to me, is not from objectivity to subjectivity, however important that shift has been, but from the objectivity/subjectivity dualism to participatory knowing.

(Heshusius, 1992, last page)

On reflective practice and pedagogy (Gabel, 2001) states that teachers with disability needed to be encouraged to reflect on the value of their own experiences of disability and how those experiences could inform the academic environment. She also noted in her participants that they were unsure of how to describe themselves as disabled or impaired. Patterson and Hughes (1999) within disability studies call for a position of the acceptance of the body as both object and subject when they call for the inclusion of people with impairments into the mainstream of society.

The community has benefited from the religious, medical and social models of disability and they do feature in my work. They have added to knowledge building from which disabled people have learnt emancipation and liberation. **The participants and this research share in "the disabled world" but my** study is not just about disability studies. I do not reject disability studies, but this research is more about the process of explaining the lives of my participants as an ethnography of embodiment, language and how they make meaning. I think it resists rigid categories or definitions and questions the stability of the many generalised notions disability studies try to label people and compartmentalise them. I see social anthropology as an eclectic discipline able to accommodate and embrace a plethora of ideological stances when it comes to interpreting people. Do we have to say what is black and white? Should Archer (2009) not be allowed to use feminist theory and ethnography in relation to social work research when critical ethnography has it roots in anthropology?

Besides, even within the disability studies discipline, scholars call for change on it becoming inflexible. When discussing the social model of disability, Hughes (1999, p. 156) says,

> **"I am, however, suggesting that it should adopt a strategy of** epistemological pragmatism (Turner, 1992) which includes a priority of setting aside its own conceptual imperatives, if and when, alternative perspectives can help to illuminate the forms of oppression and discrimination that characterise the **lives of disabled people."**

Or Beatson (2003, p. 1) in his argument on the dogmatism of oppression in disability studies:

> The assertion that relationships between disabled and able-bodied people are universally typified by oppression is not put forward as a hypothesis to be checked out against empirical reality. It is, rather, an a priore given directing deductive investigation in a full circle that ends back always

> with itself. Research is conducted simply to provide illustrations of what is already known.

I presented at a social anthropology conference McCool (2004, p. 3) in which I said disability needed some elaboration. We as social anthropologists document people's lived experiences, including people with impairments within our own culture and we should look beyond our own beliefs. I particularly quoted Groce, who said,

> The more one learns about disability in the context of societies and the various engendered, social and economic consequences of disability the more important it is for one to reach fellow academics, advocacy groups, policy makers and the general public. This means writing, speaking and advocating in more arenas than simply disability related ones. Political scientists, economists, legal and human rights advocates, all need to hear from us. If we remain silent, we give up the right to put disability on the agenda of many different groups.
>
> <div align="right">(Groce, 2000, p. 11)</div>

Beginning the Journey

In 2001 I devoted a year to the Theosophical Society and continued my **readings on aspects of "Support Groups" in relation to communities of** practice. Whilst there I took one of the first steps in this study by attending **the Disability in Education Conference called "Progress through Partnerships"** held at the Albany Campus of Massey University. I was inspired by a Keynote speaker, a man with both legs amputated as a child. His name is Tony Christensen, a motivator and a well-known New Zealander who had a zest for life. I had also reacquainted myself with other students from my days at university where I had been a board member for many years on the campus Disabilities Committee. I knew I would be unable to venture into an exotic field to study remote communities, so why not study my own communities as an insider where physical ability was less of an issue? I

thought disabled people could be considered a cultural group, and I was already interacting in their communities why not observe and describe how they interact? I thought about it and after a focussed brain storming session with a critical friend from education, I developed a proposal for a PhD research project for the School of Social and Cultural Studies at Massey University. I then sought their acceptance for writing ethnography.

The next phase was to take a year reading and reviewing the literature. Information came from an Internet search to a web page in England to a University in Bristol fea**tured the 1999 conference for "Disability in Education"**, giving a link to the papers presented. The first paper I reviewed was by Elizabeth Anders whose feminist study was on post-graduate women in tertiary education and the rest snowballed from there. The literature review helped me focus on some theoretical underpinning for the ensuing study. I had majored in social anthropology and wanted to show what justification there was for links between anthropology and disability. I sought to highlight some power relationships between marginalised people and mainstream society. The microcosm was disabled people and the macro might be the tertiary educational setting.

Developing some Theoretical Perspective

Lev Semyonovich Vygotsky was born in Belorussia in 1896 and died in 1934. He was a brilliant student of literature, philosophy and aesthetics and for a time was employed at a teachers training college in his home town of Gomel where he started lecturing in psychology. He also encountered problems of educating physically impaired children. He received his PhD in psychology in 1925, was a prodigious reader, theoretician. Founded a number of institutes

and laboratories, Kozulin (1986). In an introductory anthropology lecture at

Aberdeen University Ingold (2002, p. 3) said that,

> Vygotsky was probably the most important developmental
> psychologist of the twentieth century. Influenced by
> **Vygotsky's theory anthropologists such as** Jean Lave and
> Barbara Rogoff have approached learning as a process of
> apprenticeship, in which learners advance their skills and
> understanding through guided participation with more
> experienced partners in shared problem solving.

Vygotsky was known for his concept and work on Sociocultural-historical

theory on the psychology of learning and said children's cultural

development happened firstly at a social level and then at an individual level

(Kozulin, 1999) and (Bernstein, 1994). This idea of collective learning

happens where a more experienced person (it could be a peer) aids and

advan**ces another's, is fundamental to people's knowledge building and**

progresses their cognitive abilities. Although Vygotsky's background centred

on analysing children, it obviously happens over the life span. Lave (1991)

added to his ideas and proposed that learning is situated when it is involved

in a process of engagement with another person and said this happened in a

community of practice.

A community that involves practice relies on a process of participation; a

central component is called legitimate peripheral participation. More than the

learner being on the outside, observing, they are drawn into the centre of

the process. Then becoming masterful of that process which both absorbing

and they are being absorbed in. The learners are also actively involved in

the process of learning from each other.

According to Lave and Wenger (1991) communities of practice are

everywhere. We choose to be involved in many of them at the same time;

they are formed for a number of reasons and in their very nature a

progression of collective learning takes place by means of collaboration, a sharing of similar experiences, exchanges of idea take place. Communities of practice are diverse, informal or structured, formed by two people or groups of people who share concerns, wish to share experiences and to learn how to solve problems or gain mastery of a particular interest.

Tacit knowledge is knowledge gained not through the established and formal means of education such as lecturing or reading, but by deriving an understanding through learning from personal contact such as being in an apprenticeship. It is knowledge is acquired through practice, a hands-on approach, is observational, unwritten and is hard to define. It results from being in the company of others who may be more expert workers which may be enough. It is knowledge that is unspoken, or not necessarily spoken, and may not have to be spoken about. This becomes shared knowingness, or just a beingness and is derived from speaking a relational language.

Shared understanding is acquisition based in a peer development situation such as apprenticeship learning which is the basis of a community of practice. A shared understanding is the result of the cooperation and collaboration with others in a group. It is action orientated, sharing the moment, of being in the liminal state where members bond with each other. They can then identify with the other people in the group, something happens, By sharing the space and experiencing the gambit of withdrawal from society they are reintegrated – a transformation takes place. They then share an understanding.

Vygotsky influenced many social scientists and his work is used in many disciplines, including psychology, anthropology and linguistics and by many professions, from education to medicine and business organisations. For this

study I was interested to see anthropology intersected with the community of practice model. Lave (1991) produced the concept of situated learning and Rogoff (1991) likewise on social interaction as apprentices. It was Lave (2001) who published on Portuguese nationals learning to and trying to integrate into an expatriate British community. Lave, Duguid et al (1992) **conducted a research study of adolescents in Britain. Using Vygotsky's ideas** Lave, Rogoff, Quinn and Holland (1987) worked in the fields of culture and cognition. Aretxaga (2001) an anthropologist, researched communities of practice within wome**n's prisons in Northern Ireland to understand how they** develop structures of coping and resistance. Bunn (1999) an anthropologist studied apprenticeships in Central Asia. Cole a well known Vygotskian Psychologist (Holland & Cole, 1995) published in Anthropology and Education Quarterly on the cultural historical aspects of cognition. Holland and Lave (2001) **anthropologists edited a book on the history of people's struggles.** Hutchins (1980); (1987) a social anthropologist who researched Trobriand Islanders also discusses Hutchins (2003) distributed cognition based on **Vygotsky's works.**

I have been inf**luenced by Vygotsky's works.** I wrote my Masters thesis about a study of a community of practice of men and Multiple Sclerosis MS (McCool, 2000). I presented some findings at a conference on education in Sydney, Australia (McCool, 2002). I presented at the Association of Social Anthropologists of Aotearoa/New Zealand on the methodology of anthropologists as apprentices for learning and modelling their craft (McCool, 2003). I described another community that operated a community of practice for intellectually impaired members to co-construct meaning (McCool, 2005). Ochs, an anthropologist along with social linguists, describes the research conducted on how children made meaning in their own communities of practice over the dinner table (Ochs, Smith, & Taylor,

1992; Ochs & Taylor, 1992; Ochs, Taylor, Rudolph, & Smith, 1992). Wenger, McDermott et al. (2002) Wenger was a teacher involved in developing the idea of communities of practice with Lave. Willis (2001) a cultural ethnographer who wrote on the ideas of apprenticeships and the values they had in society for helping and educating workers into become insiders.

According to Fetterman (1989, p. 34) **"The ethnographer must reduce and crystallize a world of observation to produce a clear picture of a community."** Genzuk (2003, p. 1) **elaborates that further to show, "It relies heavily on up-**close, personal experience and possible participation, not just observation, **by researchers trained in the art of ethnography."** The use of participant observation, intensive field-work, listening to life stories are basic procedures used in this research. A dictionary of Anthropology says, **"Participant observation is long**-term, intense interaction with members of a community during which the researcher plunges into their activities as **completely as possible…"** (Barfield, 1997, p. 48). New Zealand educationalist Russell Bishop advances the value of storytelling in his own study as an **insider researcher, and says, "Stories increase the range of interpretation,** knowledge and experiences available to the potential researcher and reduce the tendency to use reifying metaphors in current discursive practice**"** (Bishop, 1996, p. 24).

Ethnographic research is similar to narrative inquiry. Clandinin & Connolly (2000, p. 63) **develop a whole chapter on "being in the field" as walking in** the midst of storytelling when they look at the experiences of researchers who negotiate complex relationships in the field. I am an insider researcher, I am partially there; this gives a distinct advantage over other researchers, as the essence of ethnographic research is, as an outsider, to show the **insider or native's perspective of reality and world**-view.

Participating in the Research Culture

The participants in this study had a long-term association with university tertiary education, and had an extensive, in many cases a lifelong connection with disability. I am a post-graduate student and a person with impairments. This gives me a privileged insider status in this study. Although we did not study together, we were all experienced students. Our impairments are individualised and intensely personal, but we shared in that feeling of disability just the same as the feeling of *communitas* as students. Being there, sharing in that similar feeling, having already achieved a tertiary qualification, there was a knowingness that a newly initiated student couldn't share. Another dimension to this study is that communal spirit or camaraderie of being a member of a small group of students with disability. It is often easier to dialogue with someone who knows, is able to grasp that inference or comprehension of what disability means. Of my participants Wayne was an exception as he hadn't yet graduated at university, but had experience of long-term tertiary study. He said,

> *You know there is closeness, between you and me, a connection that other people do not experience and that is disability. I get more out of our conversations than I do with our Disability Coordinator. Her understanding of what disability is, is pretty close, but there is an empathic connection between you and I; a knowingness. That shared experience of being disabled that she has not yet experienced.*

I intend to show this connectedness, that kindredness is often misunderstood, and, it is in sharing of the same relational language, one where the researcher's and the participant's reasoning is complimentary. By sharing an understanding that we are using similar usages of English as meanings change over time and language evolves. By participating in the

culture one is able to see subtle changes, it might be through the act of participation in their communities of practice. Bird (2004) says it is finding a consensus of meaning, when talking to her clients when counselling them and knowing they share the same meaning is the key. Heshusius (1994, p. 5) **postulated that, "Knowing as an act of participatory consciousness points** to the knower as an integral part of that which she or he wants to **understand, not as separate from it."**

Dominant themes within this participatory mode I propose are interconnected. One has to look at power relationships between people, perhaps between the researcher and their participants. Or between different groups, those that have power and those who do not. So developing a cultural competency is an integral component of the social anthropologist. To take this argument a little further, I show why knowing comes from speaking the same language as the participants. But the participants are more than just that, they are co-researchers and this gives more exact knowledge that insiders are more privy to extract, from a position of shared power emanating from the bottom-up observation rather the usual top-down. The processes of being an insider researcher have different requirements between the researcher and their fellows and these may be explained **through "communitas", "camaraderie", and support for each other. The** model used is called a community of practice.

The Meaning of Culture

In developing a theme for cultural competency, we must address culture. Concepts of culture like disability are entwined, are very broad, complex and highly convoluted. They are present everywhere and are in all aspects of life. Van Maanen (1988, p. 3) **says, "Culture is akin to a black hole that allows no**

light to escape. The observer knows of culture's presence not by looking, but only by conjecture, inference, and a great deal of faith." Because of the holistic nature of social anthropology many theorists look at disability across **this cultural concept. Groce's** (1985) ethnography highlights an historical deaf community within a much larger community as aspects of being intercultural to show how people can live relatively harmoniously. They seemed to acknowledge the diversity of difference and not let it impede interactions with each other. Others challenge this as biomythographical and it does give an air of a utopian idealism, and displays a degree of understanding that only a writer who understands as a disabled person. **Groce's** career spans disability as a cross-cultural issue in rehabilitation and explains that impairment is inevitable in life, but the way that disability is acknowledged depends on the world-view of the cultural group. Disability is cultural, intercultural and transcultural in the way society deals with it. Disabled people like students on the whole are different and are generally treated differently as they are both thought of as cultural groups, but they are also in between groups. Many see them as always being in liminality or the liminal phase.

Anthropologists Pengra & Godfrey (2001) quote Selig in discussing the complexity of the concept of culture and disability as they observed the First People in America saying that,

> Complete understanding of another culture is never possible because analysis is always "filtered through one's own cultural perspectives and experiences" (Selig, 1998, p. 8) although empathy and the tools of anthropology can facilitate increasingly sensitive interpretations. Complete understanding of one's own culture is nearly as impossible. Introspection can lead to personal insights but the insider "must almost become an `amateur anthropologist'.
>
> (2001, p. 37-38)

Many disabled people see themselves as a culture; they have signs, tokens significant to themselves, which other scientists, including traditional sociologists, do not recognise as legitimate as pointed out by some of the participants in this study. Dealing with the cultural aspects is no mistake. It takes training, and social anthropology is an ideal discipline with its research methodologies for knowing how to be sensitive and treat people with empathy. It is recognised that going into the field is difficult. There are issues of interpretation and many meanings misinterpreted between cultural expectations; ethnicity issues are the same for disability scholars who need to be culturally competent like anthropologists. Drewery (1990), a counsellor in New Zealand, comments on the colonisation of writing as,

> **… I am careful of suggesting that liberation can be** achieved through helping others to find a voice, these days I know as a speaker in the female voice, that when someone from outside your culture or reference group purports to "know" your experience, it is well to be very wary. For they may colonise you. They can take command over your experience in naming it, and thus assume power over you. Given that they can only understand what they can understand (what their language will allow them to understand), they will translate your experience into their terms. The result may be close to what you would have liked to be able to say yourself, that such sympathetic interpretations are seductive. They often lack the integrity of the meanings of those who have experienced what it is that they are naming.

(1990, p. 33)

Competency comes through awareness. For instance it is important to see how disability is viewed in other cultures. Liu (2001) has written an article on Chinese culture and disability, an information guide for U.S. service providers. In the *Anthropology and Education Quarterly* Americans McDermott & Varenne (1995) describe disability as culture. Van Soest (2003) devotes a chapter in a book on developing culturally competent

practice for social workers, which although not relating specifically to disabled people still addresses the marginality of their predicament as an "out group":

> Moral exclusion occurs when persons or groups are perceived as being outside the boundary in which values, rules, and considerations of fairness apply—that is, outside the boundaries of social justice. Persons outside our moral boundaries are seen as expendable or undeserving, but harming them appears acceptable, appropriate…
>
> (Van Soest, 2003, p. 357)

Insider Research

Representation and speaking as expert insiders is an issue in Aotearoa New Zealand. The Maori educator Linda Smith (1999, p. 139) points out, "As non-indigenous experts have claimed considerable acceptability amongst their own colleagues and peers, government officials and society on the basis of their research, indigenous voices had been silenced or "Othered" in the process." It could be said this is similar to a representation of disabled people. Davis (2002, p. 44) indicates, "Yet it is also fair to say that at this point in history most scholars still consider disability an anamorphic lens displaying distorted or grotesque subjects who were rather more "them" than "us." In other words ableism is still active in the academic world as well as the world at large."

The ideology of selfness is conditioned by the wider community much the same as the conditioning for ethnicity and differentness. In developing a model for stages of understanding multiculturalism for identity development theory, Cheatham et al (1997) explain stages individuals go through to make understanding from their own innocence and the process of coming to a realisation towards an enlightenment of what has happened to them.

Although he described ethnic differences, this rationale is easily transferred to other groups of people including the disabled other. Briefly, stage 1 he called *naiveté* where the individual is little focussed on the self; an example he gives about children and their innocence. Stage 2 he calls *encounter* which is about the experiences in the environment and in those cases where there is recognition of barriers to inclusion. Stage 3 is *naming*, which is transformative and moves from the negative slur, say, to a pride. We could use a case like the Deaf community which is at the forefront of the movement. Stage 4 is *reflection* where there is an awareness that it is OK to be who we are and we do not have to be angry at other people's ignorance. Stage 5 he calls a *multiperspective internalisation* where the individual is able to view the world through other frames of reference. For a fuller understanding of this process see appendix E.

This is illuminated by Kathryn Church, a sociologist published in a medical anthropology book called *Forbidden Language.* She talks of her insider research on language and relates this comprehension and depth of knowledge which is understood by her participants. She explains the differing forms of language spoken by the various groups in the psychiatric survivor world. For instance medical professionals, administrative professionals and those that live with the illness all use different jargon. She **could not write her research in the form of a thesis and says that** "Critical autobiography gives me permission to do something which academics rarely do: write myself into my own work as a majo**r character"** (Church 1995, p. 3). What is at stake here is her understanding of the language used. It is almost as if we have a number of different languages with separate understandings, different cultural interpretations, differing power relationships and in just one language (English) being used. Church **proposes Bakhtin's ideas on how people access their relationships on the**

words other people use. Mentoring and self-help groups might see themselves as consumers and survivors; the rehabilitation professionals see those people as clients having disability and yet the medical professionals see them as patients having illnesses. Church (1995, p. 11) sees this as competing discourses, giving meaning to their worlds.

To help highlight the complexity of language and reasoning, my close friend and medical anthropologist Margot Symes' thesis on participants' interactions within the world of foetal alcohol has a more than competent understanding of disability. But as she lives outside the world of the **"disabled other", she sometimes uses practitioner language rather than** forms of insider language as her participants are parents and caregivers of people with foetal alcohol effects. She did comment that their responses gave clearer measurements than their loved ones who had alcohol induced brain damage. Not one of the participants in my study would refer to themselves as a sufferer and many, including myself, did refer to the issue of the way they were portrayed. Symes (2004, p. 66) **did say, "…for an individual suffering" when alluding to one of the charges of on**e of her respondents.

Insider status could also be an identity issue. In his book on the photographic imagery of disabled people Hevey (1992, p. 54) said**, "In the** research for this book, I had begun to uncover sometimes hidden, sometimes open, but always a continuous construction of disabled peoples **as outsiders and then turned into culture as symbols of fear and pity."** Hideomi (1999, p. 426) refers to organisations applying to the public for the charity dollar as empathetic misrepresentation, where disabled people expose their private lives and reinforce the status of dependency. In the same way, language is used to subjugate that individual. But this is the

opposite of what Barfield **(1997, p. 348) says, "Being there and speaking the** language vastly increases the chances of comprehending the meaning of what is happening from the people**'s point of view."**

When referring to the insider research of an educationalist called Steven Webster **describing his own institution, Bell (1999, p.43) said, "There were** definite advantag**es in being an 'inside' researcher. For example, he had an** intimate knowledge of the context of the research and of the micro politics of the institute, travel was not a problem and subjects were easily reached. He knew how best to approach individuals and appreciated some of the difficulties. He found that colleagues welcomed the opportunity to air problems and to have their situation analysed by someone who understood the practical day-to-**day realities of their task."**

There are also disadvantages to being an insider researcher that must be acknowledged. Some researchers like Genzuk (2003, p. 1) argue **"It should** be said, though, many ethnographers do not believe understanding requires **they should become full members of the group being studied."**   There are some concerns about quantifying the insider role. Ideas of reliability are mentioned by many of the harder disciplines in social science like sociology and psychology and insider researchers should acknowledge these exist. One should temper the fact there will be challenges and combat these by triangulating one**'s** own subjectivities by quoting your own experiences and others in the literature. It has been noted by Van Heugten (2004, p. 204) **that, "Researchers' inclinations and limitations influence the way they conceptualize and approach research problems." As an insider researcher** she acknowledges, **"**My research inevitably raises the issue of subjectivity, as does all qualitative research. There is no control group or the usual

standardization of research instruments that appeal to scientific objectivity" (Van Heugten 2004, p. 207).

Sobrun-Maharaj (2002, p. 110) considers herself an insider researcher, that is, "...**research undertaken by a researcher who was a member of the** community being described. As an insider, the researcher does not need to negotiate their position with the subjects and serve prolonged periods of **time with them within an artificially created situation." She may have had** similar experiences as a child, she is a teacher researching students of West Asian parentage, and there are issues of power to be dealt with. Genzuk (2003, p. 3) **comments "in human service and education programs that** serve children, it is not possible for the researcher to become a student and therefore expe**rience the setting as a child..." Tregaskis** (2004, p. 2) points out there can be a problem of familiarity which can lead to over-identification with the research participants and the research. We constantly have to negotiate our positions with the participants. I believe we can not take for granted that we are members of a community and always included in it. We have some things in common; issues of being discriminated against, on the general feeling of being treated as the other. One constantly has to negotiate which boundary we cross. Group, society, community are all difficult labels and convoluted concepts; we cannot claim we are accepted. I would consider myself an insider researcher, but I am aware and have been told some people take exception, for me to be interpreting for them. These intentions have been made clear either implicitly or explicitly by disabled postgraduate students when recruiting for this research.

Another researcher, Broun (Broun & Heshusius, 2004) identified herself as **an insider, she commented, "Thus, I believed that being a member of my**

research discourse enabled me to approach my participants as an insider and receive their stories with an understanding and cognizant ear. One might argue that, because of my identification with my participants, my own **personal agenda might influence the work."** This work was challenged by another British disability researcher Tregaskis (2004, p. 2) who found it not positivist enough, saying **the critique didn't explain** researchers are in power relationships over their researched. Others such as Linton (1998) felt the need to talk about subjective experiences and have been similarly castigated by British theoreticians and disability activists such as Oliver and Barnes, that these writers are diluting the social model of disability, by particularising the experiences of disabled people.

Heshusius (1992) illustrated that in qualitative research, subjectivity was really only managed objectivity. Everything we do is subjective and constructed. She was fortunate her early academic training was in social anthropology and she cites examples of representation from Western social scientists that often misrepresented the intentions and meaning of their research participants, who they often viewed as subjects to be studied, rather than getting alongside and wishing to experience life as they live it. Another insider researcher Roseneil explains this: **"Linked to the rejection of 'value-neutrality' is the third distinguishing feature of feminist methodology:** a commitment in reflexivity. Feminist research rejects the self-obscuring and alienating methodologies which are rooted in the knower-known, subject-object dichotomies of traditional positivist epistemology"** (Roseneil, 1991, p 180).

Although Roseneil talks about feminist research being holistic, the experience of ethnographic research is about trying to become like the participants we observe and what they share. That feeling called

communitas and group identity. In that group there is a sense of belonging, that sharing of experience when several things come together. Levine, Petrie, Gottardt, & Sevig (1990, p. 188) have highlighted a plan for a working definition of social support which they developed when analysing a group of men with eating disorders. (I mention this in the exclusion section of this thesis in greater detail.)

Key ingredients of this social support develop a sense of community of practice in the interactions between members of co-mutual support groups. In my study the participants also explicitly or implicitly have created their own community of practice. By engaging in the interviewing process they are in fact sharing their experiences in a co-mutual learning environment where there is no hierarchical power relationship – despite some of them having critical reservations. As I have mentioned earlier, in the Maori concept of Ako, learners are teachers and visa versa. When I presented a theoretical position at a social anthropology conference I showed the same process for developing skills for training anthropologists:

> ...situated learning implies that activities are mutually created by a group of people, in such a way that, inexperienced individuals or novices acquire skills, dexterity, norms and the practices of their perspective profession. They advance towards the centre of their learning environment from the edge, whence they are marginal, to becoming fully **participatory members of the group. Isn't this** generally what the anthropologist does in the 'field'? We align with the novice as we act as the novice. Much of the learning that novices or apprentices or participant observers gain is implicit, they learn from observation, they imitate, are directed and acquire the necessary skills over time. As they interpret and practise, they mediate an understanding to gain knowledge.

> (McCool, 2003, p. 4)

A community of practice idea was advanced by anthropologists Rogoff (1991) and Lave (1991) who describe how and by what means groups share subtle knowledge. Wenger, McDermott, & Snyder (2002, p. 9) commented that, "Sharing tacit knowledge requires interaction and informal learning processes such as storytelling, conversation, coaching, and apprenticeship of the kind that communities of practice provide." These learning environments are generally associated with peer development, are peer led and it is within this space that a special kind of understanding is generated and is known inside the group.

Process of the Research

My participant observation component consisted of attending work shops and visiting other universities in both New Zealand and Australia. This really helped me into the field of enquiry. Personally I had been involved in many aspects of disability. In 1992 I joined the North Shore Multiple Sclerosis (MS) Society, and became their Regional Representative on the Management Board of the national body. As Convenor of the People with MS Committee I saw the benefits of peer support and solidified my conviction to a belief in Communities of Practice. I eventually became the president of the local society and in the meantime I was also on the board of Disability Information North Shore. When I started at Massey University, Albany Campus I joined the Disabilities Committee and a year or two later when another student Agnes Sneddon joined the committee, we became good friends. She was also a member of the North Shore Disabled Persons Assembly (DPA) but had recently wanted to be known as the Assembly for People with Disabilities. Agnes thought I could do some good for the DPA I became a member and went on the board. At the time I joined the committee and several years later I was asked by other members of the

committee if I would stand as their leader as they were dissatisfied with their president. At the next election I was elected president. I attended the National Assemblies where I networked with other disabled people, some of them in tertiary education.

This is how I went about conducting the study of cooperating with my fellow participants. In social anthropology the use of self is an intrinsic part of the repertoire of the research process.

Many though not all of the participants in the study had augmentative communication devices themselves. As the underlying theme behind the study revolves around communities of practice, I have learnt from the co-participants how to embellish my operating the equipment. We do not use the same equipment, but extrapolating from their methods of procedure has enhanced mine.

I have always had problems with vision, I avoided reading for pleasure and as a child I preferred comics as it seemed easier to picture a drawing in the mind's eye. Exacerbations of my MS have left me with more severe visual impairments both eyes with optic nerve damage. I am blind in one eye and have great difficulty reading fine writing. Especially complicated is reading small serif font and most of academic writing is usually Times Roman. The problem is that there is no consistency within the width of the characters, either numbers or letters, and often with reading I experience plaques which obscure my sight. It makes it particularly problematic when using laboratory computers and it is usual to have overhead lighting. I also have difficulty with reading other fine writing, like small thin Arial font. I had many problems with glare on the computer screens in the computer laboratories including the PhD room, this coupled with fatigue trying to decipher Times

Roman text, the default on all the computers, I ended cutting my workload to **a minimum and going home frustrated. I really didn't have the simple** visual dexterity at the beginning of each session to enhance the format. I am not totally blind and competently drive a motor vehicle, although that might be questionable, and I am fortunate to be able to make allowances in reading. I am conscious of my poor reading ability and compensate with magnifying the page while photocopying, using a magnifying glass or just straining my vision and waiting until my sight improves. The normal monitor on a computer has 96 dots per inch (DPI), but I use a laptop where I have increased the DPI setting 125% and convert the Times Roman to Verdana font, which is bold, consistent and uniform in structure.

An explosion has happened in a relatively short time—the computerised superhighway (The Internet) has revolutionised the way we collect literature data. My own experience of internet searching in 1996 could only easily access 95,000 uniform resource locators (URLs) or WebPages and nowadays Google, the wo**rld's largest internet provider, boasts several billion. This has** made the process of literature research instantaneous and now in the click of an electronic mouse we have access to virtually any amount of information which requires other forms of sophisticated researching techniques. No longer are we reliant on the university having an extensive catalogue of books and recently updated journal articles and this format, once conventional, has become known as hard copy.

Most of the publishing companies have now, or are in, the process of loading academic journals into electronic formats, page data files (PDF) commonly known as ejournals. This means the universities are able to access a wide range of academic literature and pass the information on to researchers. The system of retrieval is now available by remote access from home, making

visits to the library more and more an infrequent occasion. Mostly the university has paid subscriptions to these journals in bound or hard copy forms which also give them access to the electronic versions. US based Disability Studies Journal had been available for viewing without any regulatory subscription system and this was a good source of getting topical journal papers on disability. But in 2005 their system locked out non-payers and an excellent avenue for current regular bimonthly and back issues. Being a beneficiary and not having a credit card to pay directly to the United States, **it wasn't till April 2006** that I was in a financial position to subscribe and become a member of the organisation.

There has also been a plethora of electronic media known as on-line magazines (emagazines) and on-line newspapers (enewspapers) which allowed me as researcher to access dedicated awareness diverse ability issues. Ragged Edge Online, Ability News, and Ouch Team are some of the most well known international newspapers/magazines which allow all the benefits of social support through this medium, because it is more interactive than just reading the hard copy.

Integral to and associated with electronic communication, are emails and although there will be discussion of them elsewhere, the attachment capacity has meant I have been able to pass and receive papers and articles from and to my participants. As an example when recruiting, one of my prospects asked if she might read my masters thesis before she made a decision to proceed with this research and I was able to attach a copy and send it. With emails has been the ability to be part of discussion lists, and here the same advantages of instant communication also give the ability to pass and receive documents. **I am a member of "Discuss," "Anthropology**

and Disability Studies" and have been a member of "Australia and New Zealand Students with Disabilities" lists.

The World Wide Web Consortium (W3C) was initiated in response to the need for compatibility and sensory and physically impaired **people's** access to the internet. In the United States a Web Accessibility Initiative (WAI) was developed in answer to legal requirements for equal access for all. This is making and streamlining all methods of communication and providing alternative formats as mandatory. Blind and deaf people can now interact in multimedia.

Over the course of this research, I have been involved as a researcher within other projects. One of these was an Analysis of Online Access and Support for Students with Disability at Massey University Albany Campus. This followed a report presented on behalf of blind and vision impaired students by Nataline Bowker from Massey University, Palmerston North, identifying potential web accessibility issues. The Manager of Disability Services at Massey University commissioned a report on the status of the university system with reference to people with high sensory needs. As a researcher I collected personal information from students regarding their computer use and helped compile an annotated bibliography on the available literature on access for disabled students. Whilst attending the Pathways 6 Conference in Sydney Australia, we networked with Australian academic support staff on disability to enquire on web access there. I then went to Melbourne in Victoria and arranged further meetings with staff from the Centre for Equal Opportunities at Monash University in Melbourne, Victoria, Australia. I visited Elizabeth Anders at Deakin University in Melbourne and we discussed her research on post-graduate experiences and she commented Anders (1999),

like Linton (1998), that more has to be written about the experiences of disabled people in the academic arena.

The year before, I visited the University of the Sunshine Coast in Queensland Australia and conversed with the Disability Coordinator. Our conversation discussed the Liberated Learning Project of which they were **academic partners. I was keen to look at the university's Disability Action** Plan and she said she would send it to me; it never did arrive. But my awareness of the Liberated Learning Project showed the advantages of continuous voice recognition technology which was developed for disabled people in Canada along with IBM and showed that all people benefited from the universalising effects of this technology. I was fortunate enough to introduce the concept to colleagues at Massey University.

The following year when visiting the University of Southern Queensland in Toowoomba I was introduced to the coordinator of the equal opportunities who gave me a copy of their disability action plan.

I attended a post-graduate class on research methodologies in the early part of undergraduate studies. I developed a close friendship with one of the students who invited me to an off-campus function at one of the local Maori meeting houses which looked at alternative methods of healing. She is a learning and behavioural specialist working in special education and all the time I have known her, has worked with marginalised children. This friendship now stands in excess of 11 years and has had a profound impact by increasing my awareness of other ways of seeing things as our friendship has developed and I would consider her one of my closest critical friends. We have attended many *powhiri* (Maori welcoming ceremonies) at both the local

marae and at the start of several new inductions for educational psychology students at Massey University, Albany Campus.

I am indebted to the constant support given by the then campus disability coordinator, Jo Wilkins. I felt she was an invaluable informant. We were able to discuss candidly aspects of my research. We had an excellent relationship and I had known her from the first week I started at Massey University when she was one of my social work tutors. We attended many of the Disability in Education conferences together. We were colleagues in some research projects, presented joint papers and attended equal opportunities conferences and seminars.

I have attended Disability in Education Conferences in New Zealand at both Massey University, Albany Campus, at Canterbury University at Christchurch and in between travelled to the Australian equivalent in Sydney called the Pathways 6 Conference. I have attended subsequent conferences on disability at Massey University, Albany Campus, Australasian Association for the Study of Intellectual Disability seminars and workshops at functions from the Human Rights Commission to Equity Workshops.

I never thought there would be a problem in obtaining research participants and I was able to promote my study through
student contacts at Massey University, Albany Campus, presentations at the get-together functions by attending and presenting papers at conferences, seminars and workshops. I had confidence that the disability coordinator might introduce disabled people to my research.

All the participants were members of the tertiary educational environment; initially I sought post-graduate students or staff with disability. I was

interested in those people with physical and sensory impairments because I thought I could identify with them as I felt I fitted this criterion best. I found that in reading the literature and discussing with my critical friend, this might be difficult to quantify who were members of the group to be studied, who were insiders and who were outsiders. We are all students at university, as using the concept mentioned by Metge (1985), teachers are learners and visa versa. Our experience of disability is the same no matter what the impairment. So therefore the common dominator was chronicity. I thought then, a need to have experienced the effects of long-term or chronical exposure to disability and to be at university for at least three years.

I had a large network of students, and I am active in a number of communities that focus on disability issues, but I found their field officers and administrators were busy people. Just like the disability coordinators from the other universities who were more involved in their own affairs of management, I thought they felt there might be possible breaches of confidence without actually saying so to me.

For all my prospective participants I gave a prepared outline of the research. I called this my information sheet see appendix B along with a consent form asking that it be signed if they wanted to be involved with the study. The process had its problems; I insisted that one of my participants who was born blind, sign it. So we went through the formality of reading the contents and asking him to sign the consent form, which incidentally I had to place his hand on and tell him where to sign. When it came to another blind individual we dispensed with this charade and within the introduction of our taped conversation she gave her verbal consent.

The encounters with the participants, although referred to as interviews, were conversations with a minimum of structure.

There was no questionnaire; **at the start I would say, "I'd like you to tell me** your life story. I interacted with them and identified in many aspects of shared experiences in both university work and encounters in disability.

I continuously watched for cues of when the participant wanted to finish our interviews. One participant I drove to, set our meeting to last an hour, but was happy for me to call back. We arranged to meet at her home three times. I met another participant for lunch in the campus café, but it never seemed appropriate to tape-record our conversation in front of the café customers. After our meeting I wrote notes in my field journal and we arranged to meet again. This time we taped the conversation and at the start I read back the notes I had written of our previous meeting. Another of my encounters with a participant consisted of a series of three short bursts of about 20 minutes of conversation on separate days. But our encounters were more than just a stilted process of completing a questionnaire, which to me seemed an artificial social human laboratory of ticks and crosses way of getting answers to confirm **the researcher's hypothesis.**

My 18 co-participants are New Zealand residents and the interviewing process happened only in New Zealand. I was asked if Maori would be involved. I indicated that Maori are not the focus of the project. Mentioning that in a report by McKay, Rowlands, Ballard, Smith, & Gleeson (1995) indicated that an individual Maori would probably identify as Maori rather than disabled. Personally I felt it was the way the study was empirically conducted. I had a number of friends who are both disabled and Maori. I would be very happy for any person to be involved in this study. As it was,

two of my participants identify as Maori, both and had published on disability issues.

The interviews were unstructured; I gave a guideline of themes to my participants, which was just a list of topics (see appendix A). I was interested in their own life histories as I was conducting an ethnographic enquiry on how they intersected within the inclusion/exclusion continuum. I wanted a minimum of interference from me as a third party, but this did not happen. I realised that in narrative enquiry and insider research, we in fact co-constructed through sharing many similar experiences. The repartee was part and parcel, in building a relationship with my fellow participants. It was much like a community of practice where information could be exchanged on a reciprocal basis as both of us were the beneficiaries.

These conversations were audio tape-recorded and mostly transcribed or précised by me. The tapes, signed consent forms and hard data from them were always kept in a locked filing cabinet, drawer or locker at Massey University, Albany Campus. The data awaited disposal after five years. I changed the names of the participants making their nom-de-plumes from friends and family. Where I had two with the same first name I assigned different and unrelated ones.

My role as researcher was very much tied to the management of my health and wellness and this is a component of insider research that helped in identifying with my co-participants; I was seldom recognised as a healthy and robust researcher. I had a serious cancer alert which required treatment. My MS produced balance and fatigue problems which generally necessitated being off campus. I had great difficultly in walking when it was windy. I had falls and the nature of them usually meant I would have

fractures and pain to deal with. In summer I would get fatigued and favoured a more temperate climate. For the major part of the study, I was given a room by my supervisor in the College of Education. Many times I was unsure of where I would be domiciled.

When my mother returned from Australia we shared a comfortable house across the road from the university. I was able to have a study and work with my computer having made some adaptations. I still had reflective problems from daylight on my screen, but I could draw the curtains and work with low level fluorescent lighting. I mounted the laptop on a television wall-mounting so the screen was at eye-level and swivels so I can change my visual focal length with ease.

The Doctoral Research Committee asks of its candidates at the beginning of the research we how we are going to finance the project. I thought I may be **able to manage on my invalid's benefit and student loan. I believed by being** members of organisations like the MS Society and the Freemasonry movement might help; they did not. Freemasons give generously to education, but only to the best of the best students. I applied to Workbridge (a government rehabilitation organisation) for assistance in providing computer equipment. They had a scheme for providing disabled people equipment to normalise the learning experience. In the first place the computer was underpowered and could not process the software I needed.

I lost control in managing my funds. My car needed replacing and I was living 20 kilometres from university. In late 2005 I had run out of available operating capital. I was receiving firsthand experience of being poor. I **wasn't poor in** that my food and accommodation were provided for in benefits by the state. But ancillary costs for my education were covered by

being able to borrow on student loan to pay for my education. In the previous three years my accommodation benefit had not been paid and I was subsidizing expenditure by borrowing against my student loan. When the government changed accountability I slipped between the cracks. Maintenance of my vehicle for instance was not being kept up. Really I could not afford my calendar of attending to my community commitments. This is not an uncommon experience for students.

In August 2005 I applied to the Graduate Research School in Massey University for a grant in aid on the grounds of disability. I received acknowledgement the application had been received and in January 2006 a letter arrived saying my application had been successful.

On the most significant field trip to Christchurch, I was particularly unwell over the three days. The trip down was routed through Wellington, cheaper seats meant a stop there, and it just happened there was a storm when the plane was trying to land and after two failed attempts, the pilot decided to return to Auckland Airport where I changed to another later flight which flew directly to Christchurch.

One of the subjective experiences of trying to walk is self-consciousness. Speaking to my friends who have multiple sclerosis confirmed my own problems, walking in front of other people slows down the whole process. It is more difficult, it is very complicated, one is forever working out mentally scenarios of how far to walk, what happens if you walk too far and will I get back. What happens if I fall? What is the texture of the walking surface, is it even, is it a level walk. If it is not a level walk, how steep is it, are there steps. Are there any curbs to mount I would ponder. What happens if I walk and find there are no handrails and I have to retrace my steps? Already I am

fatigued just working out my accessible journey. So wheelchairs and mobility scooters are necessary not only for the fatigue, but also in freeing the mind. So what one also does is learn to lose the ability to walk.

I decided not to take my mobility scooter down with me, as I thought I would get a cab everywhere. That was a mistake. I didn't realise the fatigue levels that would affect me. Apart from the plane ride being fraught with drama, I had mentally worked out how I might get from one plane to another at Wellington terminal; it also took a lot longer to get to my destination. Physical well-being affects mental well-being and visa versa; if I could not stand up and walk I felt dreadful. If I felt weak and tired physically it affected how I thought and could not do the basics of academic work. But, I was on a tight schedule, I had three people to see and dialogue with.

The first day in Christchurch I caught a cab to visit one of my participants, and walked too far when I got there. We had a very pleasant time and my participant put on afternoon tea. When I called to be picked up it meant another long walk, though fortunately someone carried a chair close to one of the entrances. I struggled outside as the pathway meandered and the low shrubs were as much on the path as in the gardens. I very nearly fell. I was well out of my comfort zone as I was unable to have contingencies. The cab came and we made it back to where I was staying. I was very unwell that night and could hardly negotiate from the couch to the bedroom with a walking stick. I was so fatigued I couldn't get into bed and pull my legs under the covers. I would have been half hanging out of the bed. I must admit I alarmed my host. I found out later that she had a conversation with her doctor that night, as it had alarmed her and she was unsure of what to do. The next morning I felt better and went to my other participant's place and after our interview, she invited me to stay for lunch and had gone to a

lot of trouble making it. Again I felt unwell and could not eat all my lunch and made my excuses and left by cab. As my host was my third participant the next day we had a really pleasant interview and then it came time for me to leave for the airport to go back to Auckland.

Another system of collecting information and writing down my reflections was in the use of informal journals, notes in diaries and having field notebooks. I would always have one in my car, on my desk at university and at home and one beside my bed. I would always be writing notes in the margins of work I had printed.

To make sense of my reading, I entered details of the literature in a journal and then into a computerised referencing system. I purchased a licence to use this b**ecause it was my university's preferred scheme, and I expected** that the library support staff would be better informed and I could learn to use it with some dexterity. I had used another brand called Endnote for my Masters thesis but was very much self-taught and used it in the most basic sense.

I was mindful of the instability and limitations of computer hardware and the software programmes available. But I found it had invaluable management, storage and retrieval capabilities and without the development of technology it would have been impossible to complete the study. In 1996 I purchased a desktop personal computer with a 19 inch visual display unit, but the operating system was so antiquated, that it would not have been able to cope with some of the sophisticated augmentative programmes today.

Within a few months of starting the research, my borrowed laptop had an irretrievable breakdown and consequently lost all data; my bibliography

referencing programme called Procite had about 170 entries which I had not saved in electronic form. By this time the university now supported Endnote and I jumped at the opportunity of starting afresh.   Endnote is a bibliography referencing system that can be attached to the main working document called Word. The operating system by Microsoft is Windows XP and these were the main ways of storing written word on my word processor. Also I copied this into a Nvivo programme (a qualitative package management system) to help make sense of the data. This meant I had to load all the data into Nvivo; which took an extraordinary amount of my time. Every piece of information in electronic form could be imputed. Transcriptions or précis of my encounters with my co participants, articles from ejournals and enewspapers, emails, could all be installed as text documents.

I also had "Penfriend", which is a key predictor programme for people less dextrous physically, including those with vision impairments. Several features include text magnification, provide speech feedback and screen-reading of virtually any text from web or word processor and its ability to convert written text to audio text was invaluable. It was useful in duplicating modes of acquiring data, particularly helpful in downloading an electronic journal, being able to read it in another font and hearing it audibly. This facility was pointed out by my augmentative communications specialist I managed to make sense of when I observed one of my participants who was blind, using a similar system for reading. I had problems with my vision so I would copy the document into Penfriend and listen to it; this would speed up the process of analysing documents when I had afternoon fatigue problems and eyestrain.

Another software programme which assisted me was **"Dra**gon Naturally **Speaking"** a continuous voice recognition system, where the programme would be trained to listen to my voice and type by voice activation. This required an inordinate amount of cognitive loading and time to train so it could guess what I meant. It was invaluable when it came to transcribing most of my interviews or converting quotes from articles and books. Although I am a touch-typist, I am slow and the benefits were in the repetitive work.

To reiterate, programmes designed for enhancing abilities to conduct academic work were and are unstable. They were subject to many failures and seldom produced fast accurate work and required an inordinate amount of cognitive loading. Trying to understand the extra mental processes involved made it difficult to for me to comprehend. By having accessible easy-to-read instructions was by far the better choice. There was just no easy answer, I had to realise that being methodical, meant being slow.

It was particularly frustrating trying to find why problems occurred with my laptop. T**he "Dragon" programme had lots of delays in conv**erting the voice to typing. I replaced a hub as I considered it faulty, because I was getting better quality from an old microphone attached to the machine by inserting into pinholes, than using a sophisticated and expensive microphone attached externally through the powered hub unit. Eventually the system failed and the laptop was returned to IBM under warranty and they replaced the systems board. In about a year the systems board needed replacing again and the technicians said cost was outside the warranty period. I wrote a **letter to their service manager explaining the circumstances. My university's** disability coordinator suggested that perhaps the Manager of the Massey University, Albany Campus, information technology services might like to

advocate for me. And she negotiated with him and he agreed the firm would renegotiate and fix it under the warranty. The laptop worked in a dysfunctional manner and eventually in a year the systems board needed a replacement again. This time I argued that the capacity of the machine could not deal adequately with programming and to process the data required. We are reliant on using word processing, but for some having the ability not to use systemised procedures is a luxury many of us wish we could make. Van Heugten (2004, p. 212) made that choice when she summed up using another Qualitative Scientific Research (QSR) **product, "…**the use of the NUDIST programme had, I concluded, made the project mechanical and removed. Furthermore, context may have been lost as text had become **divorced from its surrounding material."**

To summarize this chapter I have shown some major cognitive anthropological themes revolve around the culture produced by the respondents (the research participants). Insider research gives a degree of cultural competence rarely found by social science investigators. Anthropologists compare and contrast transculturally and they become adept, but a first-hand understanding of the issues faced by disabled postgraduates is elucidated in subtle ways by being enmeshed in their own communities of practice. Their difficulties in negotiating time management where the pressure of production is hampered by difficulties in equity and access, is heart-felt from personal experience. The second portion of this chapter shows the process of my own journey through the study. A research project that snowballed from attending a conference and thence to focusing and writing a proposal to study people similar to myself. I attended many workshops and conferences; I even remain in the field today for this is my life and I am still inside. This study has been somewhat ameliorated by

added financial assistance through various government schemes I have been able to access through my own learning from communities of practice.

CHAPTER FIVE - EXCLUSION

This chapter will discuss exclusion/inclusion in relation to the experiences of the participants in this study and to disability in general. I will deal with the complex issues of definition – what does it mean to be included or excluded? How do disabled people deal with barriers in their working and educational environment?

The Concise Oxford Dictionary says, "to exclude is to deny access to and to keep out" (Pearsall, 1999, p. 496). But the complexity of this concept is revealed later (on p. 717) the word "include" st**ates that, "to include someone out as an informal way of excluding them". For disabled people,** there is a history of containment where people who were different were excluded from the majority of the population. But it is also meant they were labelled as being members of another, outside the mainstream. This is to **"include them out" (in this case as "disabled"). Byrne indicates that,**

> We must examine all aspects of 'social exclusion'. These include the historical development of the idea, the linguistic content of the term, the processes of the social restructuring, and industrial to post-industrial society within which exclusion is embedded and the policies which are asserted to be in the interests of inclusion.

(2005, p. 1)

I wish to go one step backwards in explaining that by excluding people or separating them it becomes what Link & Phelan (2001) see as one of the essential ingredients of stigmatisation. The insidiousness of the labelling and the history of being separated from the rest of society were fundamental in building the psyche and conditioning to **being the "other"**. There are similarities for claiming equity the same as other marginalised groups facing

stigmatisation, as mentioned by Goffman (1963). Forty years later Link & Phelan (2001) make a well balanced argument on the concept stigma by saying it exists when elements of labelling, separation, stereotyping and status loss, combine with the exercise of power against those not considered part of the majority. Link and Phelan further draw on the example of structural discrimination in institutional racism as it could equate to disablism or what I would like to call habilaphobia or fear of disabled people. Te Rangi Aniwaniwa Rangihau (1988) wrote a seminal report on structural racism as it happened in New Zealand not that long ago and perhaps it is high time something should be looked at for a group of disabled people, purported to be one of the largest minority groups of disadvantaged persons.

How do we measure whether a person is included or excluded? To a certain extent it would be similar to understanding how the other person is thinking or whether they are thinking (Cohen, 1995). Inclusion could be seen as a point on a continuum with a hypothetical total inclusion or acceptance in society at one end and a total exclusion or isolation at the other. Where a person is placed is always at the judgement of others, the individuals so judged can also actively choose to withdraw from society.

Roger said

> *it is very simple things, Michael, what happens when you are doing that juggling. I found myself refusing to answer the telephone, I can just sleep, because you start to notice not being particularly well. You actually don't eat; you really at the end of the day have to look at some very primeval instincts*

This withdrawal was perhaps for his own protection; is it something that we all go through as well? When we are not functioning to our optimum, or we are taking on a lot of work, we take on more work than we are actually

capable of doing; it is better to do one thing well. This can be a problem for all of us, especially for disabled people striving to accommodate what everyone expects of them as well as showing how capable they can be.

Some of the time being forced to address the issue of trying to include oneself can be demoralising. As in the case of Lesley as a school child she said,

> *…at high school and ball room dancing. And my parents said you go as it will be good for you, I said please don't, the boys high school comes over and they always leave me behind and blah, blah, blah. If I could see myself more positively, I would have done a lot better in later years. I did learn to do it and I love dancing, but I can still remember that wall flower, because I saw myself as into the role of a woman with a disability.*

But then again, in the case of this study they might manage to play the game of being a successful student by developing the skills that mark success, by imitating those who get acceptable grades for successful **scholarship. Once we used to be forced into isolation by the "medical police" but some reacted strongly against it. In Lesley's case her parents** cherished her and wanted to be good parents for their and her sake. Lesley said,

> *Well that is what they wanted to do with me, when you think; they told my parents to send me up to the Wilson Home. But they didn't and I went to a local school. I went to a school reunion the other day and one of my old classmates said, "You are the last person that I thought would turn up here." I said why, all innocently, and she said I just didn't think you would come to anything like this. And I said well I am a grand ma. Oh! She said, "You have done real things." I said, In fact, I am a lecturer at university. Wow it is that shaking of people, it is their attitude.*

Sometimes there are condescending attitudes of other people, then you have to cope with your own health issues and i**n Daphne's** case, head injury

from car accident, dealing with pain, associated sickness, complications, and her blindness meant she could not put any structures into place. One of the problems was verbalising the head injury. Daphne ran into difficulties with her employer, her boss presumed, that, as she had a child with the brain disorder she had a similar problem. Whereas there may have been some similar problems it was stereotyping on the boss's part and demeaning **Daphne's particular issues of il**lness. Daphne said her boss had no medical qualifications to be making judgements and so was very annoyed. Daphne found one of the great problems was the attitudes of other people. But those attitudes were not necessarily transferred to academia in an overt way. If disability is a social construction is it also a state of mind in the **"stigmatised" as well as the general population**. Some authors query whether there is such a thing or ever was, Lambert (2003) be**ing the "devils advocate" when h**e stated:

> The "disabled postgraduate" is an example of the paradox of "disability". Can there be a "disabled postgraduate" when this is an educational level so few achieve? Self-reporting at enrolment is still a choice. Some self-identify, some do not, and there are meaningful reasons for those decisions. This paper is an attempt to understand and describe these actions.
>
> (Lambert, 2003, p. 1)

Perhaps this is again fudging the disability/impairment debate, that similarly, **the "people first"** labelling brings. Bandura might describe this as possibly obtaining self-**efficacy, and surely a "disabled person" might be allowed to** grow intellectually as if they were like you and me and not remain part of that category. In other words, to overcome the struggles or barriers and thus define themselves as being capable, not disabled. The ideals of **inclusion are also highly subjective; the other or "disabled person" may**

deliberately hold back and withdraw voluntarily and exclude themselves for many reasons including safety. As in the case of Marina who explains:

> *But it's about not being painted into a corner, you know I feel it is about, and I talk quite often about control and not being painted into a corner. Because if I am painted into a corner... if I got myself into a situation where there is no way out; then that is horrible. It's really very difficult for me to cope and that's when I go to pieces. There was a time I was having panic attacks and feelings of anxiety that I found very, very difficult to deal with, because the feelings were continually there. They just get pressuring, you know up and up, but I think that was part of the medication I was on. Since I have stopped taking that medication I am not so bad. I have to have a contingency because I can start one thing and then I can move on to the next thing.*

Exclusion to someone who is a member of the Disabled Persons Assembly (DPA) might lead to challenge barriers and a desire to achieve a fully accessible society. In their vision statement they say they seek a society that provides both equity and maximum opportunity for all to participate. **The DPA's motto is "We Can" and their catch cry is "Nothing** about Us, **Without Us" (DPA 2006). When I spoke to one of their members at their** Annual General Meeting in 2006, she had a concept of full inclusion, and wanted a society with unrestricted universal access for all people. However, this is unlikely to happen since even architectural access is minimal because of resource constraints. There is always competition for resources, for which **"the disabled" ranking is fairly low in priority of getting them. The Human Rights Commission's report in 2004 states that disabled people are amongst** the most disadvantaged people in this country according to Diesfield et al.(2006). In New Zealand as in other countries there is a history of institutional separation for disabled people, even in education: it has been legislation, in one case through the Building Code (1992) that consideration

for egress from buildings has meant greater accessibility for all people. This has benefited those with mobility impairments that were in the past restricted. Unfortunately the insidiousness of minimalist architectural access and revenue -driven priorities has meant that access is not streamlined. Many new buildings do not allow full participation for people who use wheelchairs. A shopping development in Albany built after 1992, that would have needed to comply with the code has steps between shops without a handrail,I let alone for people who use chairs who had a steep gradient which they shared with cars. Many of the buildings on the Massey Auckland Oteha Rohe Campus either have ramps at the rear of buildings or if at the front have steps; handrails are not provided. Usually ramps on the new Precinct are put in areas that separate users from their friends by having to use the rear of buildings. This gives the impression that the university is culturally constructed for the non-disabled or as Dyck (1998) says, work places are socially constructed for the able-bodied relationships of power in relation to the dominant non-disabled culture. Deaken University in Melbourne, Australia has its main outdoor access on Campus in a prominent position where the steps meander around a ramp so that people with mobility devices do not need to be separated.

Branson & Miller (2002, p. 3) **point out that the "cultural constructio**n of the concept *the disabled* did not occur overnight, but was informed and transformed by the peculiar cultural conditions associated with the gradual **development of capitalist democracies". Capitalism, the specialisation of** work, the movement away from the family as a productive unit contributed to social distance and separation of those who were seen as less able to compete in the new economic environment.

The combination of excluding disabled people leads to the majority of the population devaluing them as unworthy – hence some peo**ple's** reluctance to value them as part of humanity. The New Zealand government labels dependant, incapacitated, impaired people as invalids and the implication can be that they are of little value. Roger comments on dealing with **government agencies, in fact he said this when working "mainstreamed"**[3], for a government department.

Roger also said,

> *The whole system of support that enables disabled people to actually make a contribution to the nation's wealth is so patronising and custodial, it relies on the disabled person being passive and of course many are. Because the skills of self-advocacy aren't instinctive and so again the system that is supposed to support disabled people and actually reduce disability is predicated on the basis that someone knows best what you want, the state knows best what you want, and you will just have to be grateful….The so-called policy frameworks that are supposed to support so-called disabled people are poorly constructed and poorly lead. Usually by non-disabled people, but anyway, of course then I had work. So essentially I had to make decisions in terms of health and management of the responsibilities that I have got.*

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[3] Mainstreaming is a government incentive scheme whereby employment is offered to a disabled person labelled invalid, to work within a department or affiliation for a period of two years; wages guaranteed for the 1st year and half for the second. This is so the employee can prove their capability for permanent employment. Whereas, most I know fail to capture positions. Power relationships tend to remain the status quo, in effect the manager takes advantage of the provision of labour outside the realms of their budgetary constraints. This is not to be confused with mainstreaming in schools which is slightly different.

Whether excluded or "included out" disabled people are more socially excluded than any other group (Howard, 1999; O'Grady, Pleasence, Balmer, Buck, & Genn, 2004) through such means as special education, segregated housing, special transport – Gordon & Rosenblum (2001, p. 21) say, **"all** contribute to physical segregation as do mundane architectural and information barriers**"**. In addition, there are emotional reactions to people **who are different and do not conform to "**culturally determined norms of **'attractiveness', and 'existential' fears in which the disabled person** [represents] the vulnerability of the human body which able-bodied attempt **to ignore or overcome"** (Ungar, n.d, p. 10).

There is also resentment that some people feel if special arrangements are made to compensate for difficulties or in fact are handicapped as a result of any disabling impairment. To a certain extent this is born out of ignorance, people not realising that compensations might need to made for some **people on the basis of levelling the "playing field" and creating a** more equitable environment. In some cases it could be based on fear of the unknown, usually when the difference is noticeable as with Murphy (1987) in the *Body Silent*. Varenne et al. (1999) **quote Murphy's recitation about** appearing as a wheelchair user following a major debilitating illness and bewilderment expressed by others, even politicians, that such an esteemed academic could be affected so. But they also raise the question of being impaired and disabled through non-participation.

> **A thing like," "A person of"**—what could he have been talking about? Was Murphy too successful to get a tumour? Was he too enabled intellectually by his surroundings to be disabled by a disease? Being squeezed into a wheelchair was one kind of problem. Being squeezed out of full participation from the various institutions he had been so successful in was a far greater problem (Murphy, 1987).
>
> (Varenne, et al., 1999, p. 134)

Even at university, some students and staff covertly disagree with allowances made for disabled students. I have heard of lecturers complaining of sign language interpreters competing for space at the front of the lecture theatre. I heard of a student complaining that a woman of mature age with high dependency vision impairment was perhaps not suited to academic life. It may be that in the inability to make a reasonable accommodation for the disabled person, it violates their human rights.

As an undergraduate student I was denied access from one campus to another in the early days of construction at Albany. The only footpath was poorly designed and relatively inaccessible on a mobility scooter because of steps on a steep incline, and to compensate required transversing along a bridle path. At the start of New Year, I found a gate in the path locked. When I approached the site management office for a key, they declined to give me one on the grounds that it was a health and safety issue. I said, **"No, it is not, it is a human rights issue" and made a complaint to the** Human Rights Commissioner which agreed it was. The local paper was very interested and wrote an article and at that stage I felt my grievance and point had been dealt with, to my satisfaction. Many times I had to rationalise my actions because I might have been super-sensitive and imagining I might be in the wrong.   Another lecturer who was teaching outside my field took exception to me; probably it was power playing and I suppose in the early stages of our relationship I was a little disrespectful. I had heard that she **complained to the university's registrar that I occupied** a chair and computer in a post-graduate room when I was researching topics for a colleague of hers.

All-in-all the educational environment in Western and advanced societies is considered to be friendlier for the disabled person than the workplace. Probably because their fraternity's social consciousness is more acute in educational establishments than say the common workplace where the pursuit of profit seems to prevail.

 It has not always been like that. China still insists on students passing a physical examination before a student may join a university. Kohrman (2003). It should be noted that even in New Zealand people in the past were excluded from participating in education because access and teacher attitudes to reasonably accommodating students were certainly minimalist. Dame Anne Ballin tells her story of having supervision for her masters in an office on the third floor in a building without access for her wheelchair and her having to cope in spite of the intransigence of the supervisor (Coates, 1999). But what is important is that she said, "You had to cope". The participants in my study and the methods they use for inclusion are devised in spite of their illnesses and impairments. They had a sense of self that rose above their adversities or challenges that placed them within the realms of being able to cope. A good word, because as Fran says, "*education is a privilege*" and with that goes responsibilities. At the level of primary and secondary school education in this country education is a right. But at University the undergraduate status is really a privilege, and at post-graduate it might be more seen as a personal responsibility.

Some of my informants, such as Fran, have commented on lecturers who are helpful, "*minimising the difficulties so she would be able to complete.*" Interestingly, it has been observed in some research that disabled people were rated higher on an index for integrating them into the social mainstream by social-work students than say law and natural science

students Schwartz and Armony-Sivan (2001). But then again not all lawyers and non-social scientists become like this. Although this is incongruous in **some ways big business's prima**ry objective is profit driven, whereas the natural scientist deals constantly with natural selection as a form of experimentation. But not all can be seen as unfeeling from the research of Diesfield, Patston et al (2006). Many of the respondents mentioned the callousness of the workplace as noted by Dyck (1998). From the point of view of disabled students themselves, the university environment can provide an opportunity for self-realization.

Shaun says ,

> *Education for me was about creating a mind and a framework of reference which was not based on majority ignorance*.

Success at university can contribute to the fulfilment of important survival **roles such as "orientation, physical independence, mobility, occupation,** social integration, and economic self-**sufficiency" (Bickenbach et al** 1999, p. 1175). The contribution that universities can make relies in turn on an awareness of the needs of all their students, including those with impairments. Most of these disabled post-graduate students experience extreme tiredness. Fran said,

> *I often … had to be home by two because I am exhausted by then.*

For some, the struggle is deeper than the usual stress of post-graduate education. Ross said,

> *…people with impairment have mental health issues and some of them get psyched out and have had nervous breakdowns. Most of us deal with mental health issues; the majority of disabled people live in a schizophrenic world, and remember we have been trained to be like that. We are trained to look at the ground.*

The irony is that the more confident and successful a disabled person becomes, the wider the gap between their own self perception and how others see them (Varenne, et al., 1999). What about the Invalids Benefit[4] and having someone from the Ministry of Social Development via student loans suggesting perhaps I should produce a letter from my doctor saying I am capable of working more than 15 hours per week on my study. When I am clearly breaking the rules for receiving my invalids benefit. Yet a blind person is able to work more than 15 hours and claim an invalids benefit. If they have internalized negative perceptions they may still have an almost **unconscious tendency to "look at the ground".**

> **…a cripple must be careful not to act differently from** what people expect him to do. Above all they expect a cripple to be crippled; to be disabled and helpless: to be inferior to themselves, and they will become suspicious and insecure if the cripple falls short of these expectations

(Goffman, 1963, p. 134)

Such attitudes contribute to the contradictory and confusing social field that surrounds disabled students.

Being herded into a group is always contentious as an issue for disabled people and intrinsic to the idea of treated and labelled a**s "the other"**. But on a positive side by forming a group the members learn to mutually support each other and there are various levels of support. With this goes a degree of loss of their individuality and many of my participants were displeased at this thought and generally chose less conspicuous forms of contact with each other. They preferred to observe and interact on the discuss list run

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[4] **"**Invalids Benefit is a weekly payment which helps people who are severely limited in how much work they can do. This is because they have an ongoing sickness, **injury or disability." Ministry of Social Develpoment**

nationally through Massey University. This list-service meant many did not have to meet at different functions like DPA AGM meetings, at work shops or conferences. Levine, Petrie, Gottardt, & Sevig (1990) point out the value of support by defining different aspects of it as:

> 1. *Emotional support*. The opportunity to share and express feelings, coupled with empathetic feedback concerning the authenticity and appropriateness of pressing emotional experiences.
> 2. *Esteem support*. The experience of being accepted and valued by people who are willing to listen reflectively and empathetically instead of judgementally.
> 3. *Informational support*. The opportunity to collaborate with people in order to gain information, advice, and guidance are (sic) potentially helpful in clarifying problems, generating options and developing workable solutions.
> 4. *Companionship*. Enjoyment of the friends which emerge in the course of pleasurable social activities.
> 5. *Motivational support*. The availability of encouragement and reassurance, offered in an atmosphere of hope. This enables the recipient to endure frustrations and to persist in the solution of long term problems.
> 6. *Status support*. Some mutual aid groups may produce positive changes in self-perception and social recognition by offering the individual a meaningful role and a valued identity within the larger community.
>
> (Levine, et al., 1990, p. 188)

Usually it is for the informational support that most of the participants interacted.

Hirsch (1995, p.13) points out in research she is involved in that:

> ...**when** disabled people are grouped together they are likely to actively form groups and express shared cultural bonds. In a time when integration into the mainstream of society is the goal, many people with disabilities are also discovering that they need each other, and that they can provide community and a positive sense of belonging for each other.

But within the disability world there is a hierarchy of worth related to how one attained their impairment. People who attained their impairment through an accident, especially obtained in the service of others are more valued monetarily by the state at a higher level than one who acquires or is born with illness. Those with physical impairments are rated at a higher level than those with intellectual or psychiatric impairment (Fund, 2008; Mitchell, 2000; Snow, 2006). So there is a problem that trying to find a reason for forming groups of disabled people at one level, people tend to group around similar impairments and finds support through those means of social support. At some juncture they tend to tire of being a member of a particular group and find some other way. The idea of who is included in any group could be explained by Willett & Deegan (2001, p. 141) calling it social **class hierarchy, "**Outsiderhood can be involuntary, as in the case of a homeless, unemployed person, a social status that often is associated with physical disability. Such a status may establish a permanently liminal way of life in contemporary society**" which they attribute to Victo**r Turner and they further say, on the same **page that, "**Structural inferiority, such as unemployment or jobs with poor wages, characterizes individuals in the lowest, most involuntary positions of **a social class hierarchy." But do these support groups by t**heir very nature start acting in a way of being exclusionary as Bruteau (2001, p.1) exposes the problems in religious dogmas,

> But how is this great idea celebrated? Special groups gather, segregated from one another by their allegiances to particular views and practices. They engage in ceremonies representing the great idea, but they take great care not to permit others to partake fully in them. Are not various communions, both large and small, implicitly saying that the reason why other believers cannot be admitted is because there is only one true religion—ours—and these others do not belong?

Or perhaps Krishnamurti (1991, p. 51) who discusses the evils of exclusion and separation as:

> In its very nature, conflict is separative, as all opposition is; and is not exclusion, separation, a factor of disintegration?…All ideas, beliefs, systems of thought, are separative, exclusive. Effort, conflict, cannot under any circumstances bring any understanding, and so it is a disintegrating factor in the individual as well as society.

Where do we draw the line when disabled people sometimes form support groups of their own? - An inclusive environment – that provides a measure **of social cohesion, shelter, familiarity and "family". At the same time, many** such groups have a short life, or are exclusive in relation to other support groups with a different philosophy, or clientele.

For some people, identification with a support group would contradict their **refusal of the label "disabled". "***I will not let my blindness be a problem. I do not self-identity as disabled"* (Fran) or Lesley who said that *"…on a personal level I don't have a lot to do with people with disability."* Thus some of my informants refused the label, and in turn excluded from their social contacts others who identified as disabled, finding a solution either in the struggle to be included in society in other ways or retreating to familiar domestic settings. For those who struggle and try to improve their situation there can be a cost. As Melanie said,

> *I fought and I fought – that is the thing with me, I get up and try to improve myself and in the process I have worn myself down, had mental and physical breakdown. I am recovering slowly and I think it has damaged me. I was fragile to begin with.*

Others have been encouraged from childhood to deny the permanency of their impairment, instead seeing it as an illness from which they will recover, rather than it being a chronic illness.

Arthur said,

> *I was just 'crook' and had to get over it. I never ever accepted it.*

However, it was clear that this same person knew it was not going to go away. **"My sickness"** he said **"pervades my soul."** Some groups are very exclusionary, for instance the Deaf community. A powerful and united lobby of Deaf people, and their supporters, has meant the government of New Zealand has made sign language a recognised language of the country. The culture of being deaf is recognised and in the light of the country mainstreaming all other children and adults as being out of the community. They promote the deaf community as a particular culture within the disabled community. It is OK to be deaf. The Blind are part of the disabled community, but are recognised by the government and afforded higher monetary privileges that other disabled people. Yet, Fran who is a member says only 5 per cent of the Royal Foundation of the Blind have no vision whatsoever and that many vision problems are age-related. It is interesting and somewhat adds to the confusion and complexity of the hierarchy debate; are deaf and blind people or those with intellectual impairment **considered to be more "in need" of community intervention and protection** from the rest of society and the disabled community. Shaun adds:

> *We are fighting for much the same principles, ironically, yeah we have a diversity of identity, but I think our intrinsic fundamental principles that we are all fighting for under the different labels of diversity are very similar.*

Altruism and involvement in the community can be a way to combat isolation and exclusion. To be included in a group working on behalf of others increases a personal sense of worth and is a visible connection to the wider community of volunteers or helping agencies. Sometimes the satisfactions of community work can lead to almost full-time commitment.

Roger was chairman of several disability groups and offers his time to the executive of the Auckland DPA.

In Roger's words:

> *but I think what drives us Michael to continually believe that we should be crusaders for our own kind.*

Angela said:

> *I think it does really, but that's what we do our research for. To improve the lives of our research participants.*

Ross indicated:

> *I am not doing this for myself I am doing it for everybody else.*

Karla was hugely involved in talking to groups, whether schools, service clubs or whatever, about disability. In fact in the last 30 years she has been an advocate for others marginalised by society and tries to put disability in its place. She said:

> *When I first give a speech I ask if anybody has a disability, probably one person indicates that when the whole group, then I say everyone has disability and I go on from there.*
>
> *I was a volunteer after I passed three papers at University and worked with a local college in the reading programme and I got in touch with a new local school which was founded on the principles of Summerhill in England the only true free school that England has ever known that every student chooses what he/she wants to do or which class to go to. Well I ended up with a young man who couldn't spell even his name, so he came to me three mornings a week and went to a garage for work experience that is what he chose to and do today he still keeps my van*

> *in order and still keeps in touch with me often all those years and this is what I have found over the years with people that you come close to and you have a definite relationship with.*

Daphne said she did many things in the community as a volunteer and when **I asked her, she said she was a strong socialist and that she wasn't doing it** for herself.

By working on behalf of others, self-image is also enhanced. Lynette sees it as part of being,

> *Gifted – gifted people are very sensitive to others, supersensitive in both ways, being criticised and supersensitive in as far as feeling empathy for others. I have always had that empathetic streak.*

The Salamanca Statement (UNESCO 1994) has contributed to the development of legislation and policy designed to promote the inclusion of people with disability in education. Primarily intended for children it sets the scene for the inclusion of adults within ordinary education. A British organisation relates to the report by saying:

In June 1994 representatives of 92 governments and 25 international organisations formed a World Conference on Special Needs Education held in Salamanca, Spain. The Statement begins with a commitment to Education for all, recognising the necessity and urgency of providing education for all **children, young people and adults 'with**in the regular education system. It says those children with special educational needs must have access to regular schools and adds:

> Regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all, moreover, they provide an effective education to the majority of children and improve the efficiency and

ultimately the cost- e effectiveness [sic] of the entire educational system.

(CSIE Centre for Studies on Inclusive Education, 2001)

Inclusive education, inclusiveness, separation and integration are all concepts that have been critiqued and debated. In education Avramidis and Norwich (2002) indicate that,

> **Some favour the term 'inclusion' because it is** thought to embody a range of assumptions about the meaning and purpose of schools and embraces a much deeper philosophical notion of what *integration* should mean. The term inclusion has come to take on the wider significance and popularity in linking up with the recent development of the concept of social inclusion as having broader social and political value. Inclusion in its wider sense is incomparable to equality as a social value in relating to all aspects of social disadvantage, the impression and discrimination.

(2002, p. 131).

Reintegration and acceptance can sometimes be difficult and confusing for people used to exclusion and negative discrimination in public and the work force. Many of the co-participants in the study had positive if not enjoyable experiences at university.

Shaun

> *The first thing I noticed on campus is that people didn't stare at me and didn't find me that unusual to look at. They kind of paid less attention to me than I'm used to. I'm used to people paying lots of attention to me in public. It's almost like I'm not private in public.*

Arthur

> *Certainly I haven't been discriminated here. Unless you call it a positive discrimination.*

Wayne

> *one of them had given me a lot of help over the three months in a really difficult situation. I know there were complications, getting there, I think she felt I shat on her all the time so she got angry with me, that was fair enough.*

Melanie

> *I find more acceptances at Massey, I was working in the probation service, when I think back to the early years I struggled and I didn't know what could be like in New Zealand. In the prison service when I think back, I got the feeling of utter terror; I don't know how I survived.*

Lynette

> *some of those lecturers are not taking me seriously about my PhD either, and yet my supervisor was the one that suggested because of my illness to go to the academic board and ask for…*

Karla

> *I remember my first day as an internal student and loved the total acceptance of other students and staff and remember all the young students. I was just one of the crowd, the very first lecture I enjoyed. I would say now, this is the only place I have never been patronised, the object of scorn, and being treated on equal terms.*

The way forward has been shown for members of the United Nations and Article 26.1 of the Universal Declaration of Human Rights which New Zealand subscribes to, where no discrimination can be accepted on the grounds of physical disability for granting access to higher education. Former Minister for Disability issues, Ruth Dyson, expounded on how much the Labour government has been proactive towards aiding disabled people at the Disability in Education Conference. I wonder how much of this is political rhetoric? In the United States of America (USA) the government has entrenched into law The Americans with Disabilities Act (ADA) in 1990 by

creating a statute protecting the rights of participation for people with impairment. This is under the threat that any organisation with a federal contract must comply with the laws under the act. It is certainly by no means perfect and it is treated as if it is the legal recognition of a path towards universal access to all services. It is recognised that universities in the USA contract with anyone to provide literature in an accessible format to access, whatever their sensory or mobility impairments are. Both the University of Hawaii and Madison State University and I daresay other universities in the States conform to the ADA [1990] in making access available to all. In Australia I visited universities in three states and all had developed their own disability action plans under the Disability Discrimination Act 1992 (Commonwealth) enabling participation for students with impairments at tertiary level and stating their obligations under law. In New Zealand we have a Human Rights Act 1993 which outlaws discrimination on the grounds of disability; all new Zealanders over 21 year have a right to attend a New Zealand university. We have a tertiary university code of practice, a wish list if you like, very similar to the NZDS, a guide line of hints from the disabled community, but nothing compelling for the universities. If they wish they might provide some extra resources, but only after the Ministry of Education gives the tertiary institutions millions of dollars under a supplementary grants scheme. As Sayce says we must educate, educate and legislate, Sayce (2003. P. 625) indicates, **"In particular, it would be more helpful to forge a stronger synthesis between, on one hand, securing legislative improvement and enforcement, and on the other, promoting the benefits of a more inclusive society. Each complements the other." Although her article related to discrimination**, it is relevant to the educational sector and the fact there is little regulatory institutional compliance.

But is regulation necessarily required. Some pe**ople admire New Zealand's**
"laid back" attitude and find it quite refreshing. Graeme Innes, a Human
Rights and Disability Discrimination Commissioner from Sydney, New South
Wales, Australia, commented at a workshop in 2007 that we [New Zealand]
seemed to get things done within the community without resorting to
litigation. But it doesn't always work, an example is the Association of Blind
Citizens of New Zealand (2002) made a submission to a forum following a
change to the funding by the Royal Foundation for the Blind (RFB) who had
put the focus back onto Tertiary Education Providers by stating:

> While the human rights legislation in New Zealand is
> arguably not as strong as in many other countries
> such as Australia, Canada and the USA, there is still
> some statutory obligation on tertiary institutions to
> ensure that teaching and study materials provided
> by the institution, or which are recommended
> reading for a given course, are readily available to
> blind and vision impaired students. It is not
> appropriate for a blind or vision impaired student to
> be in the situation where they are denied access to
> the same materials as their sighted fellow students.

It should be noted that universities get 75% of their funding from the
Ministry of Education for NZ citizens and permanent residents. Holloway
(2001, p. 597) who conducted research in a British Tertiary institution
commented that, **"... little is done about their experience of higher**
education", indicating lack of information obtained about the personal
experiences of disabled students in Britain   She quotes Hurst, an eminent
educationalist in that country who deals with disability and higher education
on policy and **said, "...yet, in terms of contemporary policies aimed towards**
widening access and offering improved opportunities for study to under-
represented and disadvantaged social groups, it constitutes an important
focus**"** (Hurst, 1993, p. xv).

One of the fundamental differences between the disabled undergraduate and the postgraduate as applied to this research seems to be that some of the participants have a conception of their higher selves and that they are not focused on their individual problems or pursuits against a disabling society. Unfortunately they are not always in the position of being able to concentrate on their studies through bouts of unwellness much of which is brought on by mental health issues such as dealing with depression and pain. But they have a realisation they are interconnected. This seems to be in line with Bruteau (2001) who argues against sectarianism saying:

> Surely the great ideas which celebrate the unity of the human race, an expansion of the notion of what **constitutes one's neighbour, and the need for** universal sisterhood and brotherhood, were not promulgated in order that they might become the foundation for yet another set of sects that will divide humanity. They were not proposed to justify the institution of new exclusive groupings but were aimed at exploding exclusivism. To make these ideas the unique possession of a particular tradition, over against all other traditions, is to violate the very core of their message. This is a common mistake, one often repeated in human history: An inspired Prophet arises who preached universal friendship and a way of salvation readily available to all.

(Bruteau, 2001, p. 370)

Heshusius (1992) tells a joke to explain the serious side of this interconnectedness when presenting a paper on qualitative research.

> There was this chimpanzee, Harry, who was everyone's favorite and one day he escaped from the zoo. Everyone looked for him, the zoo keepers, the police, volunteers, and finally, they found him on the top floor of the local library. He was sitting on the floor, looking exhausted, with dozens of books around him. "I'm so sorry**" he said. "**I knew you would worry about me, but I had to come here and read all of this. I have had this existential question -- I finally needed to find out: WHO AM I? "Well," they asked him, "Did you find out?"
> He shook his head, holding the Bible in his right hand and Darwin's "The Origins of Species" in his left:

"No", he said, "It is even worse. Now I don't even know anymore if I am my brother's keeper, or my keeper's brother..."
Harry had landed in a paradigm shift all right!

(Heshusius, 1992, introduction)

In summary, if exclusion is inherently wrong, the participants in the study have devised strategies to be included by being proactive and making themselves of use as volunteers in whatever community of which they are members. Motivation, like depression comes from within, although living with depression is a large part of the disabled people in this study's lived experience; it is in the motivation caused by being of service to others that seems to help them personally. Whether that is a form of being a member of a peer support group or community of practice. As Schwartz & Sendor's (1999) article says helping others is one way of helping yourself. It may be the realisation that a paradigm shift has taken place. O'Brien & Sullivan (2005) move the argument forward maintaining the emphasis that "service provision" should now change to being "of support". The United Nations Educational Scientific & Cultural Organisation (2001) states that higher education be considered a public good and call for a commitment to best practice similar to those ideas of Achieve (2005) whose best practice standards call for a need to create a fully inclusive tertiary education environment. Peters & Heron (1993) ask what is best practice in education, and whether our best is good enough?

Many of the participants have stated that being part of a community of practice relates to the promotion of disability consciousness, which they were not always in for personal interest.

Might it be a paradox as Lambert (2003) queries whether there is such a thing as a disabled post-graduate student? Might it be that disability resides outside the person, that it is a feature of what society does to a person who is impaired for a multitude of physiological and psychological reasons? Disability is out there as Garth Bennie said in a guest lecture at Massy University in 1994. The participants are negotiating their path through whatever happens, and successfully in their terms, just the same as Neilson (2005) found in her study of successful disabled women.

CHAPTER SIX - CONCLUSION

In the introduction I presented the reasons for the study and introduced the topic of disabled postgraduate students in university settings. I was an insider researcher and identified the participants as my fellows. It seemed to me the concept of a disabled post-graduate was a paradox. Do we have to show we are not capable in order to get the assistance we need and thus are in fact unabled or disabled in all matters?

The central theme of the analytical reflection is the community of practice model (COP) and the learning I gained being a member of groups and how they have similarities to my involvement in this research. My story need only go back to 1992. I tried my previous profession, but had lost the ability to perform as, firstly to communicate, and secondly my health had deteriorated, making hiding my impairments more difficult. Within a few years of my travels, on my overseas experience I developed symptoms of what turned out to be multiple sclerosis (MS). In 1992 I decided I needed help, and for the first time in 12 years I approached the local MS Society.

There, information was given to me about a support group of others like me **and here, I realised I wasn't going mad**--people had experiences similar to mine. Members of the group had gone through these rites of passage. They had been **separated from society and treated as "other" and it was** comforting to know I was not alone. I joined this group which was called the "Motivation Group**".** This was a successful support group, initiated by the Coordinator of DisAbility Information North Shore (DINS) who clearly and cleverly left the group to manage it own affairs. It was successful because it was a self-help mutual support group and the ownership of the group stayed

with the members of it. This was a community of practice. What is more, we built a community of trust and kinship, we co-participated, and members brought information and experiences where we all learnt from each other; there was reciprocity in the relationships. Subsequently the group disbanded and I became a member of another group called *boys-R-us* and eventually I conducted an ethnographic study for my Masters Degree of my experiences as an insider researcher (McCool, 2000).

The concept of support groups and communities of practice interested me and when I joined the executive of the Multiple Society of New Zealand I became the convenor of the People with Multiple Sclerosis Committee. It was here I could also see how as groups we successfully developed communities of practice as reciprocal relationships based, like successful friendships, on service and commitment to each other. At university I researched and found a theoretical basis for my hypothesis of why it worked so well.

I also realised I had been a member of other communities of practice that helped me to develop skills, build scaffolding and produce coping strategies. When I started my studies in social anthropology I noticed we gained a deeper knowledge through becoming involved with student peers who had shared interests, we learnt from each other. These were like apprenticeship modes of understanding where we shared information and experiences. It was like learning from the hands of more expert workmen, if I take a phrase from the freemasonry movement who use this model extremely efficiently in the training process of recruits. I was initiated into Freemason when over in London, U.K. As I advanced in the movement I also saw the benefits of their teachings of the socialising of men, where apprenticeships are fundamental building blocks. Newer members made sense as they co-constructed meanings with other newly initiated members. This happened in much the

same way as we learnt to become anthropologists through being members of our own anthropology club. We lived and applied our anthropology as students by almost total immersion into becoming anthropologists.

> The first Anthropology Conference I attended was as an undergraduate back in the mid nineties. It was held at Massey University in Palmerston North. A group of us came **down by train. We didn't know what to expect, we had no** history. We were only junior anthropology students. We were thrown in at the deep end of the pool. Observations and imitating were part of the process of learning to be Anthropologists. We all banded together, bonded if you like and here we experienced firsthand knowledge of the anthropological terms described as liminality and communitas.
>
> (McCool, 2003, p. 4)

There is a sense of knowingness that is a tacit way of learning and comes from being separated or othered. You do not have to speak about it, just a feeling is enough. You just know the other person has shared the moment. This is probably the bonds of friendship and brotherhood are so strong in Freemasons or where a group of students studying in the same discipline have more affinity to each other than any other students.

Contemporary ethnographic research relies on the establishment of reciprocal relationships, based on trust, understanding and respect. This is called : building a rapport**"** with the participants in the study (O'Reilly, 2009). I discuss more fully in my methodology section about speaking the same relational language (Bird, 2004) or unconditional positive regard (Drewery, 1990)**. O'Reilly comments, "This does not mean the text is about you. It** means confronting your relationship with others, it means conveying the context and your place in it. It also involves noting who your research is for; **even impartial access is not always guaranteed"** (O'Reilly, 2009, p. 191).

The participants often faced the same frustrations experienced by many other disabled people - the majority of non-disabled people are trying to safeguard the disabled person, but it also has the effect of isolating that individual as different. It becomes a barrier to inclusion, a learned helplessness for all parties.

This PhD research emerged from my personal life observations. I found the processes of education personally liberating as did all the participants in this **research. In the end this thesis is 'our story' –** mine and my participants.

I came to understand how the use of language affected the marginalisation **of a group of people considered to be "other". This required deep analysis as** there is historically little evidence of partnership, participation and representation in disability research.

I looked at access issues, expanded the debates on inclusion and what is an inclusive society both structurally and temporally.

I showed that the experience of disability has been framed in a negative light, as loss and deficit by the majority of the population who do not see the abilities and gifts of the individuals. My aim in this thesis was to heighten awareness of the diversity and to bring the positives to the fore. Through reference to current international literature, particularly that of anthropologists with their own experiences of disability, this thesis may expand our understanding of different cultural repertoires and ways of dealing with disability.

I have allowed my participants to expose their experiences of disability and disability-exclusion within the New Zealand cultural context

I looked at disability in New Zealand with its four million people and saw how resource issues are very different from other 'Western World' countries with much larger populations, who have generally implemented disability action plans and codes of practice. I question whether our systems are less cumbersome?

In the chapter on disability I gave a rudimentary history of disability showing those two prominent models, individual and social and explained the complexities of each construct. The concept of disability is both transcultural and intercultural; impairments are part of the life cycle. This discussion was about the evolution in the meanings of disability which are convoluted and lengthy. My analysis of the history of traditional and cultural influences shows how power relationships have moved through the religious and cultural to the secular and then onto a self-consciousness where disabled people write and debate issues themselves.

The two major models of disability, the individual and the social, do not adequately describe how disability affects people. Many disabled academics acknowledge the evolution of meanings. Some call for a capabilities approach while others look for a diversity of abilities. Disability seems to be the only way to describe what happens to people; we might change the label but it never changes what the majority do. It is a concept; it is out there in society and not necessarily in the individual. Both major models need each other to feed off.

I introduced my participants by showing some similarities they might possess as a group. I use a communography where insider research techniques lead to an understanding that allows me to speak the same

relational language as my participants. Anthropologist Malinowski gave credibility to ethnography; this is just a variation on that.

For my participants I described my kin. This was a joint venture - we were related not by blood, but by the very fact that we share in communities of disabled people. We are connected even if not always interacting with each other; we seldom moved in the same circles on a day to day basis. Nevertheless this is a community of shared experiences and practice; there is camaraderie between group members because of this. Many of my participants knew each other, it maybe because we share similar impairments and are associated in similar support organisations and all of us **share in society's constructions of disability.**

I believe I have empowered people with disability, by sharing the stories of success of my participants with other students and staff members at tertiary educational establishments.

The portraits of the participants described their situations and gave an indication of the challenges they faced. I gave a portion of their life history, I also described in some cases where our paths crossed and something about how our relationships with the disability movement still continued.

These are stories of adversity, where the participants have developed successful coping strategies and made achievements, not despite their being **"othered"**, but by living with and acknowledging their differences. These are reflections on our society where we compete in complex emotional relationships within employment and all other social institutions. The university seemed to be a psychologically safer setting probably because it is a place for higher learning and therefore all the people had a more highly

developed consciousness. Even though in some cases it reflected some wider macrobarr**iers, the participants' experience was positive.**

Social anthropology, as a discipline, deals with real people in their own familiar settings.

I focussed my reading and combined new literature with that I had already encountered in my previous studies. As the reading increased I developed a number of theoretical positions trying to remain focussed mainly on the work of anthropologists. My anthropologically based methodology used the self as an important tool in analysis, I remained a participant observer. But I was already participating in many of the groups deemed to be in the disability field beforehand and continued to do so.

I am an insider researcher. This is recognised by many nowadays as legitimate research. It is the very essence of what an anthropologist dreams of doing and that is walking in the footsteps of their respondents. This gave me a distinct advantage over other researchers, as the basis of ethnographic **research is, as an outsider, to show the insider or native's perspective of** reality and world-view. I was in effect already speaking the language they understood. Methods used also included intensive field-work, listening to life stories. But I have also developed through this insider research a quality of cultural competency that is unrivalled and envied by other social scientists and humanists in other forms of debate.

We found what we as joint participants shared in that feeling of disability was just the same as the feeling of *communitas* as students. Thinking about communitas, the Latin for community, brought to the fore by Turner (1967), convinced me that community was the central theme of this whole thesis.

There are communities of practice in all organisations and institutions in society and they are used by the participants in this study, not only in developing strategies for inclusion, but also for learning. Because the university is a series of communities of practice a major theorist for this study is Vygotsky and his concept of a culture of learning. We are also indebted to the social anthropologist Lave and her colleagues for bringing his ideas to Western academia.

I also wanted to show I had a communion with my participants and this connectedness and kindredness is often misunderstood. We were sharing the same language, a relational language; one where the researcher's and participant's reasoning is complimentary.

For the chapter on exclusion I wanted to draw on the experiences of the participants which I considered to be quite pivotal to the research. This briefly dealt with the definition and history of non-participation in society as disabled people, particularly in the student interactions in the educational setting. I deal with the complex issues of definition – what it meant to be included or excluded. Was exclusion a subjective experience or were disabled persons to blame for being "othered"? The physical environment is not always streamlined and how the participants dealt with barriers in their working and educational environment is illustrated.

I found that disabled people are more socially excluded than any other group (Howard, 1999). Through such means as special education, segregated housing, special transport – " all contribute to physical segregation as do mundane architectural and information barriers which Gordon & Rosenblum (2001, p. 21) attribute to Higgins. In addition, there are emotional reactions to people who are different and do not conform to "culturally determined

norms of 'attractiveness', and 'existential' fears in which the disabled person [represents] the vulnerability of the human body which able-bodied attempt to ignore or overcome" (Ungar, n.d, p. 10).

Even at university, some students and staff covertly disagree with allowances made for disabled students. It may be that in the inability to make a reasonable accommodation for the disabled person it violated their human rights.

The disabled post-graduate had a sense of self that rose above their adversities or challenges placing them within the realms of being able to cope. We have voluntary agreement, the code of practice, a wish list if you like, very similar to the NZDS, an insubstantial guideline of hints from the disabled community hoping that government and the generic university grant them permission to attend. If they wish they might provide some extra resources but only after the Ministry of Education give the tertiary institutions millions of dollars under a supplementary grants scheme.

One of the fundamental differences between the disabled undergraduate and the postgraduate as applied to this research, seems to be that the participants have a conception of their higher selves and are not focused on their individual problems or pursuits against a disabling society.

I learned that if exclusion is inherently wrong, the participants in the study have devised strategies to be included by being proactive and making themselves of use as volunteers in whatever community they are members of. Motivation, like depression comes from within, although living with **depression is a large part of the disabled person's experience; it is in the** motivation caused by being of service to others that seems to help them

personally. Whether that is a form of being a member of a peer support group or being a member of a community of practice, it covers the same territory. As Schwartz & Sendor's (1999) article says, helping others is one way of helping yourself.

Many of the participants have stated being part of a community of practice relates to the promotion of disability consciousness and they were not always in it for personal interest. They are motivated by some higher consciousness and the realisation as the Irish say, "it is in the shelter of each other that the people live."

Although disabled people are recognised as one of the most socially excluded of any group, the participants in this study were proactive in including themselves into the community. They were of service to the many communities they were members of, and had realised this as a requirement for social integration. If they needed to hold back and temporarily withdraw for health and safety reasons, they devised strategies to make these less intrusive. To a certain extent it was participation in communities of practice that helped to alleviate this. It was not pity they sought, but it was their willingness to persevere despite their own impairments. Many of the participants did not see their health-related issues as problems, but challenges to be personally overcome.

To summarise this thesis

The contribution that anthropology makes to an understanding of the participants' life stories regarding their interactions in the university environment is immense. There have been many traditional sociologists turned disability theorists who have written on disability and now there are

more social anthropologists giving personalised accounts. As I have reiterated many times conveying the experience of disability has, as a social anthropologist, given a clearer understanding of how we live as human beings. It may be the evolution of knowledge, but this gives an understanding of a language that is relational to the participants in the study. It is not medical anthropology, very little focus has been made on medicine, it is more about the relationships the respondents have had within the microcosm of the university.

The contribution the university makes towards an inclusive society has been astounding. Originally I thought there were many institutional barriers towards disabled people. There are still some residual structural barriers, there is certainly competition for resources, but the university is on the whole a kind place. Here the majority of its inhabitants are more enlightened than in the wider employment workplace which is known as a culturally constructed environment for the non disabled. Perhaps the greying western world population will become more mindful that functionality is temporary. Providing for the needs and wants of disabled people has spin-off benefits for all people in the very nature of universal access. We need to be vigilant and not regress by making barriers through resource constraints, because the university needs to lead the wider society by example. Society is moving in the right direction, it may not be fast enough, but technology has improved the lot for all students and staff.

The university is a community of practice in itself. We learn from our peers. The participants in this study operated in many communities of practice but what we did is learn from each other. And I expect that by telling their stories of success as postgraduates it will inspire others to follow their lead. It is not too difficult to latch onto masters and move from the periphery

towards the centre of education. Vygotsky's *Communities of Practice* is a reasonable model for interpreting how disabled people support each other and learn that the age old apprenticeship model is an efficient method of including oneself and learning by being of service to each other. This is one of the ways that the participants were being proactive in their own inclusion in society; they took the initiative and understood that reciprocity means "what yea sow so shall yea reap." Many of the participants functioned around depression and it motivated them; as Schwartz and Sendor (1999) say, in helping others one helps oneself. Being in a place of higher learning definitely helps one to achieve that higher consciousness that makes us distinctly human beings.

APPENDICES

APPENDIX A - INTERVIEW THEMES

Disclosure and openness
Family patterns of self-disclosure
Disability and culture
Most of the literature is imported – it is British, American or Australian—
Local or Global information wanted.
Inclusion and exclusion—the language of exclusion
Withdrawal—holding back—isolation and aloneness
Self Protection—fatigue—illness— Depression
Scaffolding—Structures for survival
Acceptance—acceptable behaviour from others
Visiblity/Invisiblity—Domestic realm—the home—domination—oppression
Public and Private issues
Personal Welfare—income support
Post Colonialism and speaking for the other
Lack of Spontaneity—longer time to plan and do things
Frustration in asking for help—autonomy
Universal nature of human rights and Human Rights and education
Powerlessness—being patient—becoming a patient—lack of command
Diminished world—size of acquaintances—Support Networks
Public domain Observation of others Face-to-Face contacts
Impersonal—urbanity—provincial—country
Stigma—discrimination—prejudice
Cognition and the learning experience—social construction
Experiences of being disabled educators—learners and teachers
Special education—Disability and culture

APPENDIX B – INFORMATION SHEET

Massey University

College of Humanities and Social Sciences
Massey University
School of Social and Cultural Studies
Private Bag 102 904, Auckland,

New Zealand
Telephone   64 9 443 9700
Facsimile   64 9 441 8162

Information Sheet

Date 29 April 03

An Ethnographic Study of the Experiences of People with Disability in Tertiary Educational Settings

Dear Participant…………………………………………**Researcher**: Michael McCool
Simi Linton, (1998) in her book *Claiming Disability Knowledge and Identity*, says '**Anthropology and h**istory are two areas of scholarship that could paint a broader **picture of disability…' She further goes on to state that; 'Few anthropologists have** systematically studied disabled peoples experience, habits, customs, in-group and out-group behavior, stories, imagery and fewer still have done so from the p**erspective of disabled people themselves.'**

I would like to invite you as a person with impairment to join this study. My aim primarily is about research of us postgraduates, and this may include staff. As all of us have valued lived experiences of disability. There is a paucity of information on **disabled postgraduate students' written in a positive light. I wish to narrate your** stories on your life in tertiary education about overcoming barriers and your thoughts on inclusion and aspirations for the future. I would hope that the production of the results of this study would help us to educate. That we are social, emotional, sexual and spiritual human beings with aspirations! We could say impairment is part of the human condition and affects everyone at some stage of the life span.

Let me introduce myself, I am a sensory impaired PhD student conducting insider research at Massey University Albany in social anthropology. My interests are in cognitive anthropology, that is, how we make meaning out of our lives, and not medical anthropology. There is no formal questionnaire to complete in this study our **friendly conversations and discussions are very 'low-key'. I am sure you will find the** experience of our informal exchanges will be emotionally reciprocal and beneficial. You will also have the chance to see how you are represented and I would welcome your critical comments, a draft will be made available. How many times have you

been the objects of research, only to find that your relationship ceases the minute the researcher has got what they want. My promise to you would be to keep you informed of the progress of our study.

In accordance with the University's code of ethical practice, you have the right to:
To decline to participate
To refuse to answer any particular question
To withdraw from the study at any time before data analysis is completed
To ask questions about the study at any time during participation
To provide information on the understanding that your name will not be used unless you give permission to the researcher
To be given access to a summary of the findings of the study when it is concluded
To have access to a counsellor or a clinical psychologist who may be able to assist in dealing with unresolved issues of grief an loss, or if more appropriate, refer participants to an experienced third party.

I would like to audio tape-record our conversations and you have the right to ask for the machine to be switched off at any time. If it is transcribed a copy will be sent to you for your acceptance.

I would like to assure you of the utmost integrity of this work. All our conversations remain confidential, information and audio tapes are kept under lock and key.

My supervisor is: Dr Eleanor Rimoldi
School of Cultural and Social Studies
Massey University Albany Campus
Private Bag 102 904
North Shore Mail Service Centre

This project has been reviewed and approved by the Massey University Human Ethics Committee ALB protocol (MUAHEC 02/074). If you have any concerns about the conduct of this research, please contact Associate Professor Kerry P Chamberlain, Chair Massey University Campus Ethics Committee: Albany, telephone 09 443 9700 x 9078 email K.Chamberlain@massey.ac.nz.

Sincerely

Michael McCool
(09) 443 9700 x 9056 email m.j.mccool@massey.ac.nz
(h) m.j.mccool/HEC and Methodology/information sheet 31 Mar 03

APPENDIX C – CONSENT FORM

Massey University

College of Humanities and Social Science
Massey University
School of Social and Cultural Studies
Private Bag 102 904, Auckland, New Zealand

Telephone   64 9 414 0800
Facsimile   64 9 441 8162

Consent Form

An Ethnographic Study of the Experiences of People with Disability in Tertiary Educational Settings

Researcher   Michael McCool

I have been given an explanation and read the information on this research project, which I understand. I also know that I am at liberty to ask other questions, and that I am able to leave this project at anytime I wish. I can ask for the return of audio tape-recorded conversations, and understand that I may withdraw without giving a reason.

My information is given in strict confidence. This information will only be used for this research project, and that publication will protect my right to privacy through anonymity. After the report is published information is in the public domain.

I agree/~~do not agree~~ (*please cross one out*) to interviews being audio tape-recorded, and understand that I have the right to ask the machine to be turned off at any time.

There is no financial reward for my information and agree to take part in this research.

Massey University Human Ethics Committee ALB protocol (MUHEC 02/074).

X...*(date)*.......................... 2004
(please sign)   name and address would be helpful

....

....

APPENDIX D - LETTER TO PARTICPANTS

Letter to participants after sending back my synopsis of them

Now folks on the vignettes, this is a sort of cobbled together generic note. It's a brief portrait as I mentioned of around 500 to 750ish words. I intend these stories to form a chapter of my thesis. I wanted to give the audience a bit of a mental picture of the people who are in our study. So yours is a story and one of eighteen and I have given you a nom de plume. The nom de plume is not to be interpreted by you that I think it reflects you. It is only a name.

I didn't want these portraits to appear as clinical assessment reports of us as patients for either the medical or psychological professions. I wanted these **glimpses to be respectful and I didn't want to give too much detail about you** otherwise it would compromise your anonymity. I wanted to be careful; the communities in which we operate many of us are known to each other.

I needed to be a wee bit pedantry, and sort of picked several areas that might explain these individuals like: 1, impairment (I know we have a raft of things that impact on our well being and impairment is the medicalised portion of disability); 2, how we live; 3, a little historical background; 4, my interaction with you; 5, something on what you do at uni.; 6, an attribute I think you have; and 7, perhaps a quote.

If you remember when it came to our in-depth conversation, I wanted you to tell me a little of your life stories and we had no set questionnaire format. I interacted with you and gave some insight into my own experiences, many were similar ones in relating and how we interacted with our wider

communities. This is inline with what I understand to be insider research and I hope will present an extraordinarily positive message about us.

Students of anthropology are people centred, to a certain degree we interpret as well as describe. Please remember in these portraits; the participant is one of 18. If there are glaring in exactitudes **that you don't like, or you feel that** the bit I write may well compromise your anonymity please flick me a note. The last thing I want to do is spoil our relationship.

Michael

APPENDIX E - CULTURAL IDENTITY DEVELOPMENT THEORY

Stage 1. Naivete. The individual has little focused awareness of self as a cultural being. This is most clearly represented by children who do not distinguish skin color as an important feature. Helms (1995) points out that many White individuals lack awareness of the meaning that "Whiteness" has in our society. Naive understanding can also be manifested by successful and educated professionals who fully or partially deny that they have been oppressed and discriminated against.

Stage 2. Encounter. Despite lack of contact or efforts to shield oneself from racism, sexism, or other discrimination, the individual encounters experiences in the environment that clearly demonstrate that the earlier naive view was inadequate. For example, the African-American goes through a critical transformation and recognizes that discrimination is real and that being African-American is different than being White or Asian.

Stage 3. Naming. The act of naming is transformative. When Betty Freidan (1963) named the "problem that has no name" as sexism, she forever changed the way women viewed themselves and their issues. The gay liberation movement named itself gay, and thus took on what was previously a negative slur as its own positive identity. At this stage, the individual may feel much anger and may actively or passively refuse to work with those considered oppressors- most often European White males. For White and majority people seeking to support liberation of consciousness, the naming phase represents a real challenge, as it often leaves the White person without any sense of a positive identity.

Stage 4. Reflection on self as a cultural being. The development of a keener awareness of being Asian-American, bisexual, or culturally deaf continues. However, at stage 3, the Black individual may turn away from White culture and become totally immersed in reflecting on African-American history and the Black community. The lesbian may move away from confronting men and focus within her own community. At this point, the majority society is less relevant. The developmental task is the establishment of a definite cultural consciousness.

Stage 5. Multiperspective internalization. The individual develops pride in self and awareness of others. This individual makes use of the important dimensions of all stages of development and thus recognizes and accepts the worthwhile dimensions of predominant culture; fights those aspects that represent racism, sexism, homophobia, and oppression; and integrates all the stages in a transcendent consciousness. The individual is able to view the world through multiple frames of reference.

(Cheatham, et al., 1997, P. 163 Table 5.2)

AUTHOR NOTE

This thesis is written in 12 pt Verdana script rather than the more common academic writing like Times Roman.

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