Good Days and Bad Days:

A Grounded Theory study of Disabled Women's Sexuality

A thesis submitted in partial fulfilment of requirements
for the degree of Master of Arts in Nursing at
Massey University, Albany, New Zealand.

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2000

Abstract

Disabled women have been considered asexual for too long. Disabled women have experienced prejudice and oppression as a result of living within a social environment that expects its members to conform to a socially defined normality. Historically, disabled people have been considered the tragic victims. This has been acknowledged as the 'medical model' approach to disability. That is, that an individual is disabled, and it is the responsibility of the health professionals to cure or care for them. By contrast, disabled people have developed the 'social model' of disability. This model recognises that society disables people with impairments by excluding them. Barriers to inclusion are both environmental and attitudinal. Nurses and other health professionals have been educated in the medical model of understanding disability. The results have been that disabled women have not been treated appropriately.

The aim of this thesis was to uncover how disabled women understand and experience their sexuality. As a disabled researcher, I am in a unique position to undertake this study. Very little has been researched about disabled women by disabled women. We have tended to be studied by nondisabled health professionals. This study includes information provided by nine disabled women, literature written by disabled women, and resources from a broad academic perspective.

The methodology used to guide this research is grounded theory as described by Glaser (1992). The process included semi-structured interviews, which were transcribed and then coded. The constant comparison method was used to discover six categories. By using the comparison method, the basic social process emerged from the data. The basic social process or pattern of behaviour was called **good days and bad days.** Simply, disabled women feel more sexual on good days as compared to bad days.

Society and nurses have an impact on disabled women's experience of having good or bad days. If nurses are to make a positive contribution they need to understand disability from a social model perspective so that they can work with disabled women in partnerships. Change is needed in society to value us. Disabled women need to speak out and support each other in promoting social change. Disabled women are sexual beings and we can be proud to be all that we are.

Acknowledgements

There are a number of people I would like to acknowledge and thank for their assistance in producing this thesis. Without their contributions, help, guidance, support and love this study would not have been possible.

The participants of this study shared with me their very personal and private stories. I am in awe of their generosity and willingness to contribute. They trusted me with their stories and I am forever in their debt. I have presented their contributions accurately, and in their own words. I hope I have done justice to their generosity.

There were a number of individuals who I wish to acknowledge:

- My mother, Isabelle Sherrard, who constantly offered support and encouragement, always believing I could do this. She was one of my first nursing teachers and continues to be a role model, as a nurse who has gained her Masters degree.

- My husband, Peter Reid, who provided editing and printing support and who did all the things I didn't do while I studied.

- My father, who provided his editing expertise just when I needed it and sympathy when the computer played up.

- My friend, Teremoana Tuau, who offered both her encouragement and physical support in order to make this happen.

- My friend, Susan Shaw, who gave generously of her resources and enthusiastically supported this work.

- My friend, Russell Vickery, who helped with computer technicalities and stopped me from saying 'yes' to other requests when I needed to study.

- My friend and 'study buddy' Ruth de Souza, who met with me every week and asked me questions, prompting the development of this theory. She offered her enthusiasm and knowledge about research. And most importantly, she shared her experience and expertise of living in a minority group.

- My supervisor, Dr Gillian White, who provided guidance as the research progressed. She was available and actively supported my study. She has maintained her involvement with me over a three-year period and been caring on both a personal and professional level.

- To all the others who were interested in what I was doing, talked through ideas and supported me through various crises, thank you.

I also want to acknowledge my disabled friends and colleagues. You have supported and encouraged my development as a disabled woman. You have welcomed me into your community and challenged me to take pride in who I am. I am now able to say that I am proud to be disabled.

Finally, I wish to acknowledge those in the disabled community who have struggled against oppression and fought for the civil rights of disabled people. They were the consciousness raisers and without their efforts, I would not have been in the privileged position to complete this research. The challenge continues for us to fight for the emancipation of disabled people.

This research was approved by two ethics committees: Massey Human Ethics Committee and the North Health Ethics Committee.

A Poem

In My Disabled Women's Group

In my disabled women's group
The facilitator asked me
"What goals do you have
For yourself in the next five months?"
I felt the panic rise in me
Thinking of the days
Without a job
The weeks without the money
Or the energy
To move my furniture
From the garage where it is stored
Six hundred miles away.
How many times will my stomach hurt
In the next five months?
How many times will I throw up?
How many times will I go to the welfare office?
In the last three weeks
I've been seven times, and still no check.
I remember articles I've read on time management.
How you plot out goals
For the next ten years
Then one year
Then six months
One month
This week
Then you figure out
What you're going to do that day
And how it relates to the master plan.
I realize her question is quite reasonable
Its what other people do.
I don't live that way, anymore
I divide the days into smaller sections-
A whole day is just too much pain
Too much responsibility to get through.
It started in the hospital
When I got morphine every three hours.
I'd watch the clock: the shot took 45 minutes to take effect
Then I slept for an hour and a half
The 45 minutes till I could have another.
It's the way I passed the days.
Now I divide it up with vitamins
I tell myself if I'm still awake at midnight
I'll take another C; calcium if I haven't got to sleep by 1:00.

I write down the things I have to do
On a good day I'll have checked off almost half the list.
Five months from now? Maybe if I'm lucky
I'll be living then
A whole day at a time.

A poem by Barbara Ruth (1988, p.32).

Prologue

We met in a small, gray institution office. This was the outpatient's clinic, which didn't make sense to me because I was still an in-patient at the time. He was an older man, probably only late forties, but I was twenty-one. To me, he was old. He was also one of my doctors, a specialist and I had only met him once before. He seemed to be quite a big man, with dark hair going gray at the temples. This was the man who knew all about bladders and bladder functioning. I needed his expertise.

I had been in the unit for about four months. By this stage I was beginning to get used to sitting in a wheelchair. I wore the uniform of a rehabilitation patient of t-shirt and track-pants. The nursing staff seemed to take pleasure in dressing me in socks that matched my t-shirt. I had become institutionalised.

Authority figures scared me. Even though I was a registered nurse I felt helpless and totally vulnerable when meeting with doctors. My fear had come from my experience of not being respected and also I had picked up the fear nursing staff seemed to have of doctors. I remember being told, "Oh, he'll never let you do that."

I don't remember a lot about the meeting. But somehow right at the end I summoned enough courage to ask the doctor a question I had been thinking about for a long time. "Can I still have children?" The response from this highly qualified professional was, "Oh, I've got three kids already and they're such a handful, you wouldn't want any."

I was totally devastated. The truth was that I did want to have children. I always had, and having my accident hadn't changed that desire. What I didn't know was if my accident had changed my ability to.

My question was also a way of asking if I could still be sexual. I was too embarrassed to ask that one. And it was not something talked about in the unit. I was one of the few women on a predominantly male ward. There were always lots of jokes and innuendo about male sexuality. But female sexuality didn't seem to exist.

Thirteen years later, I am very aware that disabled women are sexual and do have children. As a group, we seem to know a lot about this subject and health professionals still don't know much. My aim is that this thesis will encourage disabled women to talk more about their sexuality and that health professionals will listen and learn from us, the experts.

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Chapter One

Introduction

Disabled women are a group within the community about which little is known. We are a diverse group representative of all ages, socio-economic levels, educational and employment levels, ethnic groups and relationships. Having a disability affects an individual, whether that disability is congenital or acquired, physical, sensory emotional or intellectual, obvious or invisible. Sixteen percent of women are disabled (Wendell, 1996). Being disabled is what connects these women. We may not choose to be connected, nor identify as being disabled. How similar or different disabled women are from one another is unknown at present.

This research expands the knowledge currently available about disabled women and their sexuality from a disabled researcher's perspective. Shakespeare, Gillespie-Sells and Davies (1996, p.3) state:

> There is quite an industry producing work around the issue of sexuality and disability, but it is an industry controlled by professionals from medical and psychological and sexological backgrounds. The voice and experience of disabled people is absent in almost every case.

I hope to challenge assumptions made by nondisabled researchers who bring a negative bias into their study. French (1992, p.183) wrote:

> It is concluded that the assumptions underlying much disability research, especially when they are translated into practice, are oppressive to disabled people, and that participatory and emancipatory research needs to be developed in order to assist disabled people in their struggle for empowerment.

My overall aim for this research is to empower disabled women. For too long disabled women have been defined by nondisabled people. As a disabled woman I am in a good position to undertake this investigation. I am an

'insider' in the group called disabled women, I belong to the group. The disabled writer Jenny Morris (1996, p.14) maintained:

> We need to write about, research and analyse the personal experience of our bodies and our minds for if we don't impose our own definitions and perspectives then the non-disabled world will continue to do it for us in ways which alienate and disempower us.

Field (1991, p.93) explains the importance of this, "In the situation where the researcher has personal experience, it is possible to become, on occasion, one's own expert informant, being able to focus on both what is happening in the group and on one's own response."

Historically, disabled people have been considered to be asexual. Tilley (1998, p.97) argued, "The fact that women with disabilities are usually regarded as asexual has been extensively documented. ... This is seen as a truism, not only by society generally, but more importantly, by many health care professionals who women with disabilities consult." This research challenges the assumption that disabled women are asexual and offers health professionals, particularly nurses, some positive recommendations to assist them in their working with disabled women.

While my aim is to empower disabled women, a thesis is not the best route to achieve this outcome. Because few disabled women are able to undertake higher education or employment (Wendell, 1996; Fine & Asch, 1988; Morris, 1991) many will not have access to this thesis. One of the ways I hope to make a difference for disabled women is by informing health care professionals. In so far as nurses have contact with disabled women they are in a position to enhance our lives. Unfortunately, historically, nurses have not used their opportunities to enable but instead have tended to oppress and alienate disabled women. Shaw (1995, p.18) explained, "The experience of many people with disabilities is that nurses tend to be patronising and have institutionalised values and methods of working." This thesis will be available to nurses, academics and other students who are motivated to read it, and as a result they may change their interactions with disabled women.

The particular impact I hope to make on nurses and other health professionals is that they will change the way they currently relate to disabled women about our sexuality. As a result of the information found in this study health professionals may become thoughtful, sensitive and appropriate when working with disabled women. The possible implications of my research for nurses will be discussed in a later chapter.

This thesis was an opportunity for me to focus on three areas of my interest. My professional background as a psychotherapist and nurse means I have a curiosity about the lives of people. My own personal experience of my disability means that I have a passion about the lives of people with disability. I believe our experiences as women have been undervalued historically. As Sandelowski (1986, p.32) argued, "The task of the qualitative researcher is to establish the position of all subjects in relation to the group of which they are members and the meaning of their slices of life." My study is on the experience disabled women have of their sexuality, by seeking to discover the strategies they have developed for living as sexual beings with a disability. The qualitative methodology I have chosen to follow is grounded theory based on the work by Glaser (1992).

I chose to complete a qualitative research project. Schlesinger (1996, p.249) wrote, "Qualitative research emphasizes the rich detail of people's social activities and perceptions and often is attempted to uncover new or varied understandings of social life." The words "rich detail" made qualitative research attractive to me. As Smythe (2000, p.16) described, *"Capturing the meanings of life through a system of questions and answers is the essence of qualitative research."* [sic]. I liked the idea of being involved in research that attempted to capture the meanings of life.

The area of study I chose suits a qualitative methodology because it is about personal experience. It is an inductive approach to research, which means the results are generated from the data as opposed to a deductive process which involves manipulating the data to check the theory (Becker, 1993). My aim was to understand disabled women's sexuality based on their experiences and

how they cope with these experiences. The data I gathered from the disabled women who participated in this study formed the basis for the theory presented in this thesis. All the participants in this study have been given pseudonyms and details, which could identify them, have been altered. All verbatim quotations from their statements are in italics.

Disability Defined

The terms "disabled person" and "person with a disability" can be used interchangeably. In the current trend of political correctness it has been useful for society to be educated that a person with a disability is a person first, hence the term, person with a disability. Recently there is a change occurring within the disabled community that disabled people want to be recognised as having intrinsic value and therefore are proud to be members of a group called disabled people. Waxman (1996, p.237) wrote that she:

> ... uses *disability-first* [sic] language rather than the rehabilitation – oriented *people-first* [sic] language. This use of language results from the author's view of disability as a social identity, much like being African American or Latina. Hence, rather than attempting to downplay this state of being, the term disabled is used to denote a prideful identity.

Personally, I feel proud to be part of this group called disabled, therefore in this study I will use the term disabled women.

The concept of disability can be understood in a number of different ways. The United Nations (1983) defined disability as, "... any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being." This is a definition based on activity or function. It states that a person who cannot function 'normally' has a disability. The question begging to be asked is what or who is normal? Wendell (1992, p.14) challenged the United Nations (UN) definition, "Not only the 'normal' roles for one's age, sex, society, and culture, but also

'normal' structure and function, and 'normal' ability to perform an activity, depend on the society in which the standards of normality are generated."

The UN definition isolates the disabled person and makes them an 'other' separate from what is 'normal'. It implies that if the disabled person is not 'normal' then they are 'abnormal' and have a problem. This type of separateness or difference leads to the oppression of disabled people. Morris (1991, p.15) stated, "In our society, prejudice is associated with the recognition of difference and an integral part of this is the concept of normality." Disabled people are different and we all could learn more about human experience from this difference.

Disability has been defined by Peter Beatson (2000, p.42), a New Zealander with a disability as, "A disability is a disadvantage experienced by a person as a result of the interaction between a real or alleged, permanent or intermittent impairment on the one hand, and physical barriers, institutional structures, social policies and cultural attitudes on the other." His definition is an attempt to include both the body experience or impairment and the social experience of disability. Beatson offers a second definition of disability based on identity because some disabled people are not happy with disability being referred to as a disadvantage:

> Disability is a characteristic of social identity, similar to ethnicity, gender, class and sexual preference. It is based on the presence of a permanent or intermittent impairment and may be associated with structural inequalities or discriminating attitudes in the social environment, but is not in itself a cause for negative self-image. (Beatson, 2000, p.42)

My preferred definition of disability is the one based on identity. I like the fact that it includes the impairment and yet acknowledges that having impairment is not a negative thing. For me this is empowering, and offers me a sense of belonging to a particular group. As Beatson (2000, p.53-4) observed, "Some, after initial reluctance, plunge themselves totally into the disabled role, playing an active part in their particular disabled organisation or in the wider disabled

rights movement." This was my situation. I am now an active member of the disability community.

Another important definition for this research is that of impairment. Beatson (2000, p.23) offers a useful definition:

> An impairment is a bodily or psychological loss or abnormality which may cause suffering and which makes it difficult, dangerous or impossible to perform tasks, to participate in community life and to play social roles in the ways taken for granted by non-impaired people.

Richardson (1997, p.1269) refers to a definition of impairment offered by Finkelstein and French as, "... the lack of part or all of a limb, organ or mechanism of the body." The important aspect of these definitions is that impairment is biologically based, whereas disability is a social identity.

There is some debate as to whether separating disability and illness is useful or not. Beatson (2000, p.23) uses the medical condition of diabetes to illustrate the difference between impairment and illness. Diabetes is associated with the malfunction of the pancreas and a resulting chemical imbalance. It may lead to impairments such as blindness or leg amputation. The illness is what a doctor diagnoses while impairment is what the person experiences. Not everyone with diabetes has impairment; many people live with their condition, and manage it with diet or insulin. Other impairments, such as the loss of a limb, may be the result of accidents, not illness. Wendell (1996, p.19) suggests that there are two reasons why disability and illness are separated. One is that if disabled people are considered sick, then they require expensive health care. The second reason is that historically disabled people have been considered to be incapacitated, that is unable to work. By separating disability from illness these assumptions may be avoided. Yet, by separating disability and illness many people's experiences are negated.

When considering definitions of disability it is important to question why we define disability. Wendell (1996, p.23) suggests there is a danger in defining people as disabled, "But defining disability and identifying individuals as disabled are also social practices that involve the unequal exercise of power

and have major economic, social, and psychological consequences in some people's lives." This means, by being defined as disabled a person becomes eligible for community support and lack of definition results in lack of support. She continues (Wendell, 1996, p.24), "It is in the interest of many providers to define disability narrowly, so that fewer people are seen to be entitled to the benefits they are supposed to provide than if disability were defined more broadly." It is not surprising then that the disability rights movement is up against strong opposition in promoting disability as something to be proud of.

Not all disabled people want to identify as being disabled nor do they want to belong to a group of disabled people. Wendell (1996, p.25) described it:

> Of course, no one wants the social stigma associated with disability, but, as I have already pointed out, social recognition of disability determines the practical help a person receives from doctors, government agencies, insurance companies, charity organizations, and often from family and friends.

The dilemma is that in order to receive the help and support that may be required the individual needs to be defined as disabled. For many this is not a choice that can be made, having an obvious disability results in being labelled and stigmatised.

Having an impairment does not necessarily mean a person identifies as being disabled. One factor that seems to determine whether the person identifies as disabled is the age of onset of their impairment (Beatson, 2000). For example, the person may have had thirty years of being nondisabled then a car accident with a spinal cord injury. As a result the person may spend a lot of time and energy trying to walk in a nondisabled way, rather than to use a wheelchair for their mobility. In a simplified model Beatson (2000, p.54-5) suggested a four-stage process through which people are inducted into the world of the disabled:

1. 'Something is wrong'
2. Diagnosis and remedies are sought
3. As there is no cure, the 'sick role' is exchanged for the 'disability role'
4. Disability is accepted and a new social identity formed.

Self Defined as Disabled

All the women in this study identified themselves as disabled. I did not choose anyone based on her disability diagnosis. A couple of the women mentioned that they had only recently considered themselves to be disabled. Ruth said, *Oh I don't know that I'll be much help because I don't really think of myself as being disabled. Well I wasn't always so I've had a life without and a life with.* Helen's comment was, *I suppose I never really considered myself to be disabled ... and in fact I think it's a label that I've only just started to adopt.* Both of these women are adjusting to becoming disabled. In Beatson's (2000, p.54-5) four stage process for accepting disability they are moving from stage 2 diagnosis and remedies sought to stage 3 exchanging the 'sick role' for the 'disability role'. Helen is still hopeful for a cure for her disability when she said, *they are making such huge advances in the area of genetics ... one day there'll be something ... I'll just take some pill or something and my muscles will rebuild.*

The other women were at stage 4 where disability is accepted and a new social identity is formed. For Felicity her disability was clear, *He knew that I had a disability, which was obvious of course.* Later she says, *I know I have got this disability, I can cope with this disability, I have to, I've got no choice.* Maria, who identifies with disabled people as a group said, *well why aren't you getting people with disabilities on to that review ... there are many of us that want to work.* Donna said, *all my life I seem to be the only one with a disability in my Church or ...you know ...I never wanted to be just a pew sitter, people with disabilities yeah they can go to Church but they've also got gifts and can be active in the body of the Church.* Cathy spoke about her life as a disabled woman, saying she just *gets on with it* and *if I can't do it I do without.*

Fear and Hatred

People with disabilities tend to be feared and even hated by nondisabled people. This fear is prevalent and socially sanctioned, and can result in

violence directed at disabled people. Waxman (1991, p.188) in a disturbing article about the hatred of disabled people gave a number of examples:

> Many violent acts against disabled people are overt, such as the vandalism and fire bombing of a community integrated group home inhabited by disabled adults who were threatened and beaten; the murder of Cary Dickenson, a multiply disabled man found stuffed in a trash can of a local library which was deemed by authorities a cruel prank turned tragic; the abuse of a nine-year-old North California student with multiple developmental disabilities who was repeatedly thrown in a cold pool by teaching staff until she went through the required swimming motions, an instruction technique which included forcibly pouring hot pepper sauce into the student's mouth numerous times to force her to "keep quiet"; the arson of a 40-foot wooden wheelchair ramp belonging to James Lundvall, a paraplegic, who is in a coma as the result of smoke inhalation, which Denver fire investigators, who called this a random act, were surprised when the arson occurred again 48 hours later; and the shooting to death of 2½ year old Eric Bernstein by his mother, who contended that she did so because the boy was not responding to his treatment for his multiple disabilities, and as a result received a reduced sentence from first- to third-degree murder.

In New Zealand we recently had an example of a case of a mother who killed her autistic daughter and received a reduced sentence for the crime.

The high levels of sexual abuse experienced by disabled people are another example of the hatred directed towards us. Nosek (1995, p.491) cites a study by The DisAbled Women's Network of Canada as finding 40% of disabled women had experienced sexual abuse. Nosek (1995, p.489) quotes another study as finding a rate of 50% of disabled women report having been sexually assaulted as a child. Shakespeare et al. (1996, p.138) wrote:

> ...it is quite clear that both (disabled) children and adults face a disproportionate level of physical and sexual abuse. Studies have found a variety of risk factors involved. Typical suggestions are of a double likelihood of having survived abuse.

These figures of the high rate of abuse of disabled people are horrific. The impact on disabled women of surviving abuse needs further study. But the abuse of disabled people, and all people, needs to stop.

To a lesser degree the fear of disabled people affects our ability to develop friendships and relationships. Fisher and Galler (1988, p.176) discussed this fear, "Disability is frightening in our society. It taps into our fears of ostracism, illness, and death. It plants a stigma not only on the person with the disability but on anyone who might be identified with it." Daniels (1981, p.6) said of this fear, "If there is any single major problem in the area of sexuality and disability, it is the one killer called loneliness."

Through history, there are a number of misconceptions attributed to disabled people. These historical descriptions were presented by Wolfensberger (1972) and denoted as 'deviant persons'. The nine historical misconceptions are: subhuman organism, menace, unspeakable object of dread, object of pity, holy innocent, diseased organism, object of ridicule, and eternal child. These misconceptions affect the attitudes which society in general, and health care professionals in particular, have towards disabled people. Anderson and Kitchin (2000, p.1164) discuss the affect of labelling disabled people:

> Labels such as 'invalid', 'cripple', 'spastic', 'handicapped' and 'retarded' all imply both a functional loss and a lack of worth and perpetuate and legitimate defensive responses by non-disabled people including horror, fear, anxiety, hostility, distrust, pity, over-protection and patronising behaviour.

Disabled people grow up in society that stigmatises them, as a result they can develop a type of internal prejudice against themselves and other disabled people, called internalised oppression (Shakespeare et al., 1996). The equivalent in the gay and lesbian community is internalised homophobia (Clark, 1987). For example, if a person speaks to a blind person with a raised voice the blind person may say "You don't have to yell, I'm not deaf." As if there is something wrong with being deaf. Beatson (2000, p.48) described how, "... rather than automatically feeling empathy and expressing solidarity

with those who are otherwise disabled, [disabled people] may strenuously deny any kinship."

Disability Models

There are a number of different models from which to understand disability. For the purpose of this thesis I have chosen to discuss two, the medical model and the social model. These are models that provide a way of understanding the concept of disability. Simplistically, the medical model way of understanding focuses on diagnosis of the physical problem, finding an appropriate label, and then treatment with an aim of cure. In this model professionals have more power than disabled people, because they have the recognised knowledge and expertise. In the social model, disability is understood to be a social phenomenon. It is the lack of inclusion in society, which makes for the oppression of disabled people. Simplistically, disability is 'bad' from the medical model perspective, because there is something wrong with the body and from the social model disability just 'is' and society is 'bad' for not being more inclusive.

Medical model

Traditionally and historically the medical model of disability has been the one accepted by society as the "truth". Craddock (1996, p.17) wrote, "*Medical model of disability*: [sic] This approach concentrates on the individual's physical impairment and sees the way forward as curing or improving that condition using orthodox medical treatment or rehabilitation." When an individual's condition cannot be cured, as with disability, the impairment is no longer the problem, the person becomes the problem. Richardson (1997, p.1270) declares, "The medical model, along with its permutations has been largely discredited by disabled people because it reflects the personal tragedy model of disability, thereby locating problems within people."

The medical model focuses attention on the medical problem and the whole person is overlooked. This often leads to the person being defined by their 'problem' or label. De Ras and Grace (1997, p.9) stated:

> Medicalisation, therefore, can be understood as the historically-specific social process whereby medical discourses play an important role in constructing culturally powerful significations of bodies and creating the institutional structures for medical regulation and intervention.

The medical model has played a very powerful part in the treatment of disabled people. Wendell (1996, p.117) comments on the impact medical professionals have, "Their authority operates far beyond medical institutions – inside and in relation to government bureaucracies, insurance companies, courts, schools, charities, rehabilitation organizations, and institutions for long term care." These institutions all affect disabled women's lives. Wendell (1996, p.119.) continues with her description of the power of the medical model,

> *The cognitive and social authority of medicine to describe our bodies affects how we experience our bodies and our selves, how society describes our experiences and validates/invalidates them, how our society supports or fails to support our bodily sufferings and struggles, and what our culture knows about the human body.* [sic].

If a disabled person is to be considered sick, then their aim must be to get better, that is to become less disabled. This has been the aim of rehabilitation. The New Zealand Ministry of Health (1997, p.22) discusses rehabilitation as having, "...more of a restorative focus, enabling a person to regain or learn skills to resume their former role." That is, to be functioning as close as possible to the way a nondisabled person functions. O'Toole and Bregante (1992, p.167) argue, "This presumes that disabled people choose dependence over independence and completely negates the societally sanctioned physical barriers to independence."

Health professionals and medical research have offered various drugs and technology to enhance the lives of people with a disability. Wendell (1996, p.110) supports aspects of the medical model:

> I am far from wanting to advocate that we give up all forms of trying to control the body. Scientific Western medicine's quest for control of bodily injury and disease has prevented a great deal of suffering and premature death. I am especially impressed by its accomplishments in dealing with traumatic injury.

She continues with the following caution (Wendell, 1996, p.111), "We need to recognize that scientific Western medicine's quest for prevention and cure has prevented and relieved, but also caused, a great deal of suffering." While Barnes (1996, p.43) wrote from his perspective:

> While medical interventions may be appropriate for minimising and monitoring the negative effects of impairment they are inappropriate for dealing with disability. Professionals working within this perspective invariably pathologise the experience of impairment and in so doing compound the problems faced by disabled people ...

Social model

An alternative model of disability is taken from a social perspective. In this model disability is defined by Oliver (1990, p.11) as, "*Disability* [sic] the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have impairments and thus excludes them from the mainstream of social activities." In this definition the focus is away from the person having a problem to society having the problem. For example, buildings are designed and built with stairs and wheelchair users are then excluded. Wendell (1996, p.39) stated, "A great deal of disability is caused by this physical structure and social organization of society. ... This is no coincidence. Much architecture has been planned with a young adult, non-disabled male paradigm of humanity in mind."

The social model of disability was described by Bochel and Bochel (1994, p.82) as seeing, "... disabled people as disabled or oppressed by a society that expects its members to conform to the yardstick of the able-bodied normality and whose physical and social environments penalize any 'misfits'."

Richardson (1997, p.1269) includes the following definition based on the social model, "Disability is defined as the loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on an equal level with others due to physical and social barriers." My study is written from the perspective that disabled people are a minority group and is based on the social model of disability.

Shakespeare et al. (1996) have considered disability and sexuality from a social model perspective. They wrote (Shakespeare et al., 1996, p.16):

> The social model is a valuable corrective to the prevailing approach to disability and sexuality, because it encourages us to examine the social processes which make it hard for disabled people to express their sexuality, and the particular difficulties caused by the attitudes of parents and professionals, the inaccessible environment, and the lack of appropriate services.

Their research also found the impact of attitudes, access and services had a major influence on disabled women's sexuality.

A disadvantage of the social model of disability is that it implies that if the world were totally accessible there would be no difficulties for disabled people. Beatson (2000, p.106) recognises, "No matter how sympathetic and supportive the social context may be, disabled people suffer a natural deficit which even under the best conditions determines the way they experience themselves and their relations with the outside world." Crow (1996, p.208) shares this warning of the social model, "Yet, our insistence that disadvantage and exclusion are the result of discrimination and prejudice, and our criticisms of the medical model of disability, have made us wary of acknowledging our experiences of impairment." No matter how accessible and inclusive society becomes disabled people will still experience their impairments.

Even including the above criticism the social model of disability is valuable in that it acknowledges the social exclusion disabled people experience on a daily basis. Wendell (1996, p.46) argues for the deconstruction of disability, "One of the most crucial factors in the deconstruction of disability is the change of

perspective that causes us to look in the environment for both the source of the problem and the solution." Her goal (1996, p.56) is that, "Everyone should, however, have access to *opportunities* [sic] to develop their abilities, to work, and to participate in the full range of public and private activities available to the rest of society." This includes the opportunity to be sexual.

Disabled Women

I identify as a disabled woman, for this reason I will include myself as part of the group - disabled women. I have chosen to limit this work to understanding sexuality from the experiences of disabled women. Disabled men are definitely sexual beings. More is written and has been researched about disabled men's sexuality than disabled women's. White, Rintala, Hart and Fuhrer (1994, p.55) found that, "Literature on the sexuality of people with spinal cord injury (SCI) pertains mainly to men." My research adds to the knowledge related to disabled women.

Another reason for my focus on disabled women is that we are doubly disadvantaged. We are discriminated against and oppressed both for being women and for being disabled (Fine & Asch, 1988; Oliver, 1990; Morris, 1991). Harris and Wideman (1988, p.131) discuss this double disadvantage:

> It is clear that disabled women suffer a dual discrimination in the workforce participation, education, and on a variety of economic and social measures (Asch, 1984); that is, that disability and being female interact in a profoundly discriminatory and disadvantaging way.

Fine and Asch (1988, p.11) discuss this disadvantage further:

> The relationship between disability, unemployment or underemployment, and poverty for disabled women is far from clear, however, we know that regardless of age or educational attainment, women with disabilities are employed far less than are either non-disabled women or disabled men (Bowe, 1984; US Census Bureau, 1983).

Disabled women experience both oppression and discrimination due to the power imbalance in society. Historically, the research done on disabled people has perpetuated the power imbalance, and abuse of power has occurred. Disabled people have been studied by nondisabled researchers. Disabled people have not had the same educational opportunities, by which to become researchers. Boyles (1993, p.7) stated, "People with disabilities have been excluded and even alienated from the research process to the extent that their needs and their very identity are defined by non disabled researchers."

I have not separated myself from the women I worked with by creating a group known as "them". This statement relates to my awareness of the difference in power dynamics which occurs between researchers and their subjects. I have minimised the power imbalance between myself and my participants, by using the term 'participant' as a way of recognising that without the contributions made by disabled women this research would not have occurred. At the same time, I acknowledge that while I hold the position of researcher I have the power in the research relationship. Given this I am very aware of the ethical issues involved in the study, which I will address later.

Sexuality

The study of disabled women's sexuality is important because there is little written about our experience. As I have mentioned, a common misconception is that disabled women are asexual. That is, without sex. The whole phenomenon of sexuality is complex in itself. Finding a clear definition of sexuality is difficult. It can include: sexual intimacy, physical functioning of sex organs, intimate relationships, body image, femininity and masculinity, sexual orientation and many other aspects. Matocha and Waterhouse (1993, p.371) included the World Health Organisation's 1975 definition of sexuality, "The term *sexuality* [sic] refers to the 'integration of the somatic, emotional, intellectual, and social aspects of sexual being."

Some of the participants in this study defined sexuality in a broad way. Helen said, *Yeah ...because I think the whole sexuality thing also is um ...so tied up with self esteem, I think that's the main thing and um it's sort of how you view yourself how that image has been projected to others.* As another participant put it, *sexuality means more to me than physical sexual intercourse, although that's part of it.* Sharon included a wide range of things in her definition, from her appearance being important including things like *lippy* and perfume to her home being clean and tidy, which made her feel good. She described having lovely friends who provide *good feminine energy*, so that they can *compare notes* and connect with each other. These personal definitions of sexuality fit with definitions in the literature.

For others sexuality was more difficult to define. The following piece of transcript indicates how difficult it was for Felicity to answer:

> Susan: How do you understand sexuality?
>
> *Well, that's a hard one*
>
> Susan: It is
>
> *How have you answered it in the past? (Laughs)*
>
> Susan: Well, I can't give you my answer, this is your answer.
>
> *Ah. I don't really know how to answer it.*
>
> Susan: That's okay.
>
> *No, sorry, no – I can't answer that one. Sorry. Carry on ...*
>
> Susan: Does sexuality include a variety of things for you or does it just mean sex?
>
> *Not just sex no, I suppose a variety of things really. It doesn't it um, making other people aware more than us.*
>
> Susan: Making other people aware of?
>
> *That um, ...oh god, now I've forgotten. In most ways we are actually quite normal and we do things that other people do anyway. We do have those feelings too, but they don't seem to think that we may have them, you know?*

This is an indication of how difficult sexuality is to define, and that the subject itself is difficult to talk about. Felicity wants to be helpful by participating in the research but actually finds it difficult to talk about sexuality. She hopes I

will answer the question, doesn't know her answer, then forgets her answer and has trouble making her point clear. Sharon made the point that a definition of sexuality is *hard to pin down*. Its something *we know we've got it but don't think a lot about it, we get on with it.*

One way of changing the myth that disabled women are asexual is by disabled women talking about our sexuality. This research was a way of starting that process within myself, and possibly for my participants too. Harris and Wideman (1988, p.134) asked the question, "If disabled women are not imagined or treated as sexual beings, even within the constrained place women are pressed to occupy, how submerged and silenced is their sexuality?" They go on, "In regard to sexuality and feminine identity, it seems the task at this point (and it is a demanding and confusing one) is to break the silence." Morris (1996, p.2) agrees:

> We have to find a way of making our experiences visible, sharing them with each other and with non-disabled people, in a way that – while drawing attention to the difficulties in our lives – does not undermine our wish to assert our self worth.

For some sexuality has become an issue of identity. For those who identify as gay, lesbian or bisexual one of the battles has been around being accepted by society (Clark, 1987). By challenging society's views about their sexuality this marginalized group has contributed to the empowerment of disabled people to becoming sexual beings. Jagose (1996, p.41) wrote, "In order to liberate homosexuality, gay liberation was committed to eradicating fixed notions of femininity and masculinity: that move would similarly liberate any other group oppressed by what it critiqued as normative sex and gender roles."

The movement by other minority groups in society to fight for their civil rights has served as a model for disabled people. Of the American movement Shapiro (1993, p.11) wrote, "In the last twenty to thirty years, little noticed alongside the civil rights struggles of African-Americans, women, gays and lesbians, and other minorities, another movement has slowly taken shape to demand for disabled people the fundamental rights that have already been

granted to all other Americans." I made the discovery of this civil rights movement on a trip I made to the United States in 1993. This study is the culmination of my research, reading and thinking since that experience.

Some feminist writers stress the need to separate women and sexuality as being different topics. De Ras and Grace (1997, p.8) wrote:

> ... there is a substantial stream within feminist academe that takes as its starting point the statement that we cannot speak of the body, gender and sexuality as fixed entities, nor can we speak of a distinction between the body as the site of biology and gender as a social construct. The body, gender and sexuality are only meaningful within language and are thus influenced by history, culture, and the social and political, religion and philosophy.

This issue of the meaning of body, gender and sexuality is particularly important for disabled women, as we live within the culture of oppression and discrimination. This has been our history which many disabled women are attempting to change.

Unfortunately few feminist writers have considered or included the experience of disabled women. As Morris (1996, p.5) stated, "Although we feel betrayed and excluded by feminist analysis and activism, many disabled women still feel key aspects of feminism have great relevance to how we experience oppression and discrimination." Disabled women have experiences of body and gender discrimination which could further the understandings of feminist writers. Fine and Asch (1988, p.26) suggest:

> The struggles of feminism and of disability rights have much in common. In order to pursue gender and disability equality, activists have argued for the elimination of laws, institutional structures and practices, and social attitudes that have reduced women or disabled people to one biological characteristic.

Feminist writers also discuss the concepts of women and sexuality within a constructionist framework. Fuss (1989, p.5) wrote,

> *For the essentialist, the body occupies a pure, pre-social, pre-discursive space. The body is "real", accessible and transparent; it is always there and directly interpretable through the senses. For the constructionist, the body is never simply there, rather it is composed of a network of effects, continually subject to sociopolitical determination.*
> [sic]

The debate is about whether we can separate the physical body from the experience of being a woman. The following quote, from Fuss (1989, p.5) is useful to distinguish the difference between the essentialist and constructionist, "To clarify, a rose by any other name would still be a rose – for an essentialist; for a constructionist, a rose by any other name would not be a rose, it would be something altogether rather different."

Nursing

Nurses often work with disabled women. Nurses are involved in many levels of care from intensive trauma situations to institutionalised care, rehabilitation, and long-term community based care. A woman may be born disabled or develop as disabled or may become disabled through accident, illness, or the aging process. Nurses may come into contact with disabled women through their work in the community or within hospital institutions. For these reasons nurses need to have a sound knowledge of issues which relate to disabled women. Tilley (1998, p.99) makes the point that:

> If appropriate health care and well-being are fundamental to everybody – then, the challenge for women with disabilities is to have the same rights of access to services and research into our health needs as all other members of society.

Traditionally nurses have been taught about disabling conditions and the impact of impairment on a person's body. The information has been delivered from a medical model perspective of disability. Nurses need more than this. Nurses require knowledge, which relates to the experience of being disabled,

from the disabled person's point of view. French (1996, p.162) described this as follows:

> It is important that health professionals receive high-quality equality training, that they understand the meaning of disability as disabled people define it, and that they are informed about the important role disabled people have played in the development of services.

To be effective in caring for disabled people nurses need to have an awareness of different models of disability and the impact of each, particularly the negative effects of the medical model and the more positive effects of the social model. Waxman (1996, p.239) supports, "...the need to develop a new conceptual framework for appraising the health status of disabled women that recognizes that the fundamental restrictions disabled people face are located in the surroundings they encounter, rather than within the disabled individual."

Nurses are able to offer individualised, specialised care, which is based on the knowledge generated by nurse researchers. An example is the work done by Lindsay (1996) on reconceptualising health and illness. Lindsay (1996, p.465) describes reconceptualisation as calling "...for a transformation in nursing care, from a problem focus and a deficit perspective, to one which focuses on the client's capacity and the promotion of health and healing." She advocates a move away from the problem-orientated view of disability towards promoting the abilities of disabled people.

Because nurses' attitudes, values and beliefs impact on disabled people's lives, they need to be aware of their own personal attitudes, values and beliefs when working with disabled people. French (1996, p.157) stresses, "The attitudes of health professionals are influential in shaping services for disabled people and their life opportunities." One of the purposes of this study was to develop substantive theory from which nurses would be able to gain understanding about sexuality from the experiences of disabled women. The theory has emerged from the information shared by disabled women themselves. This is important as it will both add to the body of nursing knowledge and challenge nurses to think of disabled women as sexual beings.

I am a disabled woman, a psychotherapist and nurse, and a liberal feminist with a constructionist view but I am not a feminist academic. Jones, Marshall, Matthews, Smith and Smith (1995, p.119) wrote of a liberal feminist view that, "... a good society is one which allows maximum opportunity for all individuals regardless of their gender (or ethnicity or class) to develop and exercise their abilities." I believe that disabled women do not experience having maximum opportunity in our society. My personal and professional aim is to make a difference, so that disabled women become fully included and powerful members of society.

This research report is written in six chapters; the introduction, methodology, findings, discussion of the categories, implications and recommendations and conclusion. The introduction provides definitions of terms and discussion of concepts relevant to this study. It also provides the background context of this work. I also position myself in terms of the perspective from which I researched. The methodology chapter focuses on grounded theory and then outlines the specific research I undertook. The third chapter on the findings outlines the research process and how I developed the theory presented in this study. The fourth chapter discussed the categories, which emerged in this research, and how they related to each other. This is presented in a diagrammatic form and represents the theory developed by this research. The fifth chapter discusses the implications and recommendations I have made for disabled women, nurses and society. Finally, in the conclusion I evaluate the research discussing both limitations of the study and suggestions for further research.

Chapter Two

Methodology

In this chapter I will focus on presenting the methodology, and give a detailed account of the process I followed in order to complete this research. To bring this report alive, I have included excerpts from my participants, memos and field notes. The chapter is written under seven headings; Grounded Theory, The Sample, Data Collection, Ethical Considerations, Participant Involvement, Data Analysis and Validity. The basic social process that emerged in this research of the experiences disabled women have of their sexuality is **good days and bad days**. This finding and the resulting substantive theory will be discussed in the following chapters.

Where possible I have included my participant's voices. Their words, written in italics, are powerful and convey their experiences. As Sandelowski (1994b, p.481) explains, "Quoting is for exhibition, not for exhibitionism, and should draw attention to the speaker, not to the researcher." I have also included some poems written and published by disabled women. These are demonstrations of disabled women speaking out about our experiences.

Grounded Theory

Although there has been some research into disabled people's sexuality – there is little from the perspectives of disabled women. Grounded theory methodology provides a framework for this to occur. The method itself is important, because at the end of the research process a theory emerges, which provides something tangible. It is an attempt to make sense of the participants' experiences and honours what they have shared. Glaser (1992, p.16) described the grounded theory approach as, "...a general methodology of analysis linked with data collection that uses a systematically applied set of methods to generate an inductive theory about a substantive area." The strongest case for the use of grounded theory is an investigation of relatively uncharted waters

(Stern, 1995). She also suggests that this methodology is very appropriate where there are complex human situations involved.

I have chosen to use grounded theory methodology because it appears to fit my research question well. My research topic is to gain an understanding of sexuality from the experiences and perspectives of disabled women. Such a topic of investigation looks at social processes which occur within human beings (Streubert & Carpenter, 1995). As Glaser (1992, p.5) described it, "Grounded theory allows the relevant social organization and social psychological organization of the people studied to be discovered, to emerge - in their perspective!" This thesis is written from my perspective as a disabled woman, who follows a social model way of understanding disability.

Two sociologists, Barney Glaser and Anselm Strauss developed grounded theory. Strauss came from the University of Chicago, and was inspired by Robert Park, W I Thomas, John Dewey, G H Mead, Everett Hughes and Herbert Blumer. Glaser received his education at Columbia University and was influenced by Paul F Lazarfeld, Herbert Hyman, Allen Barton, Bruce McPhee and Bernard Bereldson. Glaser and Strauss wanted to generate theory in a manner which both respected and revealed the research participants' perspectives (Glaser, 1992).

The philosophical underpinning of grounded theory was developed from the symbolic interactionist school of sociology. Baker, Wuest and Stern (1992, p.1357) wrote, "Symbolic interactionism focuses on the meanings of events to people and the symbols they use to convey that meaning." Meaning is therefore individual to each person and the most common symbol used to convey meaning is language. Meaning is conveyed through language and developed by social interaction. The more talking people do together, the more meaning is conveyed. Behaviour is studied in context because the language symbols used, and the social interaction of talking, all contribute to the meaning conveyed. Becker (1993, p.257) explained, "Symbolic interactionism is a lens or framework for understanding human behaviour."

Grounded theory belongs in the interpretive paradigm and is concerned with understanding the meanings given to social interactions. From this background arise the philosophical assumptions of grounded theory. Glaser (1992, p.15) described grounded theory, "(1) It is grounded systematically in the data (2) it is neither forced nor reified (concepts which relate to no data)." This means that research using the grounded theory method is based on what emerges from the data gathered. This data is then analysed to bring out categories. Glaser (1992, p.15) continues, "A well constructed grounded theory will meet its four most central criteria: fit, work, relevance, and modifiability." The outcome of this process means that participants will recognise themselves in the theory, and that the theory will change as new data is established.

Maxwell and Maxwell are cited by Stern (1995, p.32-36) as having simplified grounded theory methodology into a five step process. The five steps are as follows:

1. Collection of Empirical Data
2. Concept Formation
3. Concept Development
4. Concept Modification and Integration
5. Production of the Research Report

I will draw from Stern's (1995, p.32-37) discussion to expand each step of the process. I will then discuss my research process more fully.

Step 1: Collect Empirical Data

At step one of the process data is collected, usually by interviewing participants. Other data may be included, such as the researchers field notes, observations or information gathered from the literature. If interviews are done, they are usually taped and then transcribed. The data held in the transcription is then coded. This initial, almost line by line coding is called substantive coding because it is from the substance of the data (Stern, 1995). From here the substantive codes are compared and when they fit together are categorised. This is done according to obvious fit.

Step 2: Concept Formation

At this step a tentative framework is generated. It is an attempt to understand the main processes experienced by the participants and how they cope with them. These are established from the data. As researcher, I had some influence over what problems were given more attention during the interviews. To reduce this bias I had previously written a story of my own experience, which enabled me to focus on my participant. I also discussed my reactions to the interviews with my supervisor.

Step 3: Concept Analysis

The aim of this step is to establish core variables (Stern, 1995). There are three main ways of doing this: reduction, literature sampling and theoretical sampling. Reduction is the process of linking categories. Literature sampling is when literature covering a certain category is scrutinised and concepts are included as part of the data. Theoretical or selective sampling is a process used to develop a hypothesis. Stern (1995, p.36) wrote, "Through selective sampling, already discovered categories are expanded, dimensionalized, and limited." By comparing the categories and reducing the numbers, core variables emerge. At this stage there are loose connections between the categories, but an integrated theory needs to be developed.

Step 4: Concept Modification and Integration

In this part of the grounded theory process core categories have been established. Theoretical coding and memoing are now used to develop a theory. Theoretical coding is the move from descriptive language to theoretical terms. Stern (1995, p.37) described theoretical coding as, "... applying a variety of analytical schemes to the data to enhance their abstraction." For some investigators using diagrams or tables enhances this process.

Memos are notes kept by the researcher during the process of the study. These are ways of keeping track of the developing theory. As a thought strikes, the researcher needs to write it down or it will be lost. The ideas are sparked by the data and therefore considered to be grounded in the reality of the

participants. When these memos are added to the theoretical coding the integration of the theory is achieved.

Step 5: Production of the Research Report

This will be based on the culmination of the previous four steps. Although they have been described in a linear process, this method is not linear. Data analysis begins following the first interview. Memoing is ongoing and literature sampling or theoretical sampling may occur as categories are established. The research report for this study is written as my thesis following the requirements of Massey University.

Although Glaser and Strauss originally developed grounded theory together, they now take separate and different views on how to analyse data. Glaser (1992) focuses on the data. He asks three formal questions; what is the problem for this group of people, what accounts for the most variation in processing the problem, and to what category or what property of what category does this incident indicate? These questions are asked while constantly comparing incident to incident. Glaser allows the data to tell the story so that theory emerges from it (Morse, 1991). I have chosen to follow the direction of Glaser rather than Strauss.

It seems, after reading Glaser (1992), that he and Strauss disagreed about the content of a book written by Strauss, entitled "Basic Qualitative Research". According to Glaser (1992, p.1) the book, "... misconceives our conceptions on grounded theory to an extreme degree, even destructive degree." The two have not been able to resolve their differences. One of Glaser's (1992, p.43) criticisms of Strauss' coding method is that, "Strauss' method of labeling and then grouping is totally unnecessary, laborious, and tedious and is a waste of time. Using the constant comparison method gets the analyst to the desired 'conceptual power' quickly, with ease and joy." Robrecht (1995, p.171) described the result of Strauss' work as, "...the newly enlarged methodological procedures have tended to encourage the production of grounded theory with poorly integrated theoretical explanations resulting from violations of the

original premises of the grounded theory method, in which theory comes directly from data."

The Sample

This study included eight participants. Grounded theory dictates that the number and type of participants relates to the data and emerging themes. The number of participants is stopped once theoretical saturation is reached. The participants in this study were all women who identified as having a disability. All had physical disabilities. The majority were born disabled, one had a sudden on-set disability and another three had a progressive disability. Below is a brief introduction to my participants:

Natalie: 30 years old, single, and heterosexual. She is studying and working part-time. She lives in a flat with other women.

Felicity: early 40s, single, and heterosexual. She does some voluntary work, and lives alone in her own flat.

Ruth: 45 years old, married to David, and has two children. She lives with her family and works part-time.

Donna: 30 years old, engaged to be married. She boards with a family and is studying part-time.

Helen: 20s, lives with her male partner Simon. She is mother to one young child and does part-time work.

Maria: 37 years old, lesbian, with two children. She lives with her children and is currently working part-time.

Cathy: Late 40s, and is married to Paul. She lives with Paul in their own home and works part-time.

Sharon: 40s, Married to Darren, and has one daughter. She lives with her family and is a full-time mother.

I have chosen not to specify any of my participant's disability for two reasons. First, it may be possible to identify the women if too many personal details are revealed. The second reason is that disabled people are often labeled by their

disability, with labels based on medical diagnosis which emphases their impairment. I have chosen not to include this information as a politically motivated stance against the medical model way of understanding disability.

Data Collection

The phenomenon called sexuality is a very broad topic. I was open to the direction the data took me and then maintained a focus on a particular common concept. As this concept emerged I engaged in theoretical sampling. My focus was on the experience of being disabled and the impact this has on sexuality. Glaser (1978a, p.36) in quoting his earlier work stated, "Theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes, his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges."

Initially I used a nominated network, or snowball technique, for participant selection. Morse (1991, p.130) described the strategy as follows:

> Nominated samples are obtained by eliciting the support and assistance of a single informant already in a study to assist with the selection of another participant. The first informant who is interviewed is invited to suggest another participant, and the researcher uses this referral...

The first disabled woman I contacted and asked to be a participant was a woman I had met only briefly. She worked for a disability organisation and I met with her and another woman in my role of psychotherapist. The three of us met in order to discuss some training they wanted me to do in the area of sexuality and disabled people. Following the meeting the disabled woman sent me a card thanking me for my input. I kept her address and made contact with her by sending her a letter and copy of my information sheet (see appendix 1). She agreed to be a participant, and following our interview, I asked her to talk to other disabled women who may have been interested in my research. If any of the women were willing to consider being a participant, I asked her to give them my contact details. This process generated three participants.

Following my third interview, this participant stated she knew of no other disabled women to pass my details or information sheet onto. This is one of the disadvantages of the snowballing method, her lack of contacts meant I had no chance of gaining more participants. At a conference I attended on disability I was able to make contact with other disabled women. During breaks I networked with a number of disabled women and spoke to them about my research. In total three women were willing for me to make further contact with them regarding my research. As a result I conducted a further three interviews.

I decided to use my contacts in the disability field to make contact with other disabled women. Because of the intimate nature of questions around sexuality, I chose not to include disabled women I currently have as friends or colleagues. I asked a male colleague if he would be willing to contact any disabled women he knew and invite them to communicate with me. I had two other disabled women offer to be participants. One of these women lived at least three hour's drive away so I decided to interview her over the telephone, and made notes of our conversation both during and after the discussion.

Ethical Considerations

Informed consent:

Following final overall ethics approval for the project informed consent was sought from the participants. The researcher gave both a verbal and written explanation of the research process. I also provided an opportunity for questions and the discussion of concerns. Participants were offered time to consider their participation in the study before being asked to give their consent. During this time of consideration, potential participants may have wished to discuss the study with their significant others. Written consent was voluntary and freely given.

Informed consent was obtained by the following process:
1. The disabled women contacted me, or gave me permission to make contact with them. I briefly described my research to them. This

included a brief explanation of the aims and a description of the process of my research. The nature of her involvement in the study was also discussed.

2. I then invited them to consider being willing to take part in the study.

3. I sent a copy of my information sheet to them.

4. After a negotiated time period, usually 2-3 days, I telephoned the women.

5. I provided the opportunity for the women to ask any questions and to have these answered to their satisfaction. Then I asked them to confirm their willingness to be a participant.

6. When they agreed to participate, I arranged a time and invited the women to my office, or a wheelchair accessible location of her choice.

7. Consent was then obtained in writing, on the attached consent form (at appendix 2).

Confidentiality:

Participants' anonymity was ensured by the use of pseudonyms of their choice. Transcripts were screened for any reference identifying either individuals or suggestions of individual identity. The transcriber was required to keep all details of the interviews confidential and signed a consent form making this agreement explicit (see appendix 3). Tapes and transcripts were kept in separate locked filing cabinets, with only my supervisor the transcriber and myself having access to them. This report was screened for its ability to retain the anonymity of informants and the information they have given. At the beginning of the study, it was decided that all tapes would be electronically deleted and transcripts shredded following the five-year verification period.

Potential harm to participants:

Participants needed to feel able and safe to describe experiences, which may include details of other individuals and places. It was essential then, that under these circumstances, participants felt assured of anonymity and confidentiality.

Participants did not find it easy to share experiences they have currently and have had regarding their sexuality. Sexuality is not an easy topic to talk about,

especially with a stranger. To ease participants into the interview I first asked them about themselves, and then about what sexuality means to them. These questions were designed to gather information, and also to provide a 'warming up' to the topic of sexuality. It was an opportunity to develop some trust and to enable the participant to get used to me and the tape recorder.

During the interviews participants did feel distressed and uncomfortable at times. While this is not necessarily harmful to the participants, it was unexpected and unpleasant for the participants at the time. As researcher, I respected the nature of this situation as it arose and remained empathic toward the participant. I am knowledgeable about counselling services and would have made a referral if necessary, but this was not needed by any of the participants.

The benefit to participants was that they were offered the opportunity to discuss their sexuality in a private and accepting environment, with another understanding disabled woman. It was possible this could be a cathartic experience. Another advantage for the participant is the knowledge she has contributed to research which aims to benefit other disabled women and health care professionals. The benefit of this study for disabled people is that our experience of sexuality is validated by research and the body of disability knowledge is expanded. This expansion is useful to nurses and other health professionals because it provides them with information, which will help in their work with disabled people.

Due to the sensitive nature of the research topic I also felt some distress as researcher. Because of my own disability and the personal nature of the proposed research question I found my own vulnerability of feeling very compassionate triggered by the stories my participants shared with me. An example from my field notes written after my first interview reads, "Natalie was open and honest. I can feel a sense of responsibility already to do justice to her story. Talking in the way she did was a big move – an illustration of how she has changed." I have good support systems in place and was able to talk about my own discomfort as it arose. I also discussed my distress with my

supervisor, and she was willing to bring to my notice any unconscious issues she suspected were impacting on me.

Participants right to decline:

Participants had the right at anytime to decline answering any particular question, or to withdraw from the study, without providing any explanation. They could have asked for some information to remain confidential and/or asked for the tape recorder to be turned off at any time. None of the participants asked for this.

Arrangements for participants to receive information:

The Information Sheet clearly states that participants have the right to ask for further information about the study during their participation in the study. The Information Sheet also gave the contact addresses and phone numbers of myself and my supervisor, which enabled the participants to contact me if they felt that was necessary. None of them did. Information was also included regarding the participants' ability to contact the ethics committee or the Health Advocates Trust. Informal discussion with myself amplified the information and allowed for clarification.

Other ethical concerns relevant to the research:

It was recognised that discussions with women about their sexuality requires sensitivity and caution. Therefore, I made every effort to be considerate of the participants. Interviews were only undertaken by appointment and these were arranged only with the participant. Ideally the interviews would have been held in my home office, and the participant paid a small sum of money towards petrol or taxi costs. It was not anticipated that this sum would lead to any coercion of the participants. Only one interview was held at my home, the others were completed at the participants' homes.

Cultural Concerns

No specific cultural concerns arose but if they had I would have contacted my supervisor and an appropriate elder or ethnic representative for guidance.

Overall, although some participants experienced brief periods of emotional discomfort during the interviews, no one asked for the interview to stop. None of the participants expressed any long-term difficulty as a result of the interview, and I was available by telephone had any of the participants wished to contact me.

Participant Involvement

Each participant was interviewed on a one-to-one basis. Interviews took place in a private location. Most women chose to be interviewed in their home during the day. One participant came to my office to be interviewed and I provided her with a petrol voucher at the end of our interview so that her participation was at no cost to her. The benefit of coming to my office is that it is wheelchair accessible and I can guarantee privacy. As mentioned, one interview was conducted via telephone at a convenient time and at no cost to her.

The time of the interviews was scheduled to be mutually convenient to both the participant and myself. Most interviews were audiotaped. I anticipated the interviews lasting between 1-2 hours, but was guided by the amount of information being shared by the participant. I was also sensitive to the needs of the participant and asked if they would prefer two shorter interviews. Cowles (1988, p.165) suggests, "Interviews during which the subject experiences strong emotional responses can be physically, emotionally, and psychologically exhausting for both the subject and the interviewer." No one asked for shorter interviews. I was prepared to return for a further interview but have not found this necessary.

I found the interviews to be exhausting. I had to concentrate and be focused on what my participant was saying. I then had to guide the interview so that trust could be built before asking participants to disclose sensitive information. After the interview I took time to write field notes. As a psychotherapist I am used to picking up therapeutic issues during my sessions with clients. I found

myself tempted to "slip" into a therapeutic mode during interviews instead of enabling my participants to share their sexual experiences. I used clinical supervision to talk about the difference between therapy and interviewing. An example from my field notes was written on the 20/9/99 as, "4th Interview. I'm just home and feel exhausted and headachy after a two-hour interview. A good interview but I had to really concentrate. I hope the tape was working because she told me such great stuff."

The purpose of each interview was to encourage each participant to provide me with data by freely describing her experience of sexuality. As this is an intimate subject I took some time with the woman to develop trust and reassure her of anonymity, and her right to stop the interview at any time or to ask me to keep part or all of her contribution confidential. Cowles (1988, p.169) stated, "Subjects who are disclosing sensitive material may also be reluctant to describe their thoughts, feelings, or behaviors fully if they are embarrassed or if they believe that they may embarrass the researcher." My aim was to put the woman at ease.

I was also willing to disclose my own experiences if that enabled the women to share more easily. Carryer (1997, p.99) in her study related to large women wrote, "...Throughout the interviews I shared the insights of my ongoing reading and thinking and many aspects of my personal experience as a large woman." I did disclose many aspects of my personal life with the women, as a way of connecting with them and sharing common experiences. I wrote in my field notes on 4th June 1998:

> Felicity began by talking – lots. She had a major difficulty of being over-protected by her mother. She is very frustrated by this and talked about it a bit. She wanted some info about me so I gave her some brief details of uni [sic] study, house, partner. She asked what Pete did.

I used my skills as a professional listener and observer to make this interview process as positive as it could be.

In order to find out about each woman's sexuality I asked her three broad questions which created a semi-structured interview. These questions are:

Tell me something about yourself.

What does the concept of sexuality mean to you?

What would you like to say about your own sexuality experiences?

These questions were designed to provide the participant with an opportunity to develop some trust with me. The move from the first question to the third allows a gradual deepening of personal sharing. The first question has a general focus, where I gathered some demographic data and got to know the participant a little. Then I moved to asking about their concept of sexuality, which is requesting a cognitive, less personal response than the third question. The third question asked the participant to share her personal experiences. This question is the most potentially challenging and intrusive. I remained sensitive and understanding throughout the interview.

During the interview I was careful not to imply that there is a 'problem' or 'issue' surrounding disabled women's sexuality. My aim is not to suggest a negative or positive experience, or as Glaser (1992) points out to preconceive the emergence of data. I was open to whatever the participants decided to share with me, both positive and negative experiences.

As previously stated, following the interview I made detailed notes of my observations and responses to the information shared with me. These were my field notes, observations, and journal response's which then become data. Here is another example from my field notes written on the 14th March 2000,

> During the interview Maria does the talking – this is her skill and she loves it. She is a passionate woman full of political ideas. She launches into her very difficult and abusive history – she takes over the interview in a "positive" this is my story way. She is considerate of my needs and not over bearing. I like her and wouldn't want to disagree with her.

Most of the interviews were audiotaped. Following each interview the tapes were transcribed, and the transcription became the data. I decided not to ask participants to read and possibly correct their transcripts. The reason is that by following the constant comparison method of analysis themes will emerge

from the data. This means that an individual's data will only add to themes and not detract from them. As a psychotherapist, I believe that people often communicate unconscious data during an interview, which is highly relevant, and having an opportunity to change it may alter the richness of the material. I also noted that Glaser (1995) stated, although not about correcting transcripts, "...constantly correcting is a waste and derailing when one could have just worked on perfecting the emergent problem and its processing." Although not written specifically about transcripts, the correcting principle still applies.

I then checked each transcript for accuracy. I played the taped interview and read the transcript at the same time. I had to make a number of corrections on the transcripts. Sandelowski (1994a, p.312) wrote:

> Transcription and proofing a transcript of an interview against the sound recording and memory (preserved in field notes) of that interview, an essential component of qualitative data preparation, become complex exercises not only in accurately representing what is said, but also how it was said.

The benefit of doing this is not only for the sake of accuracy but also it provided an opportunity for me to become familiar with the data.

Data Analysis

Code:

Data analysis began with the first interview. Glaser (1992, p.19) described the researcher as, "...continually coding, comparing, analyzing and memoing while asking the sole question of the data: What category or property of a category does this incident indicate?" To code my data I read the first statement my participant made in answer to my statement, "tell me about yourself". Her answer became my first codes. As I read her comment I coded each specific idea she was conveying. This became an almost line-by-line analysis. Glaser (1992, p.39) wrote, "Open coding is the initial step of theoretical analysis that pertains to the initial discovery of categories and their properties." The aim is to look for patterns, by comparing incidents to

incidents. The initial codes were *in vivo* words, that is they came from the language that the participants used (Glaser, 1992). Table 1. (p.49) illustrates the connection between the participants' data, my coding and the categories.

Analysis:

I was sensitive to my own experience and personal theories as I analysed the data. My experience was an important part of the data, and I was aware that my own thoughts could inhibit the natural emergence of themes. An important part of my supervision was discussing my data analysis. I focused on the possibility of any forcing of the data. In anticipation of this I had written down my own experience as a way of putting aside my story so that I could focus on my participants' stories. Following the completion of my interviews I analysed my own story. Morse (1991, p.93) observed, "In the situation where the researcher has personal experience, it is possible to become, on occasion, one's own expert informant, being able to focus on both what is happening in the group and on one's own response."

The first interview provided the first new data. My written observations and field notes provided the context of the interview and my thoughts and reflections following the interview. The transcript of the interview provided the next data. Held in the participant's words was information related to answering the research question.

Constant Comparison:

All the information shared was coded. The codes were then grouped into their common patterns and categories emerged. Through a process called constant comparison all the dimensions of the categories were considered. As more data was added and categories were expanded the underlying meanings and abstractions then emerged. As themes emerged, I began to focus my interviews by asking more specific questions related to what I was discovering. This process is called theoretical sampling, which is defined by Glaser (1992, p.102) as, "... the process by which data collection is continually guided." An example of a more focused question from my third interview is, "Well, do you think your sex life is affected by your disability?"

Theoretical sampling continues until the information about a category is saturated, and then integrated into the emerging theory (Glaser, 1992). The process of constantly comparing the categories continued until I found a core category. As Glaser (1992, p.81) explained, "Discovery of properties of a category and its relationship to all other categories over and over again is how we choose the core category." Glaser (1992, p.75) states the importance of establishing a core category as, "Since a core category accounts for most of the variation in a pattern of behavior, it has several important functions for generating grounded theory: integration, density, saturation, completeness and delimiting focus." The core category in this study is **good days and bad days**. This will be discussed fully in the following chapters.

The core category for this study can also be described as a basic social process. Glaser (1978b, p.100) described basic social processes as, "...*pervasive* [sic] since they are fundamental, patterned processes in the organization of social behaviors which occur over time and go on irrespective of the conditional variation of place." That disabled women have good days and bad days, is a process, which occurs over time, and happens wherever the woman is. Glaser (1978b, p.107) discusses the relationship between core variables and a basic social process (BSP) once it is found as:

> By discovery the analyst goes to a fairly contained social unit attempting by observation and interviewing to see as much as possible and find out the most salient social problem of the people there. He then discovers the core variable – hopefully a BSP – that accounts for most of the variation in the behavior about the problem.

Memo:

During the comparison process, I wrote memos. These were my reflections and understandings of the ongoing process and theory as it developed. Glaser (1978b) defined memos as, "… the theorizing write-up of ideas as they emerge, while coding for categories, their properties and their theoretical codes." An example of one of my early memo's is, "14.5.98 Thursday Notes following first interview: Memo= relationship between feeling good about self and

attractive to others i.e. / why would somebody like you if you don't like yourself?"

Table 1. An example of the connection between data, codes and category

Data	Codes	Category
Maria: I ran a workshop for young adults with the condition and at the end of it they said ... one said that for the first time they didn't feel odd.	Being disabled	
Natalie: Yes, in the sense that it probably takes me about three or four times the amount of energy to walk from here to there than it does someone else.	Being disabled	
Helen: But I suppose its only um ... you know ...other people that put limitations on ... or thinking that disabled people are asexual in some way.	Attitudes to disabled sexuality	**Being Disabled**
Natalie: I think that a lot has changed the more I come to terms with my disability being part of me.	Come to terms with my disability	
Helen: Maybe now with a change of government ... well they said they were going to have a Minister for Disabilities, they jolly well better do it.	Disabled People	

Validity

Once I had established a core category I was able to diagram the theory that had emerged from the data (refer to following chapters). To check for validity I interviewed another disabled woman, Sharon, and described my findings to her. Sandelowski (1986, p.30) wrote:

> A qualitative study is credible when it presents such faithful descriptions or interpretations of a human experience that the people having that experience would immediately recognize it from those descriptions or interpretations as their own.

My participant was able to concur with my findings. She made the comment that, *"I can't leap around the bed."* This comment paralleled a comment made by Ruth, *"Yes, like obviously you know, I don't sort of swing from the chandeliers that would be impossible."* Another example of the validity of my research was when Sharon talked about her sexuality being, *" a low priority on a bad day."*

My final check for credibility was to ask another disabled colleague to read my final draft and write her response to my theory from her perspective. Victoria wrote:

> Thank you for the opportunity to read the most recent draft of your thesis. I have watched it develop and felt privileged to be asked to comment on it at this stage. As you are aware I come to it from a range of perspective's; as a health professional, an educator in the tertiary sector focusing on disability studies and sociopolitical issues, a graduate student researching the attitudes of health professional educators towards people with chronic health problems and a person who lives with a disability.
>
> I feel very excited about your work as it puts into place some of the things I strongly believe – and experience. The concept of 'good days' and 'bad days' is incredibly valid. I have heard researchers talk about it and have then had trouble identifying it in their work. I observe and experience the dynamic of good and bad days constantly. I am delighted to see this concept presented in your work and feel that the model you have constructed is superb. On a personal level I find it very affirming.

I think this work breaks new ground and is particularly valid as your wealth of knowledge and expertise, both personal and professional in the field is obvious. I have observed the absolute respect and honour with which you have treated the participants and their experience. This is a tribute to your wisdom and sensitivity.

I have been delighted to see this work develop and to be able to comment on it at this time. The personal insights in it are humbling and very powerful. I wish you well as you submit this work. I think your commitment to this study and understanding of the field and desire to illuminate that which is poorly appreciated to be both brave and timely.

In this chapter I have presented the methodology, grounded theory, as developed by Barney Glaser that I used to guide my research. I then gave a detailed account of my research process, using actual quotes to illustrate the work. The discussion followed the headings of - The Sample, Data Collection, Ethical Considerations, Participant Involvement, Data Analysis and Validity. The sample included eight participants who all identified as disabled women. Data collection was completed by in-depth interviews. I gained ethics approval from two committees and followed all the requirements for ethical standards. Each participant was encouraged, in a supportive environment, to discuss her sexual experiences. The data was then analysed under the sub-headings of codes, analysis, constant comparison and memo's. Finally, this research was verified by a disabled woman who agreed with my findings.

What follows is a discussion of the findings of my research. Glaser (1992, p.111) wrote, "When the sorting of all the memos is done, it is just obvious when to write and what to write about and how to present the integrated picture." The findings include the fact that disabled women are sexual beings. I have written chapter three in a way which illustrates the development of the theory generated as a result of this study. Chapter four fully discusses the categories and the basic social process found.

Chapter Three

Developing a Theory

In this chapter and the next I will present the findings of my research, and how this developed into a theory. I will discuss the process of developing my theory, using my memos and journal entries to illustrate my points. Finally, I will demonstrate, with the use of a diagram, how the categories, which are the basis of my theory, fit together forming the basic social process.

The Process

The aim of using grounded theory methodology is to establish a theory that is based on research data. The memos written by the researcher during the process illustrate the development of the theory. The first memo I wrote followed my first interview and reads:

> Memo = relationship between feeling good about self and attractive to others i.e./ why would someone like you if you don't like yourself.

My wondering at this initial stage was based around the relationship between self-esteem and what is projected out to others. That is, if a person likes herself she will portray a likeable quality to others, this then makes her attractive. Natalie had said things like:

> *But it* (a relationship) *was something that I dearly, dearly wanted but I couldn't see that it was achievable, I mean who would be interested in me...* (and later) *...and there is prejudice and I'm willing to admit that, and I didn't have enough confidence in myself to let the light shine, and I think very much it was my own attitudes reflected. I didn't put it on someone else. I didn't give people a chance.*

At this stage of the research, I had an individual focus on sexual experiences. I was aiming to discover what her individual situation was regarding her sexuality. My thinking was that sexuality was only going to be about individual experiences, not about social experiences. My thinking was parallel with the medical model, an individualistic way of understanding disability.

That is, that sexuality was situated in the individual, not in social dimensions, as I later found it to be.

My second memo was based around thinking about the issues that effect disabled women's sexuality. I had broadened my perspective from thinking individually to thinking about a 'bigger picture'. I wrote:

> Memo = issues around
>
> - Identity – as an ok disabled woman
> - Self esteem
> - Frustration – anger and lack of release
> - Social environment
> - Intellectual maturity versus emotional immaturity
> - Family environment
>
> All affect sexuality.

This memo indicates the move in my thinking from the woman and her self-esteem, to include a broader prospective of the woman in her social context. I had moved from thinking in a medical model way to the social model of disability.

Following my second interview I was concerned about my ability to interview. I wrote in my journal:

> I have to trust this process that it will emerge from the data. I'm not sure that interview was ok. She talked about lots of other things – and sexuality only seemed to involve partners. I raised the issue of feeling attractive to which she replied 'yes' she did feel. I have a sense of incongruence and false bravado or lack of honesty. I'm not sure I got underneath.

My thinking here was around her defence mechanisms, and my ability to get underneath those defences to hear her reality. This thinking is coming more from my psychotherapy background, rather than as a researcher. As a researcher I gave her space to tell her story about her sexuality, and my response must honour that story. What this interview did highlight was when asked about sexuality the participants talked about their lives as well as their sexuality. It became essential for me to include their lives in the theory.

Following my fourth interview I wrote the following memo, "Whenever disabled women talk about sexuality they discuss their relationships." Both my third and fourth participants had been married and spent much of their interviews discussing their relationships. At this stage my thinking was about all women, both disabled and nondisabled, and how sexuality to women is about relationships or intimacy as opposed to men where sexuality is more about the act of reaching orgasm. I attempted to do a selective literature review on this topic but found minimal information. A study by Andersen and Cyranowski (1995, p.903) did support my thinking around the importance of the relationship for women:

> Within the domain of positive affects, emotions such as romantic attachment or love might be considered, as a variety of converging data indicate that for women these feelings are closely tied to sexual affects. For example, there are greater differences in content of sexual fantasies with women focusing on the personal – emotional feelings in contrast to men, who focus on the sexual content per se (Ellis & Symons, 1990); research on women's self esteem suggests that it comes, in part, from a sensitivity and interdependence with others (Joseph, Markus, & Tafarodi, 1992) rather than the more independent orientation common for men; and, finally, women's own judgements about a "sexual woman" describe her as one who is passionate as well as romantic and loving (Anderson & Cyranowski, 1994).

At this stage of the process I felt very unsure of what I was doing. When my fourth transcript came back from the transcriber I realised I had lost half an interview. Llewellyn (1995, p.118) suggested, "Researchers can easily become dependent on using a tape-recorder: disaster then strikes if for any reason a taped account cannot be obtained." All I could do was rely on my field notes for the data, but I was extremely disappointed.

On the 14th August 1999 I wrote in my journal:

> I don't know if I'm asking the right questions – do I need to ask more specific questions about sex – like how do you do it – but that feels too

intrusive – but am I avoiding or focussing on relationships, or is that what they want to tell me about? It's huge and overwhelming at the moment. There are some connections between the women but an overall picture is NOT clear to me. There is something about trusting the process. Others have done it – I guess I will too. One day.

This self-doubt, as a researcher, seems to be part of the grounded theory process. Stern (1995, p.38) commented, "The grounded theorist, then, may seem as confused and frustrated in the midst of the research as any other investigator (some say more so)." It is difficult to trust that the information will emerge from the data. I was very tempted to force the data into producing something that made sense. Instead I continued to code my transcripts and constantly compare these codes.

By November 1999 I realised I had not reached data saturation and was still gathering data to find out about the women's sexuality. My memo reads, "Disabled women are sexual beings – its as simple as that." I was still very unclear as to how to make sense of the data I had gathered but I knew that all my participants had talked about their sexuality and that made them sexual beings. In my journal I wrote: "I have read and re-coded all of my data." I was able to move from 52 codes to 33. I had also written a brief summary of each code. This was a useful process in that I became much more familiar with my data. What I had found was that some of my codes were connected and by comparing them they collapsed together.

Following two more interviews and the data analysis I wrote the following memo:

Memo 29/2/00

Discussing my thesis – came to a point of women didn't really want to talk a lot about sexuality – didn't really seem to be a problem for them but they did want to talk about their "DAY-TO-DAY STRUGGLE" that is money, resources, attendant care, transport etc.

My thinking was that day-to-day struggle might be one of my core categories. When I looked at the transcripts it seemed that the women were spending much more time discussing their everyday struggles rather than sexuality. Sexuality

did not seem to be the problem these women were focussing on. A few days later I wrote:

> I didn't go into an interview thinking that sexuality was a problem. Maybe that's why the women are not discussing their sexuality as a problem? I was very aware of the power I had as the interviewer and my ability to shape the outcome of the research.

My thinking was about the impact the researcher has on the data.

As part of my analysis I was looking at words and attempting to find the right words for my categories. This means comparing the codes with each other with the aim of abstracting a concept from a group of codes. In my journal I made the following note: "Words: resourcefulness, coping – deal with, handle, survive, get by, managing well, living/live." On the 13th June I wrote:

> I now have six categories – a start. I have compared them with Natalie's transcript. It was interesting to note that four of the categories were much frequently used than the other two. At this stage I don't know how these categories fit together. Trust the process!

I had worked with my 33 codes and created six categories. These are:

- Ordinary lives
- Being disabled
- Surviving strategies
- Day-to-day struggle
- Being intimate
- Wanting connection

My codes and categories are illustrated on the following table and form part of the audit trail required for this research:

Codes	Category	Diagram
Schooling Parents Background Growing up Children	Living ordinary lives	Ordinary Lives
Culture Comes to terms with Attitudes to disabled sexuality Being disabled Disabled people	Being Disabled	Being Disabled
My beliefs Personal philosophy Constantly adapting Take me for me Self awareness	Surviving strategies	Good Days
Health Self defeat Shut off Frustration Dependence Rules Work	Day-to-Day Struggle	Bad Days
Virgin Physically it wasn't easy Slept with him Vibrator A gift	Being Intimate	Sexuality
Closeness Wanting support Relationship Talking about sex Just friends	Wanting Connection	Sexuality

Now that I had my categories I wrote a quick definition of each so that I was clear what each category referred to. Taken from my journal these definitions are:

Surviving strategies

> I consider these as ways the women cope or manage difficulty. Examples of turning problems into solutions or negatives into positives. The ability to find good things and experience fun/joyful times – especially when the going gets tough.

Being Disabled

> This is when disability is the particular focus, or when the experience is specific to her disability. When she relates her experience to her disability either overtly or covertly.

Wanting connection

> When the woman describes her desire for relationship. It may not be about a specific person, or may be a more 'negative' position ie/ being lonely, rather than a 'positive' position.

Being Intimate

> This includes physical acts of touching, sexual intercourse, etc. May not be an explicit description but implied eg/ "a gift".

Day-to-Day Struggle

> These are the examples given of the women's difficulties, eg/ home help. At this stage I'm not clear about the difference between being disabled and day-to-day struggle. But its something to do with the overall, general experience of being disabled versus the specific, situational difficulties she experiences daily or frequently.

Living Ordinary Lives

> These are common experiences human beings have eg/ going to school, having parents, being a part of a family – they aren't specific to disability.

After writing these definitions I had supervision and discussed possible ways these categories fit together. As a result of this discussion I drew some diagrams indicating the relationships between the categories. By working with the categories, codes and the original data I was able to establish the basic social process. I was asking myself, what is the central process which describes the patterns of experiences women have of their sexuality? In my working I put the concepts of 'struggle' and 'coping' at either end of a continuum. Then 'being disabled' seemed to be the all-encompassing experience, so it was positioned at the top of my diagrams. My thinking was that 'ordinary lives' was almost the opposite or rather a mirror image of 'being disabled' so it formed the base of my diagrams.

In the centre of the diagram I put 'sexuality'. This category 'sexuality' was a combination of the categories 'being intimate' and 'wanting connection'. It was placed in the centre to indicate that sexuality is part of all women. My diagram at figure 1 illustrates the experience that an individual disabled woman has of her sexuality.

Being Disabled

BAD DAYS   SEXUALITY   GOOD DAYS
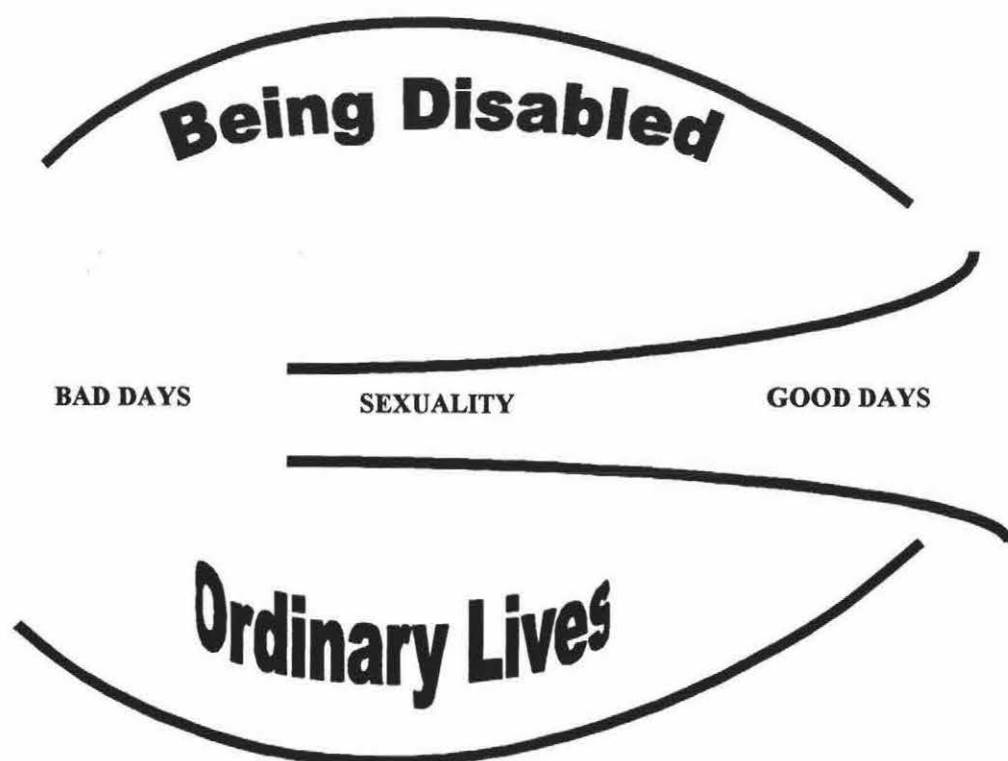
Ordinary Lives

Figure 1: Sexuality as Experienced by Disabled Women.

All my participants had talked about their sexuality in the context of the world. To add this dimension of society I drew a dotted line diagonally across my diagram and used the shape of a triangle to highlight this aspect. This dissected out the way disabled women are seen in society. That is as being disabled and struggling with bad days. It did not include the other dimensions of us as coping with good days, being sexual and as having ordinary lives.

On the 22nd June I wrote the following memo:

> Diagram: A woman is the whole thing – both disabled and ordinary with their sexuality as a core. We all aim to be sexual and so at times struggle and at other times cope. The diagonal line is how society splits us into only being disabled and struggling. Not as having ordinary lives, that include sexuality and the ability to cope/be positive. This diagram is a comment on society.

The dotted line was significant in that not all people in society see us in that negative way, but many do. The broken line indicates that some people see the whole of us. Refer to Figure 2 for the diagram illustrating how disabled women are perceived by society.

Having a diagram is a useful and tangible way of thinking about my research. I displayed my diagram on my fridge door, so that it was something I saw and thought about often. I then attempted to explain my findings to others and get their feedback. I found answering questions and being challenged a useful way to deepen my understanding. To ensure the validity of my thinking and diagram I asked two disabled women to evaluate it from their personal experiences. To do this I had to be able to clearly explain my research and findings. One of the women, Sharon, commented to me that, *this makes sense.* She affirmed my research as fitting with her experience. The other woman, Victoria, wrote the letter of feedback as seen above.

In September I wrote another memo about my core category. I wrote:

> Last night while thinking about my core variable I think I have come up with a name – Good days and Bad days. It seems to me this is what makes a difference for disabled women's sexuality. I think it is similar for all women but the difference relates to what constitutes a bad day. I

am now doing some literature sampling to back up my finding. Feeling excited!

This was an exciting experience as the theory had emerged from the data. I had not expected to discover a theory that related to sexuality in disabled women in society. I had thought I would find out more about definitions and descriptions of sexuality. What emerged is that sexuality is part of disabled women and is influenced by the nondisabled society.

The basic social process that has emerged is that disabled women feel more sexual on good days when compared to bad days. The question that begs to be asked is, what makes for a good day or a bad day? With the focus of this research being on sexuality, I uncovered some of the issues that determine good days and bad days as they relate to sexuality. There are a number of issues that effect sexuality and these are described in more detail in the following chapter.
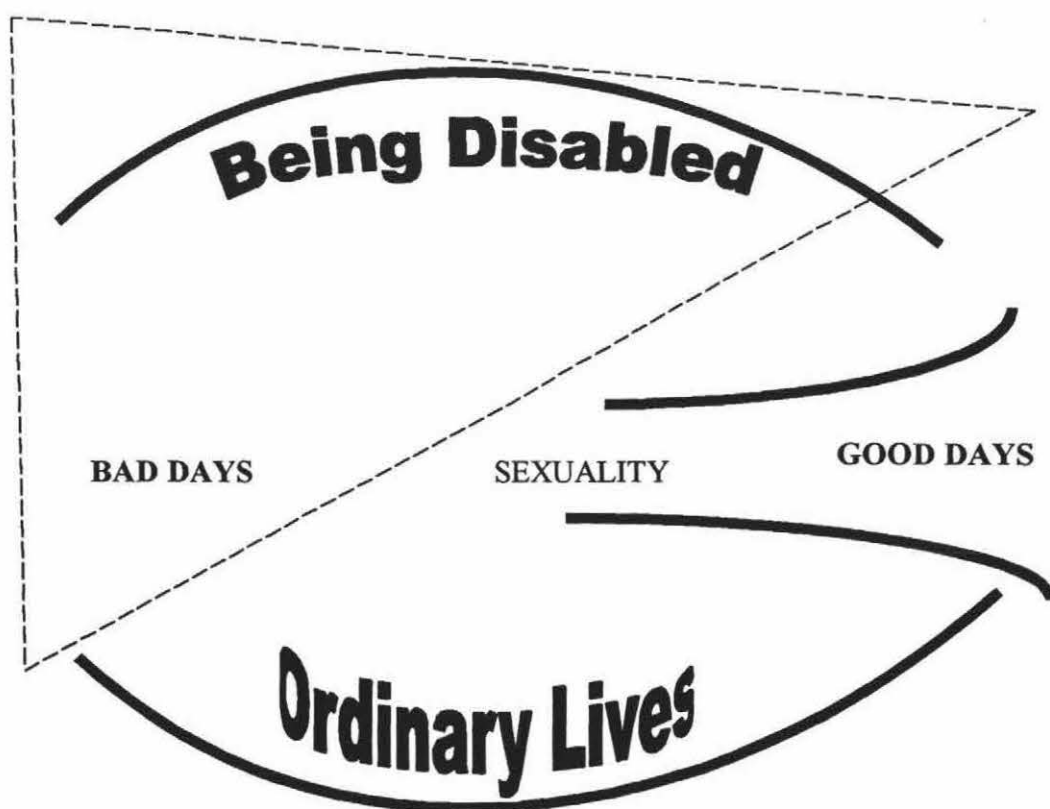

Figure 2: Perception of Society of Disabled Women's Sexuality.

Disabled women are affected by any number of different issues which result in a bad day. For example, under the category of 'being disabled' is the code 'impairment'. An impairment is what is wrong with a body to make it different from the norm. An impairment, such as arthritis in the joints, might result in pain. When that pain is experienced more intensely the person may have a bad day. When the pain is experienced less intensely the person may have a good day, and on that good day they may feel more sexual. Being able to control the pain intensity may also influence a good or bad day. Another code is about the lack of money disabled women have and how this impacts on good or bad days. When women had money and were able to buy what they needed they tended to have a good day, when they did not have enough money, they tended to have a bad day.

The above examples are over simplified, because I have discussed them as a single issue as if an impairment, or lack of money could occur in isolation. For disabled women all the issues that impact on good or bad days are happening all at the same time, and can not be separated out so simply. To refer to the examples of pain and money, pain intensity can vary over the period of a day, as does available money. Once money is spent, it is gone. On a day when the pain is severe, money may need to be spent on medication. The medication may relieve the pain, but the resulting lack of money may mean there is no food and consequently the woman experiences a bad day. Schlesinger (1996, p.254) stated, "Living with pain can drain financial resources, especially if one has inadequate insurance, has to stop or limit working or has difficulty doing certain activities and does not have informal supports to help..."

My diagrams are the visual representations of the theory which has emerged from my data. They are simple and yet illustrate the complex experiences we disabled women have of our sexuality. The second diagram illustrates more than sexuality. It places women in the context of society and shows how disabled women are perceived in a nondisabled society. It is a way of thinking about disabled women's sexuality from a social model of disability.

Discovering the basic social process of good days and bad days meant that two of my categories had merged.

This chapter has outlined how I developed the theory that has been generated from the data found in this study. It described the decisions I made, with examples from my journals and memos. This chapter provides information useful in an audit trail of my research. I have illustrated my theory with two diagrams that provide a two-dimensional, simple view of disabled women's sexuality. The following chapter presents a discussion of the categories being disabled, ordinary lives and sexuality, using the *in vivo* words of the participants.

Chapter Four

Discussion of Categories

In this chapter I will present the three main categories of my theory. This presentation will be illustrated by using the words of the participants taken from the interview transcripts. I will discuss the category, being disabled, under the following headings; impairments, attitudes to disabled sexuality, internalised oppression, access and lack of money. Following that is a discussion on the category ordinary lives. This is written under the headings; mothering, cultures, lesbians, being daughters, having partners or not, and health. The chapter concludes by discussing sexuality as it relates to the basic social process **good days and bad days**.

It is important to recognise that the first outcome of this research was that disabled women are sexual beings. All the women who participated in this study talked about their sexual experiences. None of the women considered themselves to be asexual. Much of the literature suggested that disabled women have been represented as asexual (Morris, 1991; Fine and Asch, 1988). The following are examples of sexual experiences shared by the disabled women:

> Maria: *Well, she was honest in that it gave me a big head, she said I was the best lover she ever had...*
>
> Ruth: *I have a normal sex life. My husband will probably disagree (laughs).*
>
> Natalie: *And it was different from what I had imagined that's for sure. I mean, because of the way I was physically it wasn't easy. It was a challenge in itself.*
>
> Felicity: *The guy that was living here before three weeks ago, him and I actually had an affair for a year and a half, while we were still living next door (laughs).*

Helen: *yeah...well, I feel like... I mean...I suppose... I suppose now there are things I couldn't do physically in bed but ... um... initially there wasn't anything I couldn't do.*

It does make sense that the women who agreed to be participants in this research would share sexual experiences. Kroll and Klein (1992, p.20) mentioned some of the disabled people who responded to their request for information about sexual experiences, "Like Gary, Anne, and Jay, there are millions of people with disabilities who eventually discover they can enjoy sexual satisfaction despite their physical limitations." That disabled women are sexual beings forms the base from which the following categories are discussed.

Being Disabled

All of my participants experienced the process of having good days and bad days. This process affects their sexuality, in that on good days my participants felt more sexual. Being disabled impacts on their experience of good days and bad days. There are a large number of implications that being disabled has on a person's life. In the diagram this was the all encompassing experience lived by the women. Being disabled was considered to mean both having impairment and the social model understanding that we are disabled by society.

This category included experiences that were very individual for the participant through to the social impacts of being disabled in a nondisabled world. It seemed that the participants had good days and bad days related to being disabled. Simply put that means on some days they found their physical impairment more difficult, than on other days. It also means that issues like access to services, lack of money and other people's attitudes impacted on the participant's good days and bad days. As my focus was on sexuality I have considered the difficulties discussed by my participants in relation to their sexuality. Yet sexuality is a core part of our being and can not be separated from the participant's life experience.

Impairment

Having an impairment affects sexuality. I asked Ruth if she thought her sex life was affected by her disability. Her reply was, *Um, yes like obviously you know I don't sort of swing from the chandeliers that would be impossible. Um there are certain positions that I can't get into but then it doesn't seem to matter really* .... She went on to say:

> *And I mean it still works. I can't get on top anymore its far too awkward and I probably did ten years ago but I can't now and I think it actually hurts my leg muscles, some of those positions. So we don't do that any more, which probably he would still like me to do but I have explained that really this is not comfortable for me to do and he is happy with that.*

Ruth enjoys her sexuality within her physical limitations. She and her husband have honestly discussed her limitations and then enjoy each other within those boundaries.

Ruth described being limited by pain. Other women have also written about pain impacting on their sexuality. Erica made the comment in Morris (1989, p.18):

> Pain has been the biggest factor throughout the time I have been disabled. Because the pain prevents me from sleeping, my husband and I have agreed to sleep in separate rooms, as if I lie awake he becomes upset and then he too has a sleepless night. Both of us hate this arrangement but agree it is the most sensible. Pain affects my attitude towards lovemaking.

Schlesinger (1996, p.252-3) in her study on chronic pain and sexuality found, "Nine interviewees explained that pain had affected their sex lives but that they had adjusted." She included quotes from her interviewees: "As Elizabeth put it 'we don't get as wild and woolly as we used to' ... Nan replied, um, its, we make love a lot less, cause if I'm in pain I'm not in the mood. ... As Erica noted 'I mean I couldn't even get out of bed (sex) just was not a priority'."

Donna spoke more about her impairment when we talked about the possibility of having children. She said:

> *In my heart I knew ...I knew that there must be a possibility of me being able to get pregnant and just of the fact of my body ... I mean how could I carry ...I mean there's no way ...where would the baby fit without pressing on my vital organs messing up my system yeah, I wouldn't be able to carry full term. I didn't know if I would have been able to even be able to carry to a term that's safe for the baby, you know, it would be real touch and go.*

Donna knows that because of her impairment becoming pregnant is a huge risk for her. This affects her sexuality because she uses contraceptives but this goes against her spiritual beliefs. She is willing to compromise her beliefs to be sexually active. She spoke about enjoying her sexuality, *its fine for me to enjoy those feelings that I get ...its fine for me... its okay for me to enjoy having my back rubbed and cuddles and kisses and things like that.*

For Natalie her first sexual experience was both painful and difficult. She acknowledges that she leapt at the chance of losing her virginity so that she could fit in: *I wanted to be like everybody else.* She described this experience as:

> *Well, I wasn't relaxed which didn't help and I was too frightened to use the missionary position, so it was from behind, which was quite, I didn't like it, and I found it quite painful. But, I was aware that there was a desire there, but there was a real conflict, a real frustration at not being able to move the way I wanted to. And, I still find that quite frustrating with my second relationship, if I really begin to acknowledge that I am very sexual, we all are to a certain extent. I enjoy it, but there is still that frustration at not being able to do certain things in certain ways to get the real satisfaction.*

Natalie is very open about her frustration with her impairment, in that she can't move the way she would like to. At the same time she enjoys her sexuality.

Maria has found ways to compensate for her impairments. She was in a long distance relationship and had to travel to meet with her lover. She described it as:

> *Like a lot of my lovers have said to me, with my fatigue, they've said, wow how do you have the energy in bed and I tell them I rest all day ...(laughter) you know, I mean I was only having a month at a time over there. Do you really think I wasn't resting before hand? I mean I would grab a months worth of sex, you know ...but it doesn't mean my body was going to be strong enough, or react, but I enjoyed the liaisons we had, they were good*

The pattern is similar. Maria enjoys her sexuality within her limitations and actively finds ways to ensure she has enough energy. She makes her sexuality a priority, and plans to have good times.

All my participants had impairments and were sexual beings. They all found ways to engage in sexual activity and enjoyed it to varying degrees. Helen was the only one who said she didn't enjoy sexual intercourse and she related that to having recently had a baby. She said: *I don't know I've just gone right off it actually ...gone right off it, I can't be bothered actually ...everyone says oh have a baby and then you never want to have sex again.* How much of Helen's lack of enthusiasm is due to her impairment is impossible to say. I suggested at the end of our interview that, "if you had someone [to help you] for a couple of hours a day maybe you would have more energy and feel more, you know enthusiastic in bed for example." Her reply was: *Well that's true, that might work.* The doubt relayed by her response indicated that sexuality was very low on her list of priorities and even thinking about options was too difficult.

A disabled woman, Pam Herbert, was quoted by Davis (1995, p.127) describing her wedding night:

> It was time for the biggest moment of my life, making love. Of course I was a little nervous and scared. Mark was very gentle with me. He started undressing me and kissing me. We tried making love in the normal fashion with Mark on top and me on the bottom. Well, that position didn't work at all, so then we tried lying on our sides coming

in from behind. That was a little better. Anyway we went to sleep that night a little discouraged because we didn't have a very good lovemaking session. You would have thought it would be great, but sometimes things don't always go the way we want them to. We didn't get the hang of making love for about two months. It hurt for a long time.

Pam's description again highlights the impact an impairment has on sexuality. She uses the words "normal" to describe the missionary position, and how that didn't work for them. She must believe that the missionary position is the normal way to have sexual intercourse. They had to experiment, having some bad days until they got the "hang of making love" and had good days.

Ellen Stohl is an American disabled woman who has appeared in Playboy magazine. Kroll and Klein (1992, p.85-6) quote her speaking about her sexuality:

I'm an adventurous sort, but being disabled is a strong deterrent to spontaneity. For bladder control, I need to wear protective undergarments, which make me feel about as sexy as a toad. Also, since I am supersensitive in the genital area, the feeling of impending orgasm is much like the sensation of having to pee. So often, when I'm close to climaxing, I almost stop myself. I've read studies that show this feeling is common in many women, but no one ever discusses it. These embarrassing fears tend to limit my sexual activity to my own home or a place where there's a bathroom that's wheelchair accessible. Sex on the beach, in a car, or a quickie at the office is just not in my repertoire.

Ellen has learnt how to manage her impairment in a way that means she enjoys her sexuality.

A poem by Batres (1996, p.59) offers a summary for this section on the impact an impairment has on sexuality:

Poem To A Body

Small, twisted and deformed: such is my body.

Incapable of inspiring a love poem.

Incapable of setting fire to a night of passion.

A man once said to me:

"Your eyes are beautiful."

He did not want to add:

"In spite of your body."

Do you want to know something?

That body,

Small, twisted and deformed:

It is mine and I love it,

I have no other!

Attitudes to Disabled Sexuality

Many of my participants discussed perceptions nondisabled people have of their sexuality and the resulting impact on their lives. Other people's attitudes often had a negative impact on disabled women. These negative attitudes compounded the experience of having a bad day. As Maria said: *We can live beyond our disabilities, you don't need to fit within the medical construct and part of that is our sexuality, it's very much a part, because sexuality is one area that able bodied society denies us.* Helen's comment was: *I suppose its only other people that put limitations on our thinking that disabled people are asexual in some way.*

Felicity spoke about her difficulties, particularly with her mother's attitude towards Felicity's sexuality. Felicity said:

A bit later on, then when I finally did meet somebody awhile ago, and we were engaged for several years. This came as a total shock to my mother and to his mother, and to prove how serious we were about each other we ended up sleeping together several times and it was to

them "oh my god", well, you do it Mum, and other people do it, its quite normal is it not? "But you've got ..." Yes, I know I've got, I was born with it, so I can live with it. So why can't I ... The fact that he had a disability like I've got and when there was sexuality mentioned it was like you just can't. Yes I can. If I want to I will. I am at the age when I can actually, you know, I don't have to have anybody's permission to do anything you know...

She later spoke about the possibility of having children:

Yes, I have many times thought about having my own. If it ever did happen, I wouldn't tell my mother until it was far too late, cause if I told her too early, then she'd do everything she could possibly do, or the whole family would try ... and talk me out of it, although they have all done it themselves.

It is possible that the attitude Felicity is describing is based around a difficult mother-daughter relationship, but Felicity knows the difficulty is due to her disability.

Maria spoke more generally about these issues, rather than from her personal experience. She used the following example to illustrate her point:

Well, if you look at how people address sexuality generally for people with disabilities, at the genders... Males, it's a problem, okay it's a problem, they have got a problem. If you are a young guy, tetraplegic, end up in the spinal unit and they say 'what about how I perform with my girlfriend?' 'Oh be quiet. Is that all you think about ... you think between your legs. You've got a problem.' ... Females are seen as asexual ...as not having a sexuality...so you see we have a difference there. So with men it's a problem. So if they are married, 'oh isn't that lovely, that women's going to care for him ... he's got somebody.' With women ... 'oh she's got nobody. Whose going to want a disabled woman?' ...We're asexual, we do not have sexuality, we do not have needs...

Maria is very politically minded, another of her comments about our sexuality was: *it's a basic human right and it pisses me off its not seen as that.*

In a book of disabled women's writings Keith, (1996, p.147-8) included a piece by Millie Hill. Millie wrote about her experience of being attracted to a man, and then being confronted by a woman who said,

> 'But really, love, don't you realise that you are making a fool of yourself, wasting your time sitting here every day all day waiting to see that boy? Don't you think that being the way you are no man will ever want you? You'll never have a boyfriend, love, and no man will want to marry you. Besides which,' she added, 'people like you can't have babies. I'm only telling you this for your own good, love, so you won't get hurt.'

The attitude of this woman was devastating for Millie. Kroll and Klein (1992, p.36) wrote, "Nowhere is rejection by the nondisabled society more evident than in attitudes about sexuality of the disabled, and, naturally, these negative feelings have a profound effect on quality of life."

Internalised Oppression

Disabled people's own attitudes also affect the way we feel about our own and other disabled people's sexuality. This concept is called internalised oppression, whereby we oppress ourselves with the negative prejudices we have been socialised to adopt (Shakespeare et al., 1996). Simply put, disabled people often don't like themselves or other disabled people. Helen spoke about being at a sexuality workshop for disabled people and, *the number of people at this workshop that wanted to have a relationship with an able bodied person, not another disabled person.* She went on to say that some disabled people she finds quite attractive but they don't consider themselves to be attractive, *yeah, so I think some of these limitations are self imposed.*

For Maria the idea of being in relationship with a disabled woman was quite challenging. She said:

> *Do you know what really shocked me recently, was how would I be if I started a relationship with a woman who is disabled? And, I think my god I've never thought about it, because I've been moving in and out of*

an able bodied world, and I've expected able bodied people to accept me fully for who I am, to get to know me. Now I haven't actually come across other disabled lesbians, so I don't know what the scenario would be. But I was struck by the thought god, would it be an issue, and I don't know ...I have to be honest, I don't know...and I think my god, I'm so busy asking that able bodied accept us, that I forgot about asking our own community to accept us.

For some of my participants this was not an issue. Two of the women had been engaged to disabled men, and one had married her fiancé. Donna spoke of being in a relationship with a disabled partner: *I mean, with my husband because of his disability he wasn't able to physically caress or touch without me putting his hands on my body or where he wanted his hands.* She went on to talk about the importance of communication in the relationship:

I think its being able to communicate and the whole communication and being able to talk openly and freely about what's on your mind as well as just the practical side of things. As well, like just the giving and the affirmations because I think if you are getting that, I know for me if I'm getting that from my partner, then sexually you're more responsive.

Both these women were attracted to other disabled people.

Another aspect of social attitudes is that disabled people are often treated like children. This is another way of society denying our sexuality. Maria made the following observation:

I was actually watching a woman yesterday in town here, an adult woman, maybe nearly forty, in an electric chair, scooting up and down ...and I thought my god, she looks comical. Now you know why? She had pink bunny slippers on her feet. I thought for god sake, dress yourself as an adult. People are going to be attracted to the person. But once we educate society about disabilities I think it would break down more barriers. But one of those barriers is ourselves, and our carers, and how we are presented and how we present ourselves.

Being over protected is a way of treating people with disabilities like children, and denying our sexuality (Shakespeare et al., 1996). This was an experience that some of my participants had had. Felicity said: *I've often found that living with a large family I was also protected an awful lot. And a lot of things they knew at the age they were supposed to know I didn't.* Felicity was treated differently compared to her sisters. Natalie made the following comment about a time when she was in a relationship:

> *Mum was okay with it but she was worried I was going to get hurt. When I did eventually mention it to some of my closest friends that was what they were afraid of, but I realise now that that is a big part of my growing up, a big part of bringing my emotional maturity, in line with my intellectual. I always felt that I didn't kind of go through puberty or, I did in a physical sense but not in an emotional sense, I didn't go through the first date, first kiss relationships, even talking to girlfriends about periods things like that.*

Taking risks is a normal developmental process of adolescence. From taking risks we learn and grow from our mistakes. Thorton (1981, p.28) described her difficulty growing up, "My parents did not understand how to help in this process; instead, as is common, they were overprotective." Disabled people are often protected from making mistakes, and considered too fragile to be hurt.

Sex education was another area where disabled women were treated differently. Shakespeare et al. (1996, p.22) wrote, "Teachers, parents and centre workers seemed often to place low priority on sex education, or to convey the bare minimum facts, or to protect disabled people from information which was felt to be inappropriate." Natalie had her first sexual experience when she was 24, she doesn't remember being told anything specific about her sex education. Felicity felt that her sisters were told things about their sexuality and she wasn't. On the eve of her wedding Donna asked a friend to tell her what happens to a male body during sex. She went on to explain:

> *Yeah, she described it, I couldn't believe it, naive me, but he was really good, but he knew I had no idea, I mean he did well considering he was*

very sexually active you know, ...we didn't make love on the first night
of our wedding, the second night we did. He was all right with that, he
gave me the space to ... I hadn't even seen a penis in my life before ...
and I was 26, 27 ...I hadn't even seen a male body.

For Maria the first sexual experience was abusive. She said:

I was never educated in sex at all ...in any way ...just to be suppressed,
not to be celebrated, so I was raised without any knowledge and nuns
are not good role models you know ...I'd been getting abused from the
age of three by my cousins, I didn't even know it was abuse, I was so
completely unaware of it ...I accepted it as normal.

Inadequate knowledge about sexuality seems to affect all women. Hyatt and
Riederle (1994, p.613) found that, "... by the time many women have their first
sexual experience in adolescence or adulthood, they may have already
incorporated incomplete, stereotyped, and clearly false information about their
sexuality from a variety of sources." If this is true for nondisabled women, it is
possible to speculate the situation will be worse for disabled women.

Access

Access has been discussed in terms of access to services and in terms of
physical access in the environment. Access is another huge area that serves to
create bad days, especially when disabled women do not have access to the
services they need. This was a common issue for most of my participants.
One important area of service is attendant care and home help. Shapiro (1993,
p.254) wrote, "Personal assistance, in the eyes of the disability rights
movement, is an item of social liberation – just like a light-weight wheelchair
or a bus lift – not a form of medical care." Simply put, attendant care is
attending to the personal, often physical, needs a disabled person has, while
home help is attending to the requirements of maintaining a home, for example,
cleaning and laundry.

For Felicity the difficult issue was around her eligibility for home help support. She was contemplating getting another boarder into her flat but would lose her home help unless her boarder was on the invalids' benefit. She said: *The boarder has to do the housework if they are on their feet.* She was angry about the unfairness and that this rule made her dependent on the border. She felt stuck and didn't know what to do. She was considering ringing the Human Rights Commission, but then thought her social worker may be able to help. Felicity also spoke about difficulties she was having with one of her home care workers, and the inflexibility of the rules. Felicity doesn't feel safe being around the worker but has been told she must be at home when the worker is there. Again she feels powerless to control the situation.

Ruth is not eligible for any home help. She would like some help especially around the house. She said:

> *It would be wonderful to have a carer but we can't afford it and we don't get any help. I've actually got a friend who comes on Fridays and vacuums and washes the floors and changes the sheets for us. I mean my husband could probably do those things but he works full-time and he has also got a secondary job and I just wouldn't expect or I don't think its fair so I pay her $20.00 a week to come and do those things. Because I mean I can wash the kitchen floor but I can't really go too much further than that and I can still vacuum but its hard and I can't get the vacuum in and out of the cupboard, its just little things like that.*

Ruth is able to pay a friend to help with some of her basic cleaning. But she attempts to do as much herself as possible. She also minimises the impact of not being able to do these things. She often called them little things, as if it didn't really matter that she couldn't do them. These were ways of turning bad days into good days.

Helen is also in the position of not being eligible for assistance. Her way of turning this bad experience into good is to push herself to do as much as possible. But her lack of having any help means she is very dependant on her partner. She said:

> *My arms aren't very strong so like, bathing the baby, bringing up the*
> *washing, bringing up the groceries, all those sorts of things that I can't*
> *do, so he has to do all of that which I am really conscious of ...you*
> *know I think it puts a bit of a strain on a relationship where one ... I*
> *want to do ...the thing is with me is that I want to do it but can't ... and*
> *the thing with him I think is that he doesn't want to do it but he can.*

If Helen had someone else she could ask for assistance and was then able to pay, she would be empowered rather than her current disempowering situation. It could also mean that she may be less exhausted and ultimately feel more sexual.

In Canada Judith Snow was instrumental in changing laws, making the government provide attendant care for those eligible. In the book written about the process Pearpoint (1992, p.126) quoted Snow:

> I was living in a chronic care hospital not far from here. I use the term "living" loosely because in fact I was dying from a combination of malnutrition, overdoses of prescribed drugs, and a sense of hopelessness born of ten years of fighting without success to get needed attendant care.... Within three months we had the first contract in Canada for an individually funded attendant care programme. ... Today there are hundreds of individually funded arrangements across Canada, standing as a witness to what will be the ordinary way to fund attendant care some day.

Sharon uses a number of caregivers to assist her. She has 45 hours paid for per week to help her with both personal care and home help. This is managed by an agency, so that if a caregiver doesn't work out the agency is responsible for providing another. Sharon said that making friends was an important aspect of getting along with her caregivers. They need to *fit in the house*, and must be comfortable and open. Sharon explained that if she had something private to discuss with her husband she would simply ask the caregiver to leave them alone for a while. Cathy also has caregivers. She used to rely on her husband but this put a strain on their relationship and now she relies on other people to be her caregivers. Cathy talked about how her husband copes better with her

body than she does. If he does something very personal like assisting with bowel care, she feels very uncomfortable. He assures her that he is fine, but *it's awful afterwards* for Cathy.

Maria is in the process of looking into getting a carer. She is concerned about how this will impact on her privacy and sexuality. She said:

> *Its like my issues at the moment of getting a carer, and I know how hard that is going to be for me to actually let somebody shower me when I'm unable to do it myself, um ...and allow myself to have that done...and I can joke about it because when I did joke about it with my ex the other night and I said, oh well I guess I will just lay back and say "come here" you know, she will ... but it's a serious move ...it makes me extremely uncomfortable ... what about if I need ...say my hands get that much weaker ... and I need to have something for a vibrator or say I can't do that and I need my carer to get it out for me and set it up and get it ready for me ...you know those are very personal things.*

Maria is anticipating that she will need the help of a carer at some stage and knows that will not be easy for her. To help make this possible bad day easier she jokes about it, and attempts to turn it into a good experience with a sexual innuendo. Yet she knows the reality will be difficult. Morris (1989, p.48) explained, "Other women, whether married or single, have gained strength from recognising that they would rather use the help of others in day-to-day living which has then enabled them to spend time and energy on working outside the home, on political activities, in community involvement or leisure activities."

Physical access of the environment is a major contributor to our good days or bad days. Beatson (2000, p.106) wrote, "The situation of the biologically impaired individual in a world that has been generated by both nature and society for the able-bodied can be summed up in the term 'alienation'." Beatson goes on (2000, p.108), "Each specific type of impairment, of course, brings its own particular problems, but most disabled people are alienated in one way or another from their physical surroundings." The result he writes is, "With training, practice, patience, drugs, technological aids and planning,

people with impairments may over come obstacles and outwit the intransigence of objects, but the battle with things is never-ending, seldom allowing the luxury of spontaneous, unpremeditated movement."

Helen described this experience as: *You know, the whole disabled access thing is such a nightmare.* Maria offered the following example:

> *I went to a new movie theatre but even the security staff there at the time didn't know there was wheelchair access around the back ...so they carried me in ...how embarrassing is that ...I get in there and someone tells me its round the back, where's the signage?*

Access into public buildings also affects disabled people's chances of meeting prospective partners. Again from Maria:

> *Maybe I could go out and just have sex if I just wanted, but it would be a lot harder for me now, because of 1) getting into a night-club and meeting people, um ... even the coffee shops meeting people, if you are a heterosexual its not such a big issue, if you're gay, lesie and I know many with disabilities who have never been nightclubbing, or they can't get to a poetry evening or writing evenings or women's evenings because they are in an inaccessible building. How can we be part of a community if they won't embrace us? That's a big issue.*

Shakespeare et al. (1996, p.29) wrote, "All the facilities which are taken for granted by non-disabled people are likely to present barriers to disabled people, including housing, employment, transport and leisure facilities." They go on to say, "Not only does this affect disabled people's educational opportunities and income potential, it also restricts their social life, and particularly their opportunities to find partners."

The result of inadequate access for disabled people is as Helen put it:

> *Well, you end up going and everything is frustrating, you end up never going to the loo for the whole day because the toilets are no good and ah it's just hopeless really. But that's the awful thing when you get out of your own environment, which you've got perfectly set up for the way things are for you and its all very nerve wracking and you go out there and nothing ...nothing is ideal at all ...makes life very difficult.*

The choice around lack of access for disabled people is to go and attempt to turn a bad day into a good day or not to go, and attempt to avoid the bad day.

Lack of Money

Money is another area where disabled people are disadvantaged. As Morris (1989, p.34) described, "In many ways, an inability to meet the increased costs has a more dramatic and fundamental effect on our lives than the disability itself." Maria is highly educated but is unable to find employment. She is physically unable to work full-time but can not find a part-time position. She said: *I went in for my first ever food parcel after ten years on the Invalids Benefit ...why can't I get work ... I am productive, I can be ...you know, many of us are not productive, ...75% of us live below the poverty line.* Blanche (1996, p.266) defined:

> The culture of poverty is based on deprivation or the absence of something, but it also affects the person's interactions with the physical world, creating a mind-set and system of social relations with a set of values, attitudes, and modes of behavior and lifestyles (subculture) that are different from that used by the economically more advantaged group (dominant culture).

Disabled women are often part of a poverty subgroup.

Helen works four days a week and yet is unable to get financial assistance so that she can get a car. In her words:

> *Either you help people in a small way to keep on with their employment or you do nothing and they will sit at home and you know receive a benefit ...nobody wants to do that ...I mean what gets imposed on people because the alternatives are too difficult or the funding isn't there for them to do anything else.*

Natalie is currently studying and on a benefit. She feels guilty about being on a benefit, she said:

> *But in a way I have been very hard on myself and I have some good friends who have said, look what you are doing is just as valid and my*

intent on being on the benefit is to give something back so I spend a lot of time talking to people about work experiences and wanting to contribute in some way.

The difficulty accessing services also relates to a lack of money. Ruth stated that she couldn't afford to pay for home help.

Ordinary Lives

Disabled women also have roles that are part of being members of society that are not necessarily related to their disability. Although it is impossible to literally separate a person from their disability, this concept is part of the theory and needs to be recognised as such. Disabled women are also daughters, partners, wives, aunties, cousins and mothers. We have roles such as workers, students, home owners, drivers, cooks, cleaners, community members, and church attendees, to name a few. These are our ordinary lives. Quigley (1995, p.782) found, "...that in spite of the ramifications of a spinal cord injury, the participants occupied multiple and various roles such as worker, lover, athlete, student, volunteer, family member, and employer." Schlesinger (1996, p.254) noted, "In many ways, living with a chronic illness heightens aspects of everyday life that *everyone* [sic] may experience at one time or another."

Mothering

Four of my participants are mothers, while the other four are not. Three of those four, who were not mothers, related this choice to their impairment. The other woman felt it was a choice she had made at this stage, but appeared to be open to having children at a later stage. In their introduction Wates and Jade (1999, p.3) wrote about disabled women as mothers:

Until now, silence has played a quiet, but significantly undermining and destructive, role in the relationship between disabled women and parenting. This anthology contains many examples of that silence in the lives of contributors; from the silence of health professionals who

provide nothing by way of pre-pregnancy advice but appear on the scene at the discovery of pregnancy and urge disabled women to have abortions; to the silence that disabled mothers feel constrained to keep when facing difficulties, for fear that someone will take their children away. [sic].

For Natalie the possibility of being a mother, as part of her ordinary life, does not seem possible to her. But she describes herself as, *I mean I love kids. My comfort in a sense was being able to be an auntie. A lot of my friends have kids and I help out a lot in that way.* Felicity would like to have children in the future, but in the mean time is involved with her neighbours' children and volunteers at a school. She described this: *I um talked to kids at school, what its like to have a disability, you see, and when I say to them you can ask me anything you like. And they go, "can you have sex?" and I go, "yeah" and then I go, "don't go any further down that track." They go, "why?" and I say, "that's my business how, why and when."*

Ruth described herself as; *I've been married 16 years. I've got two children. One I had before I was married.* Becoming pregnant with her first child has had a significant impact on her life. She described this time in her life:

> *I was pregnant. It wasn't planned. It was a mistake and I didn't actually tell the father about it. We had stopped seeing each other. It wasn't a lasting relationship. We'd only gone out a couple of months and he'd stopped ringing. I was pregnant. I can't see the point. I looked at having an abortion but in those days it was extremely difficult. And I didn't have any moral issues about that, and I tried several doctors who said, "Oh hell". I had to tell my parents. That was really hard and I was knocked off the pedestal that they had me on. And I got sent away to have the baby and she was to be adopted out.*

For Ruth this was a major life experience, but it had nothing to do with her disability, so for the purposes of this research it was considered to be part of an ordinary life experience.

Helen is the mother of an infant. During our interview she fed the baby, cleaned it and rocked it to sleep in her arms, all part of her ordinary life. Helen lost her parents in an accident a number of years ago. She talked about the impact of this on having a child:

> *Yeah, this was actually my parents house um ... they were killed ...which was the other major reason for ... for thinking that I didn't really want to do all this child business, because we were such a close, close family and they were like my ... you know ...my main supporters in life basically and I thought I can't do this. I can't do this without them. ...Yeah, and I think, you know, if they had been here, there just wouldn't have been any sort of doubt in my mind, you know, it would have been all wonderful and sweetness and light because they would have been thrilled.*

Again, this major life event had nothing to do with Helen's disability, so is considered to be part of her ordinary life. She is living and bringing up her child without the support of her parents, as many people do. Maria is also a mother. She talked about being a mother briefly: *I'm lucky ...I've got a child.*

Rosangela Berman-Bieler (1999, p.37-8) wrote encouraging disabled women to make the choice to be mothers, like she did,

> If you are a disabled woman, from any culture, with the desire to have or adopt a child, go ahead. It is your right. Of course you, as an adult and a responsible person, have to be in control of this decision and evaluate when it is a medical risk. Don't leave this decision to somebody else to make or for society to judge. Take for yourself the very enjoyable responsibility of exploring all of your human and social roles.

A positive experience of mothering was written by Paula in the Morris (1989, p.131) book. She described, "Being a mum in a wheelchair is great. It was not so for me at first because I had a lot of adjusting to do emotionally, and to find out who I really was."

From a New Zealand perspective Sandie Waddell (1992) wrote a book following some informal research she did with 23 disabled women who had

had children. Waddell included a quote from a participant when she had first delivered the news of her pregnancy (Waddell, 1992, p.17):

> The attitude of people around me was quite horrific when I became pregnant and my family just couldn't believe that this was a planned pregnancy and that I really wanted to go through with it and they kept talking about abortions, even when I was seven months pregnant – that was the most heart breaking reaction. (*Polio mother*) [sic].

Writing of her own experience as a disabled woman Waddell says (1992, p.17), "Fortunately reactions to me when I broke the news of our first was sheer delight on the part of both our families and a combination of congratulations and dropped jaws (I didn't realise she could…) from my work colleagues."

Culture

Two of my participants are Maori. One said, *I do know who I am now and do know my whakapapa … and that is who I identify with.* This was a very important part of her life. It is part of her ordinary life, as being Maori has nothing to do with being disabled. Little is written about the experience of being disabled and from a minority ethnic group. What has been written focuses on the triple disadvantage experienced by women of colour who are disabled. Ayesha Vernon (1996, p.50) wrote of one of her experiences, "My experience of racism started when I went to my first residential school for the blind which was all white apart from myself and an Asian boy. There I experienced physical and verbal abuse from the children and less favourable treatment from some of the staff." She continued (1996, p.51), "In employment I have experienced disablism, racism, and sexism."

Being Lesbian

Maria identifies as disabled and as a lesbian woman. Shakespeare et al. (1996, p.153) notes that, "While we have argued that disabled people are all too often seen as asexual, it is also the case that there are heterosexist assumptions that disabled people cannot be lesbian or gay." Maria explains:

I knew at 18 that I'd started having feelings for women, I knew that they were a little bit more than friendship, at 17, at about 16, I think I started ...it was all closeted back then, and the groups were all held in homes and you didn't ever publicly show it. I never had a girlfriend at that stage but I would be besotted by these older stronger feminist women, I mean they were so powerful and I was so ohhhhh, you know, wow, and it wasn't a sex thing, it was actually the concept of the person, I've always loved an intelligent mind, it's the biggest turn on in the world.

Being Daughters

All the participants discussed their parents to varying degrees. Some had had supportive parents while others described themselves as coming from dysfunctional families. Some of the comments were:

- *My father was a very ill man, he had strokes and stuff*
- *My mother is an alcoholic and always has been*
- *I came back to look after Dad, help look after Dad*
- *Mum said when I was little they wanted to do lots of tests on me, but Mum and Dad said no*
- *I am a very intense person, my Mum will tell you that straight away but there was a lot of stuff going on between my parents that was difficult in itself*
- *My father doesn't treat me as if I have a disability, like the rest of the family, they don't. But that's where my mother is, she is making me sort of feel like, I know I have a disability, and she is making me more aware of it than I really need to be.*

These examples all indicate the different experiences of being a daughter. Being in the role of a daughter is part of their ordinary lives. Some times being a daughter makes for a good day and other times for a bad day.

The relationship between mothers and their disabled daughters is an area that requires further study. Felicity described her difficult relationship with her mother:

> ...if I was like what my mother wanted me to be or wants me to be, I would actually end up doing nothing because at the moment she, must come round to the house, and she expects me to be here. There is no phone call or nothing to check that I am here or that I'm on my own or whatever and that's something she won't do I know she doesn't do that to anyone else, but she'll do it to me.

This relationship was also discussed in Pearpoint's (1992, p.99-100) description of Judith Snow's life:

> (Judith) became increasingly dependant on her mother and father to take care of the physical needs she was unable to accomplish herself. Thus, from a very early age, Judith had a dual relationship with her family, and her mother in particular there was the role of mother, but also the role of 'attendant'.

The difficulties of being dependant as a child and then becoming independent as an adult are complicated when the child grows into adulthood with an impairment which results in a level of dependence. The parent may feel protective, while the disabled adult may feel smothered, as in Felicity's example.

Having Partners or Not

Felicity would like to have a partner. The man she is currently involved with is married and she is not sure if this relationship is going to build into something more permanent or not. She described it as:

> I would (like a partner), but this one I know I can't have anyway, because there are obvious reasons, his wife, that makes it a wee bit tricky not that I, I don't know whether I really would want him full-time anyway. I don't know, I mean why because I hardly see him at all anyway. I can't even judge, choose whether I'd like him as a full-time partner or something less. Like once in every four weeks.

In Felicity's ordinary life she is choosing whether to be involved in a relationship or not. Schlesinger (1996, p.254) concluded that, "Coping strategies used by the women included decisions not to be involved in relationships or to take responsibility for defining sexual limits and desires with partners." Natalie would also like to be in a relationship. She described the one she had been in as a gift from a good friend that had taken her *a lot of work to let him go.* She has not had a significant relationship since then.

Donna is currently in a new relationship. We spoke about her first crush:

> *My first crush was this guy called Harry ... oh he was good ...it was a painful crush for me ... you know ...so painful ...I don't know how I got over him, I must have got over him ...because it wasn't long after I'd got over him that I went to this fancy dress ball with the Youth Group and I got all dressed up as a princess in a white gown type thing ...and um... Harry was something else and he walked through the door and he dropped to his knees and he took my hand and he said, "Donna will you marry me?" Ohhh I was so pleased I was over my crush.*

This experience, our first love or having a crush on another person, is common to most people and part of our ordinary lives. Again this experience has nothing to do with a disability, and results in both good and bad days.

In Pearpoint's (1992, p.73) book he wrote about Judith Snow's relationship:

> True, Judith and Laurence are separated and they have discussed divorce – just like half of all modern marriages in Canada. But I don't see why that turns into, "they shouldn't have married." Judith and Laurence are adults, over 21 and consenting. They knew the risks. They also deluded each other equally into believing that "the other person" would change. None of this is original. It happens with almost every new couple. They have the right to make responsible mistakes – just like the rest of us.

Fine and Asch (1988, p.14) quote a study which, "...found that only five of the forty-five women she interviewed were married, and more than half reported no sexual relationship since becoming disabled."

Morris (1989, p.81) in discussing disabled women has suggested, "The assumption is often made that, if we do not have a partner, our single state must be something which has been forced upon us rather than positively chosen." While celibacy may be a choice some disabled women do make, none of the participants had chosen to be celibate. Maria, however who had recently separated from her partner explained:

> *But I personally don't want just sex anymore, I can meet my own needs, I love myself enough to know that if I... if I'm feeling horny and I'm able to have an orgasm, I'll do it, you know, and I don't need someone to do that for me... um... what I want at the moment, I... I don't know if I really want anyone in my life right now, but I still identify as a lesbian woman, it doesn't mean I've given up.*

Health

I have placed this code in ordinary lives, although it also fits in being disabled. The distinction is determined by whether the health issue is to do with the woman's impairment or not. This is an example of the difficulty in trying to separate the woman from her disability. For ease of writing and to make a political statement I have chosen to put health into ordinary lives. The political statement is that historically disabled people have often been considered as sick, or been cared for in hospitals. In New Zealand the current funding for Disability Support Services is managed by the Health Funding Authority, and appropriated from the Ministry of Health. Disabled people are not sick, but disabled. We do get unwell and occasionally require health services, but generally we are healthy. Moving funding away from health services acknowledges that being disabled is a way of life rather than an illness. My political statement is that my participants have health needs that are separate from their disabilities.

Ruth spoke about needing to have a hysterectomy and her fear. She said:

> *What scares me right now is, maybe having to have this hysterectomy and that scares me. I mean I've had anaesthetics in the past, I've*

probably had six operations in my life but its got to be at least twenty odd years since I had the last one and so I'm scared at that. I'm a little bit scared that I am going to die on the table but there is also a 90% chance that I'm not, so do you dwell on the 10% chance or do you take the 90% chance and hope that you are going to be better afterwards.

In this example her need for a hysterectomy is not related directly to her disability, but she goes on to explain the connection and impact on her life:

It's going to give you a better quality of life because all this heavy bleeding and stuff I've gone through, it's wearing me out, and if I can, it's not going to make my leg any better, but it is going to maybe give me a physical well-being and the energy levels which in turn are going to help the leg in as much as I am going to want to use it more.

Ruth is connecting her symptoms of blood loss and feeling worn out with her need for a hysterectomy. She hopes the outcome will mean she has more energy, which will make managing her impairment easier. Hopefully this will result in more good days for Ruth.

Helen discussed her experience of childbirth as a health issue. She spoke about her fear of being in labour, and the experience of her hospitalisation. She said:

I was very concerned about having to go through a labour ...you know a labour and all that wondering whether I ...I actually had the stamina for it and had heart flutters and things like that ...I envisaged myself dying of a heart attack or something, um ...but then she was breech and refused to turn, I ended up having one [caesarean section] *...and thought it was fantastic.*

But the staff there were so good, they were ... they were ... they obviously ...they had like a debriefing, so every time a new person would come along, you didn't have to say ... look I can't do this ... can you do this ... they knew instantly ... so they would turn up and ...and they would know that I couldn't actually sit up in bed, because I haven't got my strong muscles to be able to sit up... but they knew that ...and even if it was a new person ...they would say "oh yeah, I know you

can't do that" or whatever ...which was fantastic ...I was really

pleased ...and surprised by the level of care and ...how great they were.

Helen's experience of childbirth was separate from her disability yet impacted on her life as a disabled woman. Her fear of having a heart attack may have related to her disability or be an ordinary fear experienced by all women in labour. Her hospital experience related to her disability in that she was pleased staff were aware of her specific needs and she didn't have to explain to them all the time.

Maria had much less positive hospital experiences. She had made a suicide attempt at age 18 after the birth of her child, in her words:

When I came out of the coma what they had done was, the hospital said we can't care for you um ... it's a psych issue, I was still unconscious, um ... so they dumped me in the psych ward and the psych ward never knew how to deal with a physically incapable person so I was shitting myself and pissing myself, lying on a mattress on the floor in the room, not even knowing who I was, what I was, seeing snakes and spiders everywhere, coming to, to find that I couldn't ...I couldn't do anything for myself, they had to teach me...

This experience was not related to her disability but impacted on it because of the lack of knowledge and understanding regarding her disability.

Natalie had a number of operations when she was a child. These were related to her impairment. Following the surgery she required physiotherapy. She said:

I didn't relate well to physio because it was painful and I had a really big thing about looking at people outside and thinking if they don't have to do this, then why should I and I hated being treated like a piece of meat. You know how doctors stand over you and talk to you as if you are not there. And I can remember after my last operation at 11, thinking I have had it with you. I don't want any more, no way.

She was aware of her difference at a young age, and didn't like being treated differently as a result of her disability. Another two examples found in Morris (1989, p.91), "For Abigail, incontinence means that she has no sexual

relationship with her husband. And Deborah deliberately decided she did not wish to have a sexual relationship with anyone because of her incontinence."

Generally speaking these examples of health care experiences described by my participants were not directly related to their impairments. Yet in the following example this disabled woman's experience was that whenever she was unwell the sickness was attributed to her impairment. Pearpoint (1992, p.62) wrote, "Judith was terrified of hospitals and doctors. She had been an experiment "too many times". She was acutely aware that hospitals immediately saw her physical reality as a sickness." The health experiences did impact on the women's lives and highlighted the need for caution when attempting to separate the woman from her disability. Hysterectomies, comas, and physiotherapy experiences are not specific to the disabled population.

Good Days and Bad Days

The core category or basic social process, which emerged from my research, was good days and bad days. Broadly speaking, on good days disabled women feel more sexual than on bad days. On bad days sexuality goes down the priority list. Sharon's comment was that if sexuality is 5% of our lives, on bad days that 5% *gets swallowed into other areas.* We do not feel as sexual when we are engulfed in a bad day. I asked Maria, "What's the difference between good days and bad days?" Her reply was:

> *Well, on the bad days my legs don't move and I don't have feeling in my feet at all. I get spasms like crazy, um... I get shakes, my hands don't work and I have very little control of bowel and bladder, so those are my bad days... and cognitively I might be really bad ... memory loss, fatigue, I get so tired, you know, ... if anyone lays any stress on me and you can imagine what its like with a relationship breaking up... well it just... it compounds, you know a thousand times more... but you know you live with it... and it's a matter of learning to live well and just realise that everyone in this world has a bad day and just because mine*

give more profound effects, what I have to do is put in place support
networks to ensure that's okay to have a bad day.

Maria's comment was a very clear summary of the basic social process, good days and bad days. On the bad days she experiences her body impairments as being very difficult to live with, and what she needs is support. The support she mentions does not take away her impairment but makes it easier to manage her life, so that she may not have a good day but at least the bad day is "okay".

This process of having good days and bad days was described by Helen as:

> *I actually feel like I've coped extremely well ...I mean I'm here by*
> *myself ... I can't actually get any help whatsoever, so basically it is me*
> *... me and (baby) here all day, by ourselves, dealing with everything*
> *and its been okay. I think basically that's what it comes down to with a*
> *lot of things... um you just um... you have to... you actually don't have*
> *a choice ... you either stop right now or you carry on and do the best*
> *you can.*

From her perspective the process is up to her, she has no support available. Either she manages the best she can and in this theory has a good day or she doesn't manage and has a bad day.

For Natalie this process was described in a different time frame but still as good times and bad times. She said:

> *When I talk to my friends at school now they say that, you never really*
> *acted as someone different, but I found that when I got into my working*
> *life, I went through a lot of jobs because I didn't have the energy and I*
> *didn't fully understand or appreciate my needs as a person with a*
> *disability. It is only in the last couple of years that I have come to grips*
> *with that.*

Natalie told me later in the interview that she had been burning her self out by working too hard and not taking care of herself. This translates into having bad days, and now that she has come to grips with her disability she has more good days. Again, her impairment has not changed but she is managing her life in a better way. It seems that having support has made a big difference for Natalie. She said: *I've gotten to points in my life where I suppose you could say that I*

have almost had a nervous breakdown. In my last year at university it was too much, so I have been lucky that there have been people there who have pulled me back onto the right track.

For Ruth some of the bad days have been about adjusting to the changes in her body and the resulting difficulties in her ability to be independent. She described this as:

Because I've gone down hill gradually, (my husband) has got used to that as well, we've sort of gone through it together, we've gone through absolutely no aids to the walking stick, then to the wheelchair, because I now have to use the wheelchair if I go out. I don't use the wheelchair in the house and I use the walking stick for work cause its so easy. For shopping, the movies, the theatre anything I have to use a wheelchair and that was hard to get used to that. When I got the wheelchair I put it in the cupboard I didn't actually want to be reminded that I was going to have to use it. Yeah that was a hard one... I lost a lot of my confidence and my self-image because I was going to have to be helped. We were going somewhere and he said, you can either go in the chair or stay at home. ... And I also came to the realisation that you either use the chair and still went out and enjoyed yourself ...My husband and the friends who know me didn't look at me any differently it was just all in my head, so when I got used to that, it became easier and sort of opened up life again for me, I've since been camping.

Ruth considers her good days as having her life opened up again. Being able to do the things she enjoys like shopping, movies, the theatre and camping. Her impairment had not decreased but using aids such as the walking stick and wheelchair, plus having the support of her husband and friends helped her to make the change from bad days to good days.

Cathy described herself as needing to keep busy. Trying not to think about her difficulties is her way of having a good day, and avoiding a bad day. She said, *when I feel good, I feel more sexual, the weather helps me feel good. I feel better in the summer.* The daily reality of her impairment is hard for her. She described herself as having less libido as she gets older. Foreplay has become

much more important, it takes a huge effort to set the scene for sexual intercourse. Cathy said that on her bad days just managing her life, survival, absorbs everything. Takes all her energy. The good days are ones she gets on with, she knows her limitations and deals with it. Her philosophy is that life is all about experiences and she has had some and not others, it's all about balance. She said, *you can't have it all.* As Morris (1989, p.145) explained:

> As Celia says, 'Growing older is something that all women must come to terms with, disabled or not. But I do worry that other problems of aging will loom and cause trouble. I also sometimes find it hard to imagine myself as an old disabled person. I sometimes do not accept this disability is forever'.

This research did not focus on how disabled women actively manage the process of having a good day compared to a bad day. This is an area that requires further research. My participants did mention some strategies they use in the hope of having a good day. For example, having support appears to make quite a difference, as was discussed previously. Another example is from the code entitled constantly adapting.

Ruth offered the following illustration of how she is adapting:

> *Constantly, one of the things I've lost since we have lived in this house three years and they put all the handrails and things in for me when we moved in, and there is one over the bath. Now I used to be able to get in and out of the bath on my own when we came here but I can no longer do that, so there's a deterioration. I can't lift this leg up over the other but (my husband) can, so I get myself undressed and stand and he lifts the leg over, and this one, I can get. And I can't get out of the bath either, but he can bring me up the other end of the bath and I've got a little stool there. So I mean its no problem, I can still have a bath. It's just that, that is an adaptation I had to make.*

To many people the process Ruth described of having a bath probably seems complex, time consuming and dependency based. Yet she described this as no problem. She has found a way to manage with support of both her husband and a stool. She has creatively turned having a bath into a good experience.

Helen also spoke about adapting:

> *But that's the one thing, with what I think I have, is that it's this gradual process, so you know, although we've got this thing, its always deteriorating, you never know where you're going to be a year from now, but its happening so slowly that you are adjusting mentally to it as it happens and some days you think, god I used to be able to do that, but you can't actually pinpoint when you did...*

Helen thinks this gradual deterioration is preferable to suddenly becoming disabled. The ability to adjust mentally over time to the changes she experiences is an advantage and possibly results in a good day.

I asked Ruth about this process of adjustment, if she got scared of the future. In her reply she said, *Its not like someone has given me a final date, so I sort of want to live my life and be happy now and don't want to worry about what's around the corner.* This statement became part of the code called personal philosophy. Ruth believes it is important to live now, and not worry about the future. This is another way of having a good day, by being happy now and avoiding thinking about future bad days.

Other comments my participants made about their personal philosophies were:

- *I would just think, you know, you can have what you want basically, go out there and get it...*
- *And I look at those people who don't get the same opportunities that I did, and I think Oh God, everyone deserves to have the right in what ever ways its achievable.*
- *Anything you want is attainable if you really want it, and I really believe that, and I suppose that sort of attitude gets confirmed from time to time*
- *We were both very strong willed people and we knew where we wanted to go in life and what we wanted to get out of it* (both disabled)
- *You know if you are confident and believe you can go and get it, whatever the 'it' is*

- *I've come to realise its so important to claim my identity, so important to be proud of who I am.*

These are very powerful statements given by four of my participants. They indicate a high level of self-confidence and a positive sense of who they are. This philosophy will be instrumental in having good days. Kroll and Klein (1992, p.35) wrote, "Self-esteem, the feelings we all have about our physical and emotional selves, is a vital component in how we face the challenges in life." It is important to note that not all the participants spoke with this level of confidence. Future research would be useful to find out how disabled women developed this degree of confidence.

This chapter has been a discussion of three categories, being disabled, ordinary lives, and sexuality. Sexuality was discussed in relation to the basic social process of good days and bad days. Further research needs to be done to identify what constitutes a good day, and how disabled women turn bad days into good days. This process emerged from the data related to sexuality, and further study would clarify if good days and bad days affect other aspects of disabled women's lives. The following chapter presents the implications and recommendations made as a result of this research. The implications and recommendations are suggested for disabled women, health care professionals and society in general.

Chapter Five

Recommendations

In this chapter recommendations arising out of this research are outlined. These are written under a number of headings, the first being, Implications for Disabled Women. In this section I discuss the need for disabled women to be sexual in a positive way, and to support each other in understanding the social model of disability. The second heading is Implications for Nurses. In this part I will discuss ways nurses and other health professionals can choose to change their practise as a result of this research, to enable the development and liberation of disabled women. The third heading is Implications for Society. In this brief section I suggest that society needs to change and the New Zealand Disability Strategy might provide a useful framework.

Implications for Disabled Women

The first major implication for disabled women is that this research has highlighted that we are sexual beings. This is vital for disabled women to claim. Sexuality is an important aspect of health. Historically, we have been considered asexual, now with an increase in the literature being written from our perspective and from the findings of this and other research, disabled women should celebrate their sexuality. Shakespeare et al. (1996, p.115) quoted Sara as saying:

> Experiment, try new positions, new games, make it fun. I find not letting my disability hinder me or cause me lack of confidence was hard at first, but once the partner didn't seem bothered I relaxed and forgot about it and had a lot of fun, laughs and good sex.

The basic social process found in this research is **good days and bad days**. Disabled women feel more sexual on good days compared to bad days. Many of the issues, which make for a bad day are discussed in this thesis. Rousso (1988, p.142-3) summarises some of these issues that have also been found by other researchers, "The studies suggested some of the obstacles that the

disabled women faced: transportation problems, architectural barriers, lack of self-confidence, rejecting peers, pessimistic parents and community, and lack of role models for social success." The issues mentioned above were also relevant findings in this research.

The question of what makes for a good day is yet to be fully answered. The participants in my research discussed some of their strategies but further research needs to be done in this area. Disabled women need to find out what makes a good day for them, so that they can increase their experiences of good days. One example discussed was coded as constantly adapting. With the support of her husband Ruth finds it no problem to have a bath. What makes the difference is having the support. These solutions are individually based and can not be generalised. What one person finds helpful, another may not. Hales (1996, p.86) included this description from Sian:

> The problem for me is centred on relationships and particularly about how you have a sexual relationship when you need help getting to bed, turning over in bed, someone to come into the bedroom in the morning to get you up, and so on.

Another one of the implications as a result of this research is that disabled women's sexuality is influenced by society. Sexuality is more than an individual experience. This is illustrated in the diagram of my theory (Figure 1) by the diagonal dotted line. This finding is consistent with Shakespeare et al. (1996, p.12) when they suggest, "... we do think it shows that the barriers to sexual and emotional fulfilment do not reside in the impairment of the body but in the restrictions of our society." This is also consistent with the social model of disability.

In what could be considered as a contradiction to the social model of disability, individuals can change their lives. The social model challenges society to change. Shakespeare et al. (1996, p.182) challenges disabled people with, "The only true empowerment is self-empowerment. ... We believe that only disabled people can achieve the liberation of disabled people, and for that they need to develop a sense of their own strength and resources." They continue:

There is a tendency within disability studies literature only to explore the barriers and structures which disable, which can sometimes detract from focusing on the individual strengths and potentials of disabled people, as social actors, to resist and create space for change.

Once we have realised our personal power, we gain strength politically. A poem by Aviles (1996, p.37) from El Salvador is an example of personal empowerment of a disabled woman:

I have been born again

I used to live locked up between four walls.
I did not know what it was like to enjoy life.
Then, one day, I had the opportunity of meeting
Many people who shared my condition,
Or worse.

They were always strong; they always looked ahead,
And never felt defeated.
On the contrary, they wanted to conquer,
Show their true worth.

They gave my spirit strength
And taught me that life must be lived
As it manifests itself.
Taught me that we must accept ourselves
No matter what we are like, no matter our suffering.
All that counts is that we feel good about ourselves.
The rest doesn't matter.

Some disabled women are in a position to support other, more disadvantaged, disabled women. Maria believes disabled women are not very good at supporting each other. She said:

I think we are very isolated, I think women with disabilities are very different to other women in that houses are not accessible, umm... we don't have the money to finance transport, and unless you are doing

studies or whatever you don't get a car... you know and that's very vital for many of us... some of us are trapped at home with kids.

Those of us who are more advantaged can be an active force for changing society. We need to educate ourselves and then pass our knowledge on to other disabled women, thereby working to build capacity within the disabled community. It is disabled people who are creating the most changes for us (Richardson, 1997).

As a community we must support all disabled people. Disabled women who are members of other minority groups experience even more oppression, for example, disabled lesbian women (Shakespeare et al., 1996). We must work together to change society and be careful not to recreate power imbalances which serve to marginalise other minority groups within our disabled community.

Another way of making a difference for other disabled women is by speaking out about our experiences. Sandie Waddell is an example of a New Zealand disabled woman who spoke out. She wrote a book based on her experience and interviews she conducted with 23 disabled women. In her foreword (Waddell, 1992) she explained:

> On discovering I was pregnant with my first child, my immediate reaction was to find out all there was to know about what to expect as a woman with a spinal cord injury. My dismay at finding nothing was available, apart from a few scary medical articles that I wouldn't recommend, motivated me to write a book in the hope that others will be more informed than I was able to be.

In a book of disabled women writers (Keith, 1996) Judith Heumann wrote the following in the foreword:

> What is particularly wonderful about this book is that all the pieces are written by disabled women. With much of what we have seen and learned about disabled people focused on men with disabilities, there is a real need for disabled women to be able to come together and share our unique experiences. I do believe the experiences of disabled

women, like those of women without disabilities, are different from those of disabled men. As disabled women, we have been starved for role models. This book provides them in spades.

Having role models and being a role model are both important issues for disabled women. We need to have role models to emulate. We need to see ourselves highlighted in the media and portrayed as sexual beings. The function of a role model is to offer us an example to aspire to. Morris (1991, p.184) described our need:

> Our history is hidden from us, as are role-models to whom we can relate. Because the presentation of our experience is controlled by non-disabled people, most of the recording of the lives of disabled people is done in a way which is deeply alienating to us.

Being a role model is not easy. I am considered by some to be a role model for other disabled women. I believe it is important for disabled women to see other disabled women who are living successfully. I think of myself as successful and happy, and I am willing to share my experiences with other disabled women.

Disabled people must be willing to take the risk to lead social change. We must be willing to become political and use our organisations, which represent disabled people to push the barriers that we face. Shakespeare et al. (1996, p.9) wrote, "The neglect of sexual politics within the disability movement, and its absence within disability literature, mirrors the wider attitudes of society to disabled people's sexuality." We must volunteer to work for organisations and be proactive in making a difference. We may need to be involved in non-violent protest action, in order to create change. We must be the voice for other disabled people who can not speak or have not yet found their voice. We must represent disabled children so that they can be proud of who they are. There is much we can do.

The disabled women who participated in this research have all been active in changing the lives of disabled women. They spoke out and told their individual stories so that other women and health care professionals would

benefit. They wanted to see society change in a way that acknowledged and encouraged sexuality for disabled women. Natalie described the reasons why she agreed to participate in this study:

> *...one of the main reasons that I agreed to participate in this study was because when I worked part-time, I just happened to pick up a book that they had there - a survey and a couple of the comments just really touched me. One I remember most was that "I became disabled after an accident, my boyfriend left me because he couldn't handle it, what he didn't realise was that I was a woman first and my disability was secondary" and that kind of thing. And it really got something inside me just reading that, having an understanding of what the attitudes are like and of course just watching "Shelley's Having A Baby"- a documentary and I like the way she said that disabled are considered asexual so that is why I am here to change that.*

Implications and Recommendations for Nurses

There are a number of recommendations and possible implications for nurses as a result of this research. The implications will only be realised if nurses decide to change their practice. This research recommends that nurses and other health professionals change their thinking about disabled people. The first major change that needs to be made is for nurses to accept and adopt the social model of disability. Richardson (1997, p.1270) calls the social model the barriers model and states:

> Once professionals working with disabled people accept the barriers model it behoves them to form alliances with disabled people, assisting them with citizenship rights, with managing personal support, liaison with other services and advocacy in support of the removal of social and physical barriers in the local environment...

Nurses need to recognise the importance of the basic social process of **good days and bad days** in relation to disabled women's sexuality. Nurses can help to establish what is contributing to a good day so that they and disabled women

are more aware of what makes for a good day. This is also relevant for bad days. Nurses and disabled women need to be aware of what makes for a bad day so that strategies can be developed to turn bad days into good days.

Nurses have a responsibility to their patients regarding sexual health and education. A study by Anderson and Kitchin (2000, p.1172) on access to family planning clinics found:

> Disabled people do have sexual health issues that extend beyond the general population. The family planning clinics in Northern Ireland need to recognise this and undergo a program of improving their levels of access and the information and services they provide. This should be accompanied by disability awareness training and an examination of the ways in which the clinics reproduce cultural ideologies in relation to disabled people and sexuality.

Nurses can initiate the changes needed by requesting disability awareness training and auditing their information, looking for relevance for disabled people. They can also ensure that the buildings they work in are fully accessible.

This research has found sexuality is greater than the individual disabled woman, in that the way society treats disabled women has a major impact on our sexuality. As Richardson (1997, p.1271) declared, "Nurses will need to support disabled people to challenge society's expectations that disabled people will live asexually and assist and advocate where necessary for the income, control and autonomy that underpin friendships, and social and sexual relationships." When nurses work with disabled people around our sexuality issues, it is important to include the impact society has from a social model level of understanding of disability. The impact of society is discussed under the category being disabled, and includes issues such as attitudes towards disabled sexuality and access.

Many disabled people understand their disability from a medical model perspective. As Richardson (1997, p.1271) discussed, "However, there is evidence that young disabled people appear to have been conditioned into

accepting a devalued role as sick, pitiful and burdensome. In other words they have internalised the personal tragedy model of disability." Disabled people may have not been educated about the social model of disability. For this reason many disabled people agree with the personal tragedy way of understanding themselves and as a result lose their power. Nurses are able to inform and educate disabled people about the social model. The result can be empowering for disabled people as the "blame" for being disabled is removed from the individual and placed within society.

Nurses are in a position to enhance disabled women's sexuality. According to Finger, Hall and Peterson (1992, p.85) due to the fact that nurses have the most frequent patient contacts, "... patients are more inclined to discuss their sexual concerns with the most familiar and accessible health provider, the nurse." Nurses have the opportunity to discuss sexual health with disabled women. A study by Waterhouse and Metcalfe (1991, p.1048) found, "Ninety-two percent of subjects thought that nurses should discuss sexual concerns with clients." They go on (Waterhouse & Metcalfe, 1991, p.1053) to recommend, "Discussion of sexual concerns initiated by the nurse is valuable for all patients and it is time nurses stopped assuming that clients do not wish to discuss sexuality."

There are a number of ways that nurses can use their role in sexual health for disabled women. Rieve (1989, p.275) noted that, "The nurse's role as it relates to sexuality in persons with disabilities is to assist clients to find, implement, and integrate their beliefs and behaviors into a healthy and satisfying lifestyle." For Richardson (1997, p.1272) this role incudes the ability, "... to be able to work with and communicate alongside people with sensory, physical and psychological impairments, providing information, assess barriers, offer health education and counselling and support rehabilitation." The key for me is in the word 'alongside'. Being alongside means a different use of power. It is a shift from assisting disabled people which is a power over them place of doing to them, to a shared power place of working with them in alliances or partnerships.

In order to make this change in the power dynamics, nurses must change their attitudes towards disabled people. As Finger et al. (1992, p.82) described it, "While nurses often need sexual education, the environment may not be receptive due to prevailing attitudes." When this is the case attitudinal change must be facilitated. Webb (1988, p.236) suggested that nurses, "… need to have both attitudes which are favourable to disseminating information to patients and the necessary skills to deliver this care effectively." Changing attitudes is not easy Sines (1994, p.897) stated, "Attitudinal change is the greatest challenge facing the nursing profession today."

The attitudes of health care professionals towards disabled people have been found to be very powerful. Paris (1993, p.818) in her study suggested, "Evidence indicates that physicians with negative attitudes are more likely to withhold treatment from, or provide inferior treatment to, the chronically ill or disabled patient than are physicians with neutral or positive attitudes." As a result of the impact on disabled people of these negative attitudes, Paris continues, "… it has been suggested that people with negative attitudes should be excluded from professions that require or emphasize interaction with people with physical disabilities." Perhaps attitudinal testing should be included in all interview processes when hiring health care workers who will work with disabled people. Those workers with negative attitudes should not be offered employment.

Nurse managers must support the attitude change required by nurses. Sines (1994, p.894) explored power relationships within nursing. He described the need for managers to support attitude change by nurses as, "… few managers and leaders of nursing have fully appreciated the complexity of the task involved in moving from a seemingly professional led service to one that is based on a true sharing of power between clients and their supporters." To do this power sharing, nurses must give up some of their power and managers must be willing to support this. Schlesinger (1996, p.255) suggests that clinicians need to be sensitive to their clients:

> If clinicians are sensitised to how their medically derived definitions of successful coping may differ from their clients', serious

misunderstandings that could undermine practitioner/client relationships might be avoided. Clients benefit from advice and assistance that 'makes sense' given their life experiences.

Ultimately what may happen if disabled people are truly emancipated is that we may not require nursing support, except in times of illness.

In order to be effective, nurses and other health professionals, not only need to change their attitudes but they also need to increase their knowledge in the area of disabled women's sexuality. Woods and Mandetta (1975, p.10) wrote twenty-five years ago that, "Health professionals have tended to exhibit a lack of adequate knowledge about sex education and counselling." McKown (1986, p.25) described the need for increased knowledge fourteen years ago, "The nurse, along with the rehabilitation staff, must see sexuality counseling as a necessary task. To be effective in this area, the nurse needs to know the physical and psychological aspects of sexuality and disability." Bieler (1999, p.35) described her experience as, "We faced a major lack of information about disability amongst doctors and rehabilitation service providers; for example, I was the one who provided information to my gynaecologist on spinal cord injury issues." It seems this lack of knowledge is still an issue for nurses and health professionals today. Disabled women have waited long enough for professionals to get the information they need, to know about us.

It is clear from all the data gathered in this research (interviews, personal and literature) that nurses need to increase their knowledge and change their attitudes towards disabled women. In order for this to occur there needs to be changes in the undergraduate teaching programmes for nurses. Webb (1988, p.243) described the need for curriculum development:

This would need to include content relating to sexuality in its widest sense ... In addition, students would need help in exploring their own attitudes towards sexuality so that they reached a level of self-acceptance and comfort which freed them to discuss sensitive topics with clients. Even this would not be sufficient to ensure that they were able to realize their potential, because knowledge and comfort would

need to be augmented by communication skills which many nurses have been shown to lack.

For registered nurses already practicing educational input and encouragement for attitude change must be provided through inservice training, conferences and post-graduate education programmes. Rieve (1989, p.267) suggests ways for nurses to increase their knowledge by:

> Attendance at inservice programs, professional workshops, and seminars; availing oneself of topical literature and audiovisual materials; and discussing feelings, concerns and questions with colleagues and experienced clients are methods that nurses can utilize to increase their competency and comfort level.

Educational input must be based on research evidence. As French (1992, p.185) argued, "Although professional practice in the absence of sound theory and research is sometimes justifiable, professional practice based on little or no research can do serious harm." Therefore more research must be completed in the area of sexuality and disabled women. Ideally, this research on sexuality should be completed by disabled women, but due to our history of oppression, many disabled women are not in a position to undertake research projects. Nurses are in a good position to do emancipatory/participatory research with disabled women, aimed at increasing the knowledge about our sexuality. French (1992, p.185) continued by suggesting:

> Many disabled people and their organizations now believe that a more participatory style of research should be adopted where disabled people are consulted at every stage of the research process, and assisted and encouraged to carry out research into disability issues themselves.

Clinical supervision is another avenue nurses could use to help them change their practice and attitudes. Dwan (2000, p.25) in discussing clinical supervision for nurses suggests the following list of benefits:

> It allows quality time to:
>
> - Acknowledge and affirm one's strengths, the skilled practice, experience and knowledge one brings to the job and displays consistently;

- Reflect on one's own clinical practice – what is good and less good;
- Debrief particular issues or situations;
- Identify new or different ways of approaching particular issues or situations;
- Analyse how successful or otherwise the trialling of new ways of doing/viewing something has been;
- Discuss and consider a different perspective on particular issues or situations;
- Celebrate the successes;
- Consider ongoing professional development needs;
- Prepare for particular situations or tasks;
- Provide protection for patients;
- Be challenged to improve personal standards, eg provision of care, ongoing education, upskilling, attitudes;
- Advance nursing practice; and
- Discuss their professional relationships with colleagues safely and confidentially.

All of these benefits are relevant for nurses working with disabled women, if the supervisor understands disability from a social model perspective. It may be important for the nurse to educate their supervisor if they do not understand disability from a social model.

Clinical supervision provides the opportunity for a more experienced practitioner, hopefully another nurse, to over see a nurse's practice. The aim is to provide a time and space for reflection on both their professional practice and personal life. The disadvantage of clinical supervision is that it is expensive and many employers will not pay or provide the time for supervision. Farmer (2000, p.26) found the results from research in the United Kingdom into supervision that, "...professional supervision significantly reduces work related burn out and stress and that it results in increased feelings of work satisfaction." This can only serve to improve nursing practice as a whole.

Once nurses have the knowledge and enabling attitudes they need to be proactive in talking about sexuality issues with disabled women. It is clear that, we, disabled women are sexual beings and therefore nurses must acknowledge us as being fully human. In a study on spinal cord injury White et al. (1994, p.61) found that, "... only 37% of the women reported having been given information on sexuality issues since injury as compared to 66% of the men." They went on to say that, "The limited information on sexuality for women with spinal cord injury should be of concern to all nurses." And that the findings from their study, "... indicate the importance of nurses' addressing both physical and psychosocial needs when discussing sexuality with patients." In a study by Matocha and Waterhouse (1993, p.371) 155 registered nurses were surveyed regarding the inclusion of sexuality issues in their practice. They found, "Twenty percent of subjects indicated they were never involved in any sexuality-related activities and only about 12% addressed sexuality with a majority of their clients."

A research investigation by Nosek, Young, Rintala, Howland, Foley and Bennett (1995, p.516) found a number of barriers for disabled women in maintaining our sexual and reproductive health. The researchers made the following recommendations for health care practitioners:

- Regard women with disabilities as experts on the functioning of their own bodies.
- Assist women with disabilities to increase their knowledge about reproductive health maintenance.
- Increase your understanding of how disability affects reproductive health.
- Be sensitive to histories of traumatic interactions with medical environments.
- Create policies that will increase access to reproductive health services for women with disabilities.

The results of my study reinforce the above recommendations.

Nurses could improve disabled people's lives in other ways too. For example, nurses could advocate for the employment of disabled people. French (1996,

p.160) states, "… and many writers advocate the training and employment of disabled health professionals as a means of changing attitudes within the professions." If disabled professionals were employed in the area of health, then disabled people, as clients, may not be seen as frightening and as 'others'. French (1996, p.160) went on to write, "Contact on an equal level is more likely than professional-client contact to breakdown stereotypes and promote effective interaction." To have disabled employees the environment would need to be accessible. This would ultimately benefit all disabled people. Along this line it is important to note and consider the implications behind the situation, that disabled people are excluded from becoming nurses for medical reasons (Richardson, 1997).

Nurses need to become political. Nurses are a powerful occupational group that could lobby government on behalf of disabled people, doing it in a way that promoted the rights of disabled people. Morris (1996, p.12) relates the social model of understanding to civil rights, "It is the social model of disability with its emphasis on social and economic oppression rather than on individual inadequacies and personal tragedies which forces a recognition of disability as a civil rights issue." Nurses can encourage and support disabled people becoming politically aware and active. Richardson (1997, p.1272) on this topic wrote, "Disabled writers have argued that the most radical improvements in the lives of disabled people over the past decade have come not from the charities, health or social services professionals but via disabled people themselves becoming politically active." In New Zealand the organization for disabled people, run by disabled people is the Disabled Persons Assembly (DPA). Nurses are able to join this organization and support the emancipation of disabled people.

Implications for Society

This research has found that the attitudes of nondisabled people have an impact on disabled women. We are not considered by society in general as being sexual beings, and we are feared and even hated by some nondisabled people.

Society needs to change. The Women's Liberation movement has made a difference in many women's lives, with regard to the power dynamics that exist between the two sexes. As opposed to thirty years ago, some women are now in more highly paid and responsible positions. Historically speaking, thirty years is not long to make this type of social change.

The change for women has occurred primarily in the Western world. Women are still living in major disadvantaged situations in the so-called underdeveloped countries. For disabled women, change is occurring but for those living with oppression, this move cannot come soon enough. Driedger (1996, p.10) describes the move:

> Although women with disabilities have faced discrimination throughout the ages, there has been some positive change since World War II. In wave after wave of social movements, oppressed people have discovered their histories and challenged injustices. It has been important for marginalized, disadvantaged and colonized people to confront their histories of oppression, to throw off society's view of them as different and society's tendency to decide for them.

Change is occurring within New Zealand. This year there has been the appointment of a Minister for Disability Issues, which is the first time a Member of Parliament has been appointed with the specific task of attending to disability matters. This year has also seen the appointment, of a 15 member team representing disabled people, to produce the New Zealand Disability Strategy. To date, they have produced a discussion document entitled, "Making a World of Difference: Whakanui Oranga". The discussion document (2000, p.1) stated:

> The way New Zealanders think about disability today is very different from the views our society held only a few decades ago. Previously dominant was the 'medical model' of disability, which considered disability as a personal problem to be 'fixed'. Now the trend in thinking is towards a 'social model' of disability, where individuals with impairments are considered to be disadvantaged by the social and environmental barriers to participation that exist in a hostile

environment. As a result of this disadvantage, people with impairments experience disability.

These are exciting developments for disabled people, and suggest a hopeful future for our full inclusion in society.

Society also needs to be aware of the social process of **good days and bad days.** Although this research has focussed on disabled women, I suggest that all people experience good days and bad days. A better understanding of this process would enable all people to aim for more good days. If it was widely recognised that we all have bad days perhaps people may become more tolerant of our differences.

This chapter has presented the implications and recommendations that have emerged from this research. The implications and recommendations in this study are based on the information gathered as data i.e. the voices of the research participants, my own memos, and the literature utilised when theoretically sampling. They were discussed under three headings, specific to disabled women, nurses and health professionals, and for society in general. The trend underpinning the recommendations is that disabled women need to be considered as valuable members of society with the same rights for health care as any human being. In the next chapter the evaluation of this research is presented along with areas for further study. Finally an overall summary of this document is offered.

Chapter Six

Conclusion

In this chapter I will evaluate my research, suggest further research and summarise my thesis. The evaluation section considers the limitations of this research. The 'further research' section highlights areas that require further investigation. Finally, the summary provides a clear and concise description of this research and the resulting theory.

Evaluation

All research projects have limitations. Researchers make decisions on the best way they believe an area should be studied. Others would have done the same research differently. The aim of this report is to demonstrate my ability to complete research in a way that can be understood and followed by others. The decisions I made should be clear. Given this study is part of a university course requirement, the first major decision I made was in selecting an area to study. I chose to study disabled women's sexuality, an area important to me, and one I believe is important to other disabled women. The lack of previous research, especially conducted by disabled women, indicated a need for this study.

This area may been particularly significant to me for a number of reasons. First I have an acquired disability, which means I have had experiences of being both disabled and nondisabled. My experience of my sexuality is different after becoming disabled when compared to my previous nondisabled experiences. Secondly, I became disabled at age twenty-one which is a time developmentally when young people are looking to establish their intimate relationships, as opposed to being isolated (Erikson, 1963). My sexuality and relationships were a very important aspect of my life at the time of my accident. Finally, the combination of my personal experience of my sexuality and struggle to become a powerful disabled woman, plus my reading and

understanding of the social model of disability, which I was introduced to in the United States, all contributed to the development of this research.

Once I had decided the area I was interested in, I formulated my research question. This then guided the methodology I chose to use. I knew I wanted to complete a qualitative study rather than a quantitative one. As my interest is in the meanings people give to their lives and in research which focuses on personal experience and understanding what is happening, a qualitative methodology was the most appropriate. Grounded theory methodology provided the structure from which I could discover the way sexuality is experienced by disabled women. The aim of grounded theory is to find the social process which describes patterns of behaviours that are going on in a specific area (Glaser, 1992). As Keddy, Sims and Stern (1996, p.450) described, "In league with the current feminist research approach, grounded theory allows for the voices of the participants to be heard as they tell their stories."

Researchers who use quantitative methodology may be able to design a way of establishing how disabled women experience their sexuality. By doing so, they would have perhaps been able to design a tool where a large number of subjects could have been tested. I believe the voice of my participants and their rich experiences, that have been described in chapter four, would have been lost. Qualitative methods such as grounded theory, honour and include the participants.

Sample

The focus of my research was on sexuality and this was clearly stated in my information sheet. It is possible that disabled women who are not sexually active with another person would not have volunteered to be participants in this research project. Sexuality is often mistakenly considered to only mean intimate physical contact of another person. This may have been one of the limitations in this study and the reason why all participants had been or were

currently sexually active. That is, the women may have agreed to participate because they thought I only wanted sexually active women, whereas I consider all women to be sexual beings. I did not provide a definition of sexuality in terms of selection criteria, but asked women to self select as suitable participants. Therefore the participants decided that they were sexual beings.

Following the methodology, I did not have a preconceived idea of the number of participants I would need. This research is based on the data collected from 8 transcribed interviews, field notes, memos and selected literature. Eight is a small number of participants from which to generate a theory. Sandelowski (1995, p.179) discusses sample size:

> A sample of 10 may be judged adequate for certain kinds of homogeneous or critical case sampling, too small to achieve maximum variation of a complex phenomenon or to develop theory, or too large for certain kinds of narrative analysis.

It appears the sample size is a matter of judgement and depends on the research. Sandelowski (1995, p.180) goes on to suggest, based on a personal communication she had with Stern, that, "...we often have all the data we will need in the very first pieces of data we collect, but that we do not (or cannot) know that until we collect more."

In grounded theory Glaser (1992, p.102) described sampling as continuing until, "... it is saturated, elaborated and integrated into the emerging theory." I believe I did this. I continued to interview participants until I was not forming any new codes. Llewellyn (1995, p.122) suggested, "The question is not 'when is data collection finished?' but rather 'when is the fieldwork no longer contributing to further understanding?'" I am also aware that as a beginning researcher I may have prematurely stopped looking for new codes. I noticed that initially I was coding almost line by line of the transcript and at the end I was coding paragraph by paragraph.

Given the academic nature of this study, I believe the sample size was appropriate for the time constraints and requirements in which to complete and manage this project. Giddings and Wood (2000, p.13) quote Denise Dignam as

saying, "Although there are time constraints on those involved in Masters studies, the use of a modified form of grounded theory will produce useful nursing and midwifery knowledge." Initially this study was to be completed within one academic year. Due to my hospitalisation three times in the past two years, this study has taken three years to complete. It is also important to note that this study is a beginning, and further investigation to extend the current findings is required.

Interviewing

As previously mentioned I found the interviewing of participants difficult. Both in the amount of energy they required and in the structuring of the interview. Biklen and Moseley (1988, p.157) described this difficulty as, "Interviewers feel challenged to provide enough structure so that the subject knows what is being asked of them, yet not so much that subjects' answers are prescribed." I was also challenged to maintain my role as researcher, rather than to make therapeutic responses. I found it difficult to know how much detail to ask for, while being sensitive to my participants. In the interview with Natalie, approximately half an hour into the process, I say:

> Susan: Will you tell me about that?
>
> *Natalie: How explicit do you want me to be?*
>
> Susan: That's up to you – what ever you're comfortable with.

This is an example of me attempting to get more information and being sensitive.

Another area of difficulty I found was in being given answers the participants thought I wanted. Biklen and Moseley (1988, p.159) report that, "All interviewers worry about the extent to which the interviewee says what the researcher wants to hear." In the interview with Felicity I found this to be a problem, as previously mentioned. I also noted in a memo written on 29/2/00:

> In discussing my thesis – came to a point of women didn't really want to talk a lot about sexuality – didn't really seem to be a problem for

them but they did want to talk about their DAY-TO-DAY STRUGGLE
that is, money, resources, attendant care, transport etc.

We (participants and myself) have a different agenda, that is power. Do
women talk about what a researcher wants when there is a power
imbalance?

In this memo I am wondering about the interviewing process and the impact of
the power imbalance between the researcher and participants.

Participants were only talking to me about their sexuality because I had asked
them to. Therefore they were influenced in the interview to talk about
sexuality. It was up to each individual to speak from their perspective as
opposed to trying to guess what I wanted to hear. In a counselling theory,
Transactional Analysis, any recognition of participants is called stroking.
Human beings need strokes to survive. In the interviews I was stroking what
my participants said, simply by listening to them. Stewart and Joines (1987,
p.74) described the power of stroking as:

> ...Stroking reinforces the behaviour which is stroked. Grown-ups, need
> strokes just as much as infants, are just as ready to mould their
> behaviour in whatever ever ways seem effective to keep the strokes
> coming.

In order to get more strokes it is only natural that the participants would
attempt to give me what I wanted.

Due to my neophyte researcher status, it is possible a more experienced
interviewer may have found different results. Perhaps they would have
produced more information around details of my participant's sex life. Perhaps
there may have been more about body image and femininity. Bogle and Shaul
(1981, p.92) describe the importance of body image as:

> A positive body image is critical to the sexual well-being of women
> with disabilities. In the work we've done with disabled women body
> image has been the hub around which sexuality revolves. Being
> comfortable with and learning to live with one's own body prepares the
> way for sexual acceptance and growth.

I thought originally body image would be more of an issue for my participants, but this was not one of my findings.

The majority of the literature I have included in this report from my theoretical sampling does provide some credibility to the interviewing process. That is, much of what I found in the literature was similar to the experiences described by my participants.

Transcribing

Transcribing an interview changes the spoken word into the written word. Sherrard (1996, p.145) described the results of transcribing as, "The spoken word with the non-verbal cues of tone or voice, spaces and emphasis on the tape, did not read the same once it was a typed transcription." The transcribing process results in the loss of some emphasis and meaning because it can not include non-verbal cues of facial and body language. To compensate for this, researchers need to take accurate field notes.

A limit of this research was that another person transcribed the audiotapes of the interviews. This person, the transcriber, did sign a confidentiality agreement not to disclose any of the material she heard on the tapes. In an effort to reach accuracy the transcripts were carefully checked and modified where needed, by me. Sandelowski (1994a, p.314) discussed the influence researchers have on transcripts, "As DeVault (1990) observed, the process of transcription emphasizes the importance of capturing research participants' own words, but it also gives the researcher great authority as editor, translator, and interpreter of those words."

Being the interpreter of my participants' words was an even greater responsibility for me, as I decided not to ask my participants to check their own transcripts for accuracy. This is another area of possible limitation of the study. My participants did not have the opportunity to change or clarify the meanings they originally offered in the interview. My rationale was that I

wanted to capture their unconscious communications, which I believe I did. The disadvantage is that it put me into an even more powerful position as researcher, and decreased my participants' involvement. Keddy et al. (1996, p.451) declared:

> With the exception of Strauss & Corbin (1990), who tend to put the direction of the research back in the hands of the principle investigators, grounded theory as it has evolved in nursing, relies for accuracy and 'rigour' (Sandelowski 1989) on participants.

I was aiming to follow Glaser's grounded theory methodology, not Strauss and Corbin. With my decision not to ask my participants, I moved away from Glaser's method. As Glaser (1978a, p.47) maintained, "Grounded theory's ready modifiability allows openness to correction and change in emerging theory..."

In retrospect, I believe that I did not gain enough unconscious data to make this a worthwhile decision over valuing the input from participants. This was an important learning for me as a new researcher. My lack of faith in the richness of the data produced by participants may have clouded my judgement. Yet, my participants may have requested changing some of the richness if I had given them the opportunity. As Sherrard (1996, p.47) wrote from her research experience, "Several participants gave very careful and detailed attention to the transcripts before being prepared to return them to me." In her words, "A few participants made corrections" (personal communication, 11 November, 2000).

Developing a Theory

The aim of grounded theory research methodology is to develop a theory. Kearney (1998, p.185) explained, "The challenge is to develop a meaningful and rich theory that represents the varieties of experience without being cumbersome in complexity or over general in its simplicity." I have described how I achieved this in the previous chapters. To develop the theory I first analysed the data by coding it. By constantly comparing the codes, categories were developed. Charmez (1990, p.1169) describes some of the decisions involved in this process:

Raising a term to a conceptual level means making a series of *decisions* about it. Again, the researcher actively shapes the research process. The researcher creates an explication, organization, and presentation *of* the data rather than discovering order *within* the data. The discovery process consists of discovering the ideas the *researcher* has about the data after interacting with it. [sic]

It was my decision what code I used to label some data, and then my decision about which codes would fit together. I also had the responsibility to create the more abstract categories, which were describing the process I called good days and bad days. The constant comparison method takes time and patience. Charmez (1990, p.1168) suggests, "The comparisons include data with data, category with category and concept with concept." Again, due to my inexperience I may have not completed this process fully. When I found the core category of good days and bad days, it made sense to me. I then compared the other categories and decided I had found the basic social process.

I believe the process I followed is appropriate for this academic study. Again, in hindsight I could have continued with the constant comparison process for longer and as a result may have developed a different theory. Due to the time constraints I did stop comparing when I found the good days and bad days process. In my excitement at finding something that made sense I may have forestalled the process. Further research needs to be done to confirm this finding.

The diagram used to illustrate my theory, shown at figure 1, has the aim of clarification. It may or may not achieve clarification. It is a two dimensional diagram that is attempting to explain the complexity of disabled women's sexuality. For this reason a diagram is hopelessly inadequate. Disabled women are complex human beings who cannot be explained in a few words and lines. My hope in producing the diagram was that it would be a visual representation of my theory, and act as a memory aid.

The importance of the diagram is that includes the good days and bad days process in relation to disabled women's sexuality. It also illustrates the significance of the impact on our sexuality of being disabled and having ordinary lives. Finally I included the political statement of how we are seen by society. The diagram needs to be recognised as a simplification.

Credibility

I discussed credibility in chapter two, under the heading validity. In many grounded theory studies the researcher asks the participants to check transcripts and even the research report for accuracy (Keddy et al., 1996). As discussed above, I did not do that. Instead I asked two other disabled women to check the credibility of my study. Sandelowski (1986, p.30) described credibility as, "A study is also credible when other people (other researchers or readers) can recognize the experience when confronted with it after having only read about it in a study."

Auditability

The chapter on methodology provides some evidence of the audit trail. LoBiondo-Wood and Haber (1994, p.497) define auditability as, "... the ability of another researcher to follow the thinking, decisions and methods used by the original researcher." I have provided two tables that show my thinking process with regards to codes and categories. I have included the process I followed in forming the theory as evidence of an audit trail. I have also kept my audiotapes and transcripts should an audit of this research be required.

Fittingness

Fittingness has been defined by LoBiondo-Wood and Haber (1994, p.497) as, "... how well the findings fit outside the study situation." By asking two disabled women to comment on this study, and the fact they agreed with my findings as being relevant to their experiences suggests fit of my findings. That

I was able to include quotes from research participants indicates a level of fit and credibility. The findings of other studies have produced similar results. I also provided quotes from a biography that indicated similar experiences to that of my participants, and provided quotes from books of disabled women's writings.

Further Research

There are several suggestions for further research. Schlesinger (1996, p.254) emphasised, "There is a need for more sociological research, both qualitative and quantitative, that is focused on sex/sexuality and disability (including chronic pain), as experienced by people outside of clinical settings." The suggestions I have made have been mostly included in a question format, under bullet points below. They are not written in any particular order of priority.

- More research on disabled women be conducted by disabled women and written from our perspective. As French (1992, p.186) declared, "Ways must be found of encouraging and enabling disabled people to carry out research into their own situation, and for research practice to be adapted to ensure their full participation."

- Can the theory of **good days and bad days** be expanded? This research found that disabled women feel more sexual on good days. How do disabled women create, maintain and extend their good days? What makes for a good day? What other experiences are affected by having a good day?

- Do nondisabled women have a good day and bad day process about their sexuality?

- Is this study relevant for disabled men and nondisabled men?

- Is there a difference between the experiences of people with acquired or congenital disabilities?

- How does the age of onset of disability affect disabled people's sexuality?

- Where do issues such as self-esteem, body image and self-identity fit with the good day and bad day theory?

- What are the experiences of the partners of disabled people? As Rieve (1989, p.275) notes, "No studies could be found that investigate and/or describe the profiles, perceptions and/or reactions of partners of persons with disabilities in relation to sexuality."

- What is the relationship between mothers and daughters when the daughter has a disability? How does having a disability impact on parental relationships? These are a number of different areas that would be useful to study.

- Do the results of this study relate to the literature and research on quality of life?

- Does turning a bad day into a good day have something to do with coping and adaptation studies?

- Are there studies from other minority groups that would support people with disabilities in our fight of oppression towards recognition in society?

- How else can nurses support the emancipation of disabled people?

- What do nurses need in order to feel able to support disabled women in our sexual health?

A useful research process for further studies would be to follow a critical approach. A critical approach was discussed by Smythe (2000, p.16) as it:

> ...starts with the premise that there are issues of power involved in our social constructions of reality. ... Research from this perspective brings a political agenda for change. Its aim is to expose inequities, to enable the oppressed to be empowered."

This approach looks to answer questions around power dynamics and economic influences. This research has found that disabled women are often powerless.

My responsibility

This study has included a number of suggestions for disabled women, nurses, society and for further research. I feel a sense of responsibility towards the participants to make some difference as a result of my findings. It is my intention to support disabled women by encouraging their sexuality. I will offer presentations to disabled women at conferences. I will create a workshop for disabled women, and offer it at a reduced rate. I will accept disabled women as clients in my private practise, and offer therapy at a reduced rate.

For nurses I am willing to present these findings at conferences. I will publish my findings in a nursing journal. I will offer training in sexuality to nurses and other health professionals, from a perspective of the social model of disability. I will encourage nurses and other health professionals to engage in supervision. I will also advertise my services as a supervisor.

Ideally, I will continue research in this area addressing one or two of the questions raised above. At this stage it is difficult to commit to further study. Being in the unique position of being a disabled woman nurse researcher I feel a sense of responsibility towards my community of disabled people to continue researching.

At a societal level, I am already involved as co-chairperson of the Auckland regional Disabled Persons Assembly. I am also a member of a local advisory committee for a national service providers organisation. I am also involved in the current Health Funding Authority transition to District Health Boards, with a particular interest in strategic planning for disabled people.

Summary

The social model of disability has been offered as a way of understanding disability. The social model explains that people are disabled by an inaccessible society that excludes people with impairments. The inaccessibility includes the physical environment, such as stairs instead of ramps, and includes attitudinal barriers held by the majority of the nondisabled population, such as the belief - disabled women are asexual. Disabled women have experienced double discrimination because of our gender and our impairment. This oppression of disabled people and women in particular has meant we have been studied and defined by nondisabled researchers. As a disabled woman and a nurse, I was in an excellent position to research the experience disabled women have of their sexuality.

My own experience set the scene for this research. I was not treated well when I wanted information about my own sexuality. This experience, combined with my reading led me to complete this research. Health professionals often treat disabled women poorly and ignore our sexual health needs. We have been considered as asexual and regarded as tragic cases from a medical model perspective of disability. The civil rights movement of disabled people has begun to challenge this perspective, so that disabled people can identify and be proud to be disabled.

I decided to complete a qualitative research project, guided by grounded theory methodology. Grounded theory, as defined by Glaser (1978b, p.2), was an appropriate methodology because:

Generating theory and doing social research are two parts of the same process. How the analyst enters the field to collect the data, his method of collection and codification of the data, his integrating of the categories, generating memos, and constructing theory – the full continuum of both the processes of generating theory and of social research – are *all* guided and integrated by the *emerging* theory. [sic]

This means that the aim of grounded theory is to generate theory from the information supplied by participants. Grounded theory has enough flexibility that feminist principles, for example my concerns of power imbalance, can be included (Keddy et al., 1996).

Eight disabled women agreed to be participants for this study. The majority were interviewed using a semi-structured, in depth format. The interviews were audiotaped and then transcribed. I began the data analysis following the first interview. This was done by coding each piece of data. This process continued for each of the transcripts. By constantly comparing the codes they were refined, and then grouped to form categories. The result was five categories; living ordinary lives, being disabled, surviving strategies, day-to-day struggle and sexuality. Eventually the categories of surviving strategies and day-to-day struggle became the basic social process called good days and bad days.

After the basic social process emerged I was able to construct my theory of disabled women's sexuality. I found that disabled women feel more sexual on good days and less sexual on bad days. There are a number of issues, which the participants spoke about as affecting their sexuality. Under the category 'being disabled' there were issues such as their impairment, other peoples attitudes, internalised oppression, access and a lack of money. Under the category 'ordinary lives' the women spoke about mothering, culture, being lesbian, being daughters, and health. To illustrate this theory two diagrams were provided.

To ensure credibility for the above finding I contacted two disabled women and explained the theory to one and asked the other to read this report. Their initial comments were very positive. Sharon immediately said, *yes, that makes sense.* The second woman, Victoria wrote, "The concept of 'good days' and 'bad days' is incredibly valid.

From the outcome of this research I have suggested some implications and made some recommendations for both disabled women and nurses. Simply put, disabled women are sexual and health professionals need to acknowledge us as full human beings. Disabled women need to support each other and educate themselves so that we can become powerful and fully active members of society. Nurses need to change their model of understanding to the social model, which is favoured by disabled people, and become proactive in supporting disabled people's emancipation.

Finally, this research has suggested areas requiring further research. Like many research reports this seems to have produced more questions than provided answers. Questions around the generalisability of this research and whether the finding was relevant for the nondisabled population were both included. But the most important future research that needs to be done is to support more disabled women to express, explain and describe our experiences of life from our unique perspectives.

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Appendix One

Information Sheet

DISABLED WOMEN'S SEXUALITY

Information Sheet

You are invited to consider participating in a research project.

My name is Susan Sherrard. I am a graduate student in the School of Health Sciences at Massey University where I am enrolled in a Master of Arts (Nursing) degree and am currently undertaking my thesis requirements. I am a Registered Comprehensive Nurse and have a Diploma in Psychotherapy. I currently teach psychotherapy and have my own private practice.

You are invited to participate in this study which is entitled "Disabled women's sexuality". A person you know will have told you about this study and provided you with my contact details so that you can call me if you are interested. I chose to use this networking process so that people's privacy is not compromised. If you agree to participate in this study only myself, my supervisor and a typist will know. We will keep your name and identifying details confidential.

In this study, it might be important to include information from people other than disabled women. I will ask for your consent to approach anyone else. I will then provide you with an extra information sheet and ask that you give it to the person. They will then be able to contact me if they are willing to participate in this study.

I am a disabled woman. I believe that disabled women are sexual beings, yet there is very little written about our experience of our sexuality. My interest in this topic is to find out about our sexuality. What do we, as disabled women, have in common around our sexuality? This information will be useful to other disabled women and to health professionals who work with us. This work is important because people tend to think we are 'asexual' that is, without sex. One benefit of research into our sexuality acknowledges that we are sexual. Another benefit is that the result of the research adds to our understanding of ourselves and other disabled women. It will also benefit health professionals by contributing to their theoretical knowledge, from our perspective.

You will need to share information about your sexuality. This is not an easy subject to talk about. Talking can bring up memories that may be good or bad, and they may surprise you. Talking about these experiences and memories might be good. It may be of benefit to talk openly and honestly with another disabled woman who understands. Or it might be difficult and bring up painful issues. In this case I would be able to suggest a counsellor you might like to continue talking with. If you did decide for some follow up counselling you would need to pay for that yourself.

Take your time to decide if you want to participate.

What is required?

You are asked to consider being interviewed in depth, on one or possibly more occasions. Interviews will be recorded either by audiotape, by written record or in whatever way best enables your communication. Each will take approximately one hour, but I will be guided by you. The information you give will be written into a transcription. If you request to add material a second interview will be arranged. Information collected from the transcripts will then be analysed and a theory developed.

If you take part in this study, you have the right to:

- Refuse to answer any particular question, and to withdraw from the study at any time, and/or ask for the tape recorder to be turned off.
- Ask any further questions about the study that occur to you during your participation.
- Provide information on the understanding that identifying data remain confidential to the researcher, her supervisor and a transcribing typist who will sign a confidentiality agreement. All information transcribed will only include pseudonyms (your choice) of any names or institutions, and it will not be possible to identify you in any reports prepared from this study.
- Be given access to a summary of the findings from the study when it is concluded.

The tapes of the interview will be transcribed and then stored in a locked metal filing cabinet. The transcriptions will be stored in a separate filing cabinet. Transcripts will also be saved on computer disk and these will be stored separately from the transcripts. I will keep this data for ten years for verification purposes of my thesis. I will also ask your permission to use the information for secondary analysis. This means if I decide to do more with the research, following completion of my Masters degree, I would like to continue using the information you provided. At the end of my study I will erase all tapes, shred transcripts and electronically erase computer data.

Once I have established the findings of this research I will plan to present the information at conferences, in the classes I teach and possibly by writing journal articles. The area of sexuality and disability is one I have been involved in for a number of years and plan to continue this work. The outcome of this research will be a valuable resource in this work.

This research project has been approved by the North Health Ethics Committee and the Massey University Humans Ethics Committee. If you have any queries or concerns regarding your rights as a participant in this research you may contact the Health Advocates Trust, phone: (09) 623 5799.

I can be contacted at Auckland Institute of Technology: (09) 307-9999

Extension: 7294

Supervisor: Dr Gillian White

School of Health Sciences

Massey University   (09) 443-9373

Appendix Two

Consent Form

DISABLED WOMEN'S SEXUALITY

Consent Form

I have read the Information Sheet for this study and have had the details of the study explained to me. I have had time to consider giving consent for being a participant in the study. Any questions about the study which I had, have been answered to my satisfaction, and I understand I may ask further questions at any time.

I understand that I am free to withdraw from the study at any time, and to decline to answer any particular questions in the study. I agree to provide information to the researcher on the understanding that my name and other identifying details will not be used without my permission.

REQUEST FOR INTERPRETER

English	I wish to have an interpreter.	Yes	No
Maori	E hiahia ana ahau ki tetahi tangata hei korero Maori ki ahau.	Ae	Kao
Samoan	Oute mana'o e iai se fa'amatala upu.	Ioe	Leai
Tongan	'Oku fiema'u ha fakatonulea.	Io	Ikai
Cook Island	Ka inangaro au i tetai tangata uri reo.	Ae	Kare
Niuean	Fia manako au ke fakaaoga e tagata fakahokohoko vagahau.	E	Nakai
	Other languages to be added following consultation with relevant communities		

I agree to participate in this study under the conditions set out on the Information Sheet, of which I have a copy.

I agree/do not agree to have the interview audio-tape recorded.

I also understand I have the right to request that recording be stopped at any time.

Signed:

Name:

Signature of Witness:

Investigator:

Date:

Appendix Three

Transcriber Consent Form

DISABLED WOMEN'S SEXUALITY

Transcriber Consent Form

I have read the Information Sheet for this study and have had the details of the study explained to me.

I understand that I am to type the transcripts of interviews given to me, deleting identifying data and using pseudonyms where required.

The information contained in the interviews is to remain completely confidential. I will not discuss or disclose information related to this study to anyone other than the researcher or her research supervisor, Dr Gillian White.

Tapes and transcripts will be stored in separate locked filing cabinets while they are in my possession. Electronic data will be stored on disk, not saved into a hard drive, and will be stored with transcripts when not in use.

Signed:

Name:

Signature of Witness:

Date: