Our Stories:
Women, Life and
Intellectual Disability

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This thesis is presented for the degree of
Doctor of Philosophy
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The Social Justice and Social Change Research Centre
University of Western Sydney
STATEMENT OF ORIGINALITY

The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

............................................................

Signature: Janette Welsby

Date: / / 2009
ACKNOWLEDGEMENTS

This thesis is the story of my doctorial experiences. As with any story, it includes the voices, stories, experiences and time of many people in its telling.

Firstly, I would like to thank Moira Carmody and Debbie Horsfall who have travelled with me throughout my many years of learning at the University of Western Sydney. Their very different styles have influenced, mentored, guided, pushed, infuriated, confused and challenged my ways of knowing, thinking and being. I have enjoyed the collegiality and professionalism that has characterised my supervisory experience and their belief in me over the last five years.

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<tr>
<td>AAMR</td>
<td>American Association on Mental Retardation</td>
</tr>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
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<td>ACT</td>
<td>Australian Capital Territory</td>
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<td>AFPC</td>
<td>Australian Fair Pay Commission</td>
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<td>AHRC</td>
<td>Australian Human Rights Commission</td>
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<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
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<td>ATO</td>
<td>Australian Taxation Office</td>
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<td>BSWAT</td>
<td>Business Services Wage Assessment Tool</td>
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<td>CSTDA</td>
<td>Commonwealth-State/Territory Disability Agreement</td>
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<td>DADHC</td>
<td>Department of Ageing, Disability and Home Care</td>
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<td>DEEWR</td>
<td>Department of Education Employment and Workplace Relations</td>
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<td>DET</td>
<td>Department of Education and Training</td>
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<td>DSP</td>
<td>Disability Support Pension</td>
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<td>FACS</td>
<td>Department of Family and Community Services</td>
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<td>FaHCSIA</td>
<td>Department of Families Housing Community Services and Indigenous Affairs</td>
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<td>IDRS</td>
<td>Intellectual Disability Rights Service</td>
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<td>NEDA</td>
<td>National Ethnic Disability Alliance</td>
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<tr>
<td>NGO</td>
<td>Non-Government Organisation</td>
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<td>NSW</td>
<td>New South Wales</td>
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<tr>
<td>OECD</td>
<td>Organisation for Economic Co-operation and Development</td>
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<td>SACS</td>
<td>Social and Community Services Award</td>
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<td>TAFE</td>
<td>Technical and Further Education</td>
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<td>UK</td>
<td>United Kingdom</td>
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<td>UN</td>
<td>United Nations</td>
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<tr>
<td>UPIAS</td>
<td>Union of the Physically Impaired Against Segregation</td>
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<td>US or USA</td>
<td>United States of America</td>
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never realised when I started this research project it would take me to the depths of despair and, if I did, I would have changed topic. Shirley, Kay, Lara, Cindy and Evie embraced and touched my life in such a profound way that my life will never be the same. I feel the burden of knowledge, the guilt of leaving them behind and the fear of repercussions for them in telling of the oppression of their lives. These feelings have left me in many ways voiceless and unable to write the things I want to say. The tension between honouring the women’s stories and the oppressive regimes that I observed has been consuming.

Going into this research I had the naivety of an outsider and thought that my past experience with people with a disability was preparation enough. Now I realise that it wasn’t. In the early 1980s I was part of a small dedicated team that trained “special guide/brownie leaders” in Queensland. We pushed for integrated groups and I was central to uncovering and stopping the practice of taking away communication boards1 and/or putting young women/girls under cold showers for punishment. The right of individual choice became paramount and rather than being treated as small children and being locked in Brownies the girls progressed at their own pace onto Guides and then Ranger Guides. Disability awareness became part of the Guiding program with the implementation of activities such as ‘walk a mile in another girl’s shoes’ for Brownies, which explored for example what it was like to be deaf and introduced the girls to sign language.

As a child I grew up with Peter2 who would regularly visit our house and bake cup cakes, wear an apron, mum’s high heel shoes and pearls. Peter wanted be a

1 Communication boards are picture based communication aids that help people who have difficulties communicating their need verbally.
2 All the names in this thesis have been changed except for my two supervisors – Moira Carmody and Debbie Horsfall and Moi the artist who facilitated the art workshops.
housewife when he grew up and so came to our home to learn from my mother the
finer arts of being a woman: cooking, cleaning, applying lipstick and walking in
high heel shoes. This was during the late 1960s and early 1970s. I don't think my
parents knew about transvestites and anyway Peter had Down’s Syndrome so
wanting to be a woman was taken as a funny quirk rather than an expression of his
gender identity. Although Peter was in his late teens he was still treated as a child by
everyone except his parents. I realise now that Peter’s parents were ahead of their
time and fought for him to be treated as ‘normal’ to attend the local Catholic school,
 obtain a drivers licence, live independently and work in a regular job. Peter’s mum in
 particular was adamant that he be treated as any other person. Behind her back she
was ridiculed and pitied; a tragic figure who travelled the world trying to find a cure
and unable to accept that her son was not normal. Both Peter’s parents had died by
the late 1970s and he was put in an institution. We never saw him again.

My place of escape all though my years at school was at the Bays’ home.
They lived around the corner from us and their house always seemed to be filled with
noise, music, laughter and Cracker Barrel Tasty Cheese. Amy Bay and I went
through school together and I spent a lot of time at her home on weekends and after
school. Amy’s sister is Sue. Sue is a year younger than me and has an intellectual
disability, so for over forty years Sue has been part of my life.

This is really the distinction isn’t it? The different people who have a
disability I have met over my life time have been part of my life. For a time they
touched my world, my reality, my life in which I’m at the centre, but this research
project took me into the lives of five women: Lara, Kay, Shirley, Cindy and Evie. It
was their life, their reality, their world in which they are at the centre and I am their
brief encounter. For them, this research was a small moment in time that broke the
monotony, took them out of their daily routine into a space where they talked and
laughed about their lives while they painted, drew and sculptured.

3 It was said that Peter had “challenging behaviors” so he could not stay in the family home after his
parents died. I suspect it had to do with his gender or cross dressing.
4 We only ever had Kraft Processed Cheese that came in a blue packet. It doesn’t have to be
refrigerated, has little flavour and the consistency of rubber.
**Bearing Witness**

Their lives have moved on,  
mine hasn’t  
I am disempowered.  
Caught in the headlights.  
Adrift in time.  
In the second that’s past.

Lost  
in the spaces between  
letters in a word  
hope and despair  
guilt and loyalty  
good intentions and betrayal.

Paralysed  
Diminished  
Vanishing  
Falling  
The silent scream  
eyes wedged open  
voiceless.

(Janette Welsby 2006).
To bear witness is to carry the burden of responsibility and it is something I had never really thought about until now. In the course of picking the women up and dropping them home after workshops and interviews I witnessed the reality of their everyday lives. Drawn in like a vortex. Some of the things I saw shocked me while others confused me. Their lives were at times a paradox of human rights empowerment self advocacy discourse on one side, governmental and institutional policy, procedure and practice on the other and the women inhabiting the space in between. It seemed that the further an individual was drawn into ‘the system’ the less personal freedom and autonomy they had over their own lives.

Throughout this journey I have often captured myself in the moment. The simple taken for granted moments of my everyday life: meeting friends for coffee, jumping in the car, organising what I have to do for the day, going shopping, talking on the telephone. Juxtaposed against the lives of these five women, my life holds few commonalities with theirs. My purpose here is not to place these women in a binary position subordinate to my own, nor is it to define them as ‘other’. It is to tell the stories of their lives, to weave their story into my journey. At the beginning it was to be a celebration of their lives and to some extent it is. But I have stepped ahead of myself. I am coming to the end of this journey while you are only at the beginning of this story ....
THESIS SUMMARY

My thesis, *Our stories: women, life and intellectual disability* tells part of the life stories of five Australian women with an intellectual disability between the ages of 29 and 52, who live in the suburbs of Sydney. There is an increasing body of work about intellectual disability, however, there is little written about the lives of women with an intellectual disability from their perspective, and even less about what is important to them in their lives. This thesis foregrounds knowledge and voices that are usually ignored within the dominant intellectually-abled culture.

I recognise that this thesis has been shaped by my personal tenets of social justice that come from feminism, my Catholic upbringing and my Marxist Socialist father. Although at the beginning of this research it was not my intention, this thesis is a “conscious political action to change women’s position in society” that aims, in this instance, to shift the centre from which knowledge is generated and place women with an intellectual disability at its centre (Helen Callaway, 1991 pp. 459-460). Using an interpretive paradigm and influenced by post-modernism and feminism, my representation of the women’s stories interrupt the dominant discourses about self-autonomy, women with an intellectual disability, and the management of perceived risk. By placing these women’s stories at the centre of the discussion, I hope that new ways of thinking about the lived experiences of intellectual disability will emerge. These stories also provide information about what is important to these women and how they want to live their lives.

In 2005, I approached a number of different disability services to see if they might know any women likely to be interested in being part of this research
The stories that are included here are some of the stories and artworks of five women who agreed to take part, and the story of my research journey. Through the layering of stories — the women’s stories, my story and the wider social world in which we live, the power structures within the narratives begin to emerge.

I have chosen to use a multiple methods approach incorporating both feminist and arts-based research design practices to re-tell and explore these stories. These included a series of art workshops and one-on-one interviews that provided the opportunity for the women to express themselves and tell their stories in more ways than just the spoken word. The art expression exercises gave each woman time to think and reflect on her own life and decide which stories she wanted to share. In this way knowledge production worked on two different levels. The first level consists of each woman’s individual narrative. The second level is the narratives shaped by the collective story process.

In the collective sharing of individual narratives within the group the women became co-researchers, in that they witnessed the other women’s stories, asked questions and discussed the similarities and differences in their own life experiences. This collective sharing of narratives enabled knowledge to be constructed collaboratively. Other forms of data collection included observation, field notes and reflections.

In analysing the data, I used a thematic approach. I had little experience or knowledge of intellectual disability and I naively ventured forth with my eyes wide shut trusting in the research design and where it would take me. As the data analysis began to unfold I found inconsistencies between the women’s stories, my observations and government policies. The contradictions in my data made it evident that a ‘normal life’ for the women in the study was illusive, elusive and ultimately defined and often controlled by a person who is

5 The intention of this research was not to produce works of art but rather to use art as a way to collect data.
intellectually-abled and that the women knew and could talk about specific situations.

In light of these contradictions, much of my journey has been spent wrestling with how to write this thesis in a way that does not diminish the participants, experiences and voices. In my writing I have worked against oppressive regimes of power that feed into dominant discourses about women with an intellectual disability that positions them as powerless and dependent. It would have been easy just to say that these women’s lives are oppressed. That is only one truth — one layer of story. The women never used words such as silenced, powerless, or oppressed in any of their self-narratives. Like many women, they go to work, do domestic chores, discuss men, think they are too fat, spend their money on clothes, shoes, make-up or going out, are involved in the lives of their family and enjoy the company of good friends. This is also a truth — another layer of story.

Like all stories, this thesis is layered and it is experimental in design. I have chosen to write using different textual representations – narrative, poetry, short stories; visual images; changing fonts; colour; space and texture. I have done this to separate and position different stories and voices, to make authorship as clear as possible in the re-telling of stories, and to re-present and locate these stories within the broader social context of the women’s lives. I aim to respect the integrity and entirety of Kay, Shirley, Lara, Cindy and Evie’s stories, experiences and knowledge and come as close as I can in text to the embodied reality that these women live. I have done this so that you, the reader, begin to know these women as the living, breathing and feeling women I know.

Included within the text are small interludes that disrupt the reading of the thesis. Their purpose is to sign-post a shift or to take you by surprise and re-create a moment or evoke an emotion and cause a mis-understanding. I have used these different techniques to textually re-present the multiple realities or worlds that exist at the same point in time and to convey how dominant
discourses are embodied as they influence, control and shape notions of competency, normality and intellectual disability.

I found that in many ways Kay, Cindy, Lara, Evie and Shirley still struggle to obtain what the rest of us in the community would consider to be an ordinary life. There is a significant gap between the principles set out in Australian disability policies and the lived experiences of the women who took part in this study. These women were subject to covert and overt forms of discrimination and segregation through policy funding, duty of care and attitudes held by the community. The further the women were drawn into the welfare and disability services systems the less personal freedom and choice they had over their own lives, resulting in them having a community presence rather than being participants in community life.

The history of and research on people with an intellectual disability has traditionally been documented and owned by the intellectually-abled (Jan Walmsley, 1991, Tim Booth and Wendy Booth, 1996, Dan Goodley, 1996). This thesis contributes to the small but growing historical literature that “recounts and reclaims” the everyday/everynight lives of people with an intellectual disability from their perspective (Sally French and John Swain, 2006 pp. 394). It also makes a methodological contribution as a creative method of story-gathering was developed so that the women were able to express themselves both verbally and visually. The creative process facilitated opportunities for the women and myself to reformulate and reflect on our everyday stories and narratives to locate them within a wider context. It provided a fresh perspective on the diversity of experience and controlled boundaries these women live within. This research also contributes to feminist knowledge about the lives of women and fills a gap in disability and feminist literature that has failed to take account of the needs and voices of women with an intellectual disability.

**Overview Of The Chapters**
This thesis is a blend of traditional and non-traditional forms of writing. There are no discrete literature review or findings chapters. Instead these are
distributed throughout the thesis. This document is written in a plain English style so that it can be read by academic and non-academic readers. Most of the chapters are song titles to honour *Shirley* and *Cindy* — two participants whose ‘thing was music’ rather than art. This research is about voice and being seen. To clearly distinguish each participant’s voice/story from the other participants and my own voice, I have used different fonts throughout the text. Each participant’s voice is recognisable through the use of an individual colour and is written using a size 12 Arial font. Further reflecting the aims of this research and feminist methods that places recognition on who is speaking, a size 11 Cambria font and the first name and surname of all authors has been used within the text and in the reference list.

Chapter 1 – **Introduction** Explains the genesis of the research, begins to frame it within the literature and provides an overview of my personal and theoretical approaches. It locates the research problem and introduces the core questions.

Chapter 2 – “**Sisters are doin’ it for themselves**” Outlines the purpose, context and theoretical approaches I have taken in this research. The chapter provides a review of the medical and social models of disability and feminist disability theory. It explains the reasons why I have chosen to reject the dominant theories of disability and adopt a post-modern and feminist perspective that explores individual experience of what it means to be a woman who has an intellectual disability.

Chapter 3 – “**I’m coming out**” introduces the women who took part in the study. Accompanied by their artwork it re-tells some of their stories. The chapter is written in a style as close as possible to the women’s own words. It speaks directly to the reader so you begin to know each woman.

Chapter 4 – “**My way**” explains my rationale for the research design, the decisions about location and recruitment, the use of art workshops, interviews and other supplementary data sources. I explain and describe the ethical and logistical considerations and how I analysed and interpreted the data.
Chapter 5 – “Show some emotion” sets the epistemological approach I have taken in this research and marks out the places from which my own discourse speaks. This chapter details the places that are important to the production of knowledge in this thesis: emotion, ethics of care, sharing stories, community and using art.

Chapter 6 – “Another day” explores the every day work experiences of the women. It begins with the re-telling of the stories of a typical working day for Evie, Shirley and Kay. This is followed by an exploration of the social structures in which they work, focusing on the implications of relying on a disability support pension as their main source of income, their career aspirations and workplace training.

Chapter 7 – “You don’t own me” begins with a discourse analysis of NSW State and Federal Government policies and regulations that relate to supported accommodation. The analysis uncovered three dominant discourses: rights, neoliberalism and risk management. Rather than promoting social inclusion the discourses embedded within the documents and the implementation of neoliberalist and risk management practices create a significant gap between the lived reality of Evie and Cindy and disability rights.

Chapter 8 – “Tubthumper” uses some of Lara’s stories and reflections as a platform to begin a discussion on self identity. It also explores the importance of friendships in the women’s lives, how maintaining old friendships and making new ones is impacted upon by physical restrictions and having a limited income.

Chapter 9 – “You’re the voice” draws together the significant findings of this research and recommendations for further research.

Appendix – Contains additional relevant documentation of the research project.
Figure 1 - Your window into my research.

6 This idea was adapted from an example used by Patrick Diamond and Carol Mullen (1999)
Opening windows

This window (Figure 1) represents being on the outside looking in. ‘Opening Windows’ is the first of a number of ‘interludes’. This interlude marks the way into this thesis and my research journey. The use of a window is symbolic as research is about drawing back curtains and shining a light onto a particular subject.

My research design created a relationship where the women shared some important aspects of their personal lives with me. They took me into their lives and for a brief moment in time I was able to see and share part of the social world in which they live.

In Opening Windows I have used phrases that encapsulate my research experience. The window is designed to be read; from the top left corner and down each column, line-by-line as with traditional text; diagonally; or from the bottom left-hand corner, going across and then up the rows. Whichever way you decide to read the window, the text is disjointed and jarring, reminding us that the process of research takes sections of a person’s life and fragments them into smaller pieces of data to support or refute a point of view.

Attempting to minimise fragmentation presented one of the greatest challenges in writing this thesis. How to compress the women I grew to know, from people to story to text, so that you, the reader, are able to take the flattened, largely black and white text, mould on the flesh tones and transform the stories back into living feeling people (Lisa Armitage and Janette Welsby, 2009).

The idea of a window as a way of separating worlds is repeated in the following story titled ‘Walk On By’ on page 15.
1. INTRODUCTION

Our Stories: Women, Life and Intellectual Disability, aims to make clear some of the personal ambivalences and complexities that lie hidden under cultural myths and official rhetoric about intellectual disability by exploring the stories of real people. The thesis re-tells some of the stories of how Kay, Lara, Shirley, Evie and Cindy, women who have an intellectual disability, live within the tightly controlled boundaries of policy and practices that seek to control and define their lives. It provides a place for them to tell stories about their life and what matters to them: a space to hold their knowledge so that it can be told — but more importantly heard. Knowledge about intellectual disability is often told from the perspective of an advocate, professional, family member or carer, leaving the voices of women with an intellectual disability suffocated, or dismissed as unreliable, incompetent or untrustworthy. These dominant narratives hide the reality that many women with an intellectual disability work, study, vote, cook, have sex, maintain long term relationships and bring up children (Debbie Horsfall and Janette Welsby, 2007).

Images and stories about women with an intellectual disability as being strong, independent and capable, destabilise and interrupt the dominant view of what it means to have an intellectual disability. These views have been historically, socially and institutionally constructed to place women with an intellectual disability at the margins.

In this thesis I have tried to locate the embodied experiences and lives of the women through the use of multiple voices and images within the text (Laurel Richardson, 1994b, 1997, Kathryn Church, 1995). Within these many voices
there are my own voices first as a woman and then as an academic, the voices of Kay, Evie, Shirley, Lara, Cindy, the official voices of government policy and the voices of other researchers and academics. I start with my story, and how I came to be here.

**A Research Project Began**

The place I am in now, is a vastly different place from where I began in 2004 and although the distance between the two points can be measured linearly, the journey cannot. This research began as a result of my Bachelors Honours project that was an analysis of the different discourses that prevented men who had been sexually assaulted from seeking help (Janette Welsby, 2003, 2005). As a result of discussing and presenting this work I began to be told ‘rape horror stories’, a number of which were about women who had an intellectual disability. *Walk On By* (over page) is a story that brings in elements of each of those accounts and explains why I wanted to understand the experiences of women with an intellectual disability.

Out of respect for the women who were sexually assaulted and the people who told me the story of their friend, sister, daughter or niece, I made a decision to write a fictional re-interpretation of the real stories that were told to me. A common thread of the true stories is that the sexual assaults often took place regularly over a period of time, by someone they knew, and were never reported to the police. As in this story, some took place during the day in public places and often people witnessed the assault but did not stop to intervene.
Walk On By

We always met here every Thursday for lunch. The
Woodhen Café was in the High Street. It is painted blue, has two
large picture windows and a recessed entry door. It’s rather old-
fashioned and quaint, with a little gold bell that softly rings when
the door opens to announce the arrival and exit of its patrons. I
suppose there would be ten small round tables inside. The walls are
cream with large pictures of other flightless birds on the wall. It’s
one of those places that are warm, familiar and out of sync with
time: where you can sit and watch the world go by.

We meet inside about a quarter to one. We sit at the
table in the corner on the right near the espresso machine. There are
always people coming and going, but there are a couple of regulars.
The young couple come in about one-ish. They sit at the first table
near the window on the left with their backs to the window: lost
in each other. She has her arms wrapped around his arm, her head
resting on his shoulder. They eat and talk always entwined. Just
the two of them.

Grey suit is always there when I arrive. He is by himself
in the same light grey suit, white shirt, black shoes. Only the ties
change. There is something comforting about the routines of his
life. He reads until his meal arrives; politely thanks the waitress;
closes the newspaper, folds it in half and then in half again, places
it on the table under his black wallet with his mobile phone on top,
turns the plate around, picks up his knife and fork and eats slowly,
precisely and focused on the task at hand. When he is finished, he
turns in his chair, crosses his legs, unfolds the paper, finds his place
and drinks his coffee. He must work close by because around
1.30ish he refolds the paper, puts it under his arm, takes out some
money from his wallet, places it on the table, straightens his suit,
nods his head to the waitress and leaves walking up to the right.
The two old biddies usually arrive around the same time as we do. I suppose they would be in their late sixties. They sit at the table next to ours towards the window. They kiss European style and immediately fill the space with noise and chatter. They twitter on about children, husbands and the town gossip.

I remember the first day we noticed them. Frilly white, the waitress, walked to the window to watch them. They were on the other side of the street, he had hold of the woman’s arm, and they walked away down towards the park. I remember because frilly white had had a conversation about it with the biddies as she wasn’t sure if something strange was going on. She knew the woman by sight as a person who lived in the local group home but not the man. It was a strange conversation about the dangers of getting involved: there was the man who got shot for trying to help a woman in the paper, and the guy in outback Australia.

We started noticing them after that. He would be waiting for her on the other side of the road opposite the café leaning back on the wall on one leg. She would walk up, he’d stop, say something, take her arm and they would walk back the same way she had just come. About twenty minutes later, she would walk back again only this time she was alone. I suppose I shouldn’t have been surprised when you asked me about them. We thought it was a bit odd. The routineness of it made it seem normal and they blended into the scene becoming as familiar to us as grey suit, the couple, frilly white and the biddies. How were we to know he was a predator and she his easy prey? Stalked, trapped and captured.

Grey suit opened the newspaper and started reading as if nothing had happened. The story had somehow become the biddies’ drama “no one is safe anymore” they declared. Their chatter was interrupted by the sound of the bell as the door to the café opened. The couple came in entwined, separating only to walk around the table, they moved the chairs, sat together with their backs to the window, folded back into each other’s arms, oblivious to the chaos around them.
Real stories
In the initial stages of planning this research and at odd times during my candidature, when speaking to different people about how I came to do this research I have sometimes re-told one of the real stories that make up *Walk On By*. What I found interesting was that the female listeners were initially shocked when hearing the story of the sexual assault of a woman with an intellectual disability; however, they were always able to justify the inaction of any witnesses/passersby. Most of the discussion focused on the reluctant witnesses rather than the female survivor. Shifting the focus away from the woman with an intellectual disability in *'Walk On By'* was done to emphasise how women with an intellectual disability are culturally visible yet not present, present but not visible, existing in both spheres at the same time.

What I realised in the re-telling and discussing of these stories was that many of the women I spoke to, including myself, did not have regular contact with anyone who had an intellectual disability and/or knew little about their lives. I started to look at research about the sexual assault and sexuality of women with an intellectual disability.

The fusion of social policy and the disability rights movement had resulted in the increased recognition of the lives of people with an intellectual disability. I noticed an extraordinary focus on sexuality and sexual rights. For example, *Sexuality and Disability* is a journal devoted to the subject. In addition to this journal, if the following list seems long, I am glad because it is my intention to visually demonstrate what I feel is an inordinate focus of attention on the sexual lives of people with an intellectual disability:

For research on sexuality of people with an intellectual disability see:
AJ Shaddock (1979)
Paul Koegal and Robert Whittemore (1983)
Hilary Homans (1987)
Bill Robbins (1990)
Winifred Kempton and Emily Kahn (1991)
Tim Booth and Wendy Booth (1992)
Ann Craft (1993)
Hilary Brown (1994)
Sandra Welner (1997)
Christine Tilley (1998)
Michelle McCarthy (1999)
Paul Cambridge and Bryan Mellan (2000)
Glenys Carlson, Miriam Taylor and Jill Wilson (2000)
Pamela Block (2002)
Randi Chance (2002)
Lynne Hillier, Kelley Johnson and Lyn Harrison (2002)
Joan Lesseliers and Geert Van Hove (2002)
Wolfgang Plaute, David Westling and Brigitte Cizek (2002)
Anthony Thompson (2002)
Danette Crawford and Joan Ostrove (2003)
Katrina Scior (2003)
Rose Galvin (2006)

For research about the sexual knowledge and sexual education of people with an intellectual disability see:
Marita McCabe and Robert Cummings (1992)
Marita McCabe and Agi Schreck (1992)
Marilyn Stromsness (1994)
Michelle McCarthy (1996)
Michelle McCarthy (1998)
Jane Chivers and Sue Mathieson (2000)
Ben Spiecker and Jan Steutel (2002)
Stephen Greenspan (2002)
C Coren (2003)
Glynis Murphy (2003)
Jennifer Galea, Jenny Butler, Teresa Iacono and Daniel Leighton (2004)
Martin Lyden (2007)
Carolyn Tice and Diane Harnek Hall (2008)

For research on the attitudes of disability workers and family members towards people with an intellectual disability as sexual beings see:
James Chapman and Amanda Pitccathly (1985)
Gilles Trudel and Gilles Desjardins (1992)
Pamela Boyle (1993)
Bob Heyman and Sarah Huckle (1993)
James Murray and Patricia Minnes (1994)
Bob Heyman (1995)
Agi Szollos and Marita McCabe (1995)
Roger Levesque (1996)
Michelle McCarthy and David Thompson (1996)
Jill Manthorpe, Mike Walsh with Andy Alaszewski and Larry Harrison (1997)
Pamela Wolfe (1997)
Orieda Horn Anderson (2000)
Kirsty Keywood (2001)
Marjorie Aunos and Maurice Feldman (2002)
Joanna Karellou (2003a, 2003b)
Monica Cuskelly and Rachel Bryde (2004)
Monica Cuskelly and Linda Gilmore (2007)
Carol Anne Hamilton (2009)
Andrea Hollomotz and The Speaking up Committee (2009)
Chapter One

My intention here is not to take away from this important and often groundbreaking research into the hidden nature of physical and sexual violence and intellectual disability. This literature, however, raised two concerns for me. One of the ripple effects of this research was that it directly fed into the dominant discourse that positions people with an intellectual disability, and in particular women, as vulnerable victims in need of protection. Secondly, the voices of people with an intellectual disability were often missing.

Not having control over the production and distribution of knowledge about their lives, women and men with an intellectual disability are often not in a position to provide counter-narratives to those of the dominant discourse. In terms of research practices and policymaking, men and women who have an intellectual disability are marginalised, and seldom seen or heard (Edward Hall, 2004). This lack of attention reflects the marginal or subordinate social position that the majority of people with an intellectual disability hold in Australia and other Western societies; people with an intellectual disability have fewer opportunities for employment and education, less choice of where they live, commonly experience discrimination, abuse, poorer health and a lack of control over the key decisions that affect their lives (Foundation for People with Learning Disabilities, 2007).

Historically, people with an intellectual disability were rarely seen as full subjects in the research process. They were (and often still are) positioned as not sensible, unreliable or untrustworthy research respondents or participants (Janette Welsby and Debbie Horsfall, 2006). This generalised incompetent construction of people who have a disability has resulted in information being gathered about them from ‘more reliable’ sources such as a parent, professional, carer, or advocate (Mike Oliver, 1992, Marjorie Aunos and Maurice Feldman, 2002, Annabelle Grundy, Michelle McGinn and Dawn Pollon, 2005). When people with an intellectual disability have been part of a research study they are often not empowered to define their lives on their own terms (Carol Rambo Ronai, 1996). Instead, their lives are defined for and about them by other experts – teachers, social workers, parents, psychologists (Mike Oliver,
1992, Josephine Jenkinson, 1993, Jackie Kilbane and Tom McLean, 2008). This demonstrates how parents and professionals control the boundaries of freedom and responsibility based on their knowledge and beliefs, and involvement with women with an intellectual disability (Joan Lesseliers and Geert Van Hove, 2002). There is however, a growing body of work written by and with women with intellectual disabilities see Dorothy Atkinson and Fiona Williams (1990), Dorothy Atkinson, Michelle McCarthy, Jan Walmsley, Mabel Cooper, Sheena Rolp, Simone Aspis, Pam Barette, Mary Coventry and Gloria Ferns (2000), Rannveig Traustadottir and Kelley Johnson (2000), Kelley Johnson, Lynne Hillier, Lyn Harrison and Patsie Frawley (2001), Mary Stuart (2002), Kelley Johnson and Rannveig Traustadottir (2005).

Through the process of reviewing the literature in these early stages of the project I realised I wanted my research to be different. I wanted to know what people with an intellectual disability thought about their lives but it was difficult to find their stories in the literature. I wanted to work with women rather than men or a mixed group. I chose to do this for a number of reasons. I am a feminist and interested in women’s experiences. As a new researcher I felt that some women may not be comfortable talking about themselves in a mixed group. Also, I wanted to disrupt the negative stereotypes of women with an intellectual disability that positions them as ‘less than’ intellectually-abled women. These stereotypes hide the reality that people with an intellectual disability do live interesting and varied lives.

**Settling on a topic**

In 2004, the Australian Federal Government introduced changes to the Disability Support Pension (DSP) that incorporated mutual responsibility, where people with a disability are expected to work for benefits. The work requirement was fifteen hours per week. Payment was contingent upon the recipients’ demonstration of community participation and designed to move people with a disability who have the capacity to work back into the workforce. There was extensive public debate about the proposed changes to the DSP, which government rhetoric claimed was about making sure that “people with disabilities
The picture on the nextpage is of Lara hiding behind her rubbings at the third workshop.

This story reflects some of the hidden nature of intellectual disability. Staff hiding behind practices that make their work easier and not the lives of people they support. Hiding information – withholding information or not suppling the full information inhibits people with intellectual disabilities ability to make informed choices. Hiding populations – people with intellectual disabilities often work and live in closed environments of group homes and sheltered workshops where they have limited contact with the wider community
I had to go and do self advocacy training at … Lots of the staff don’t like it you know. It makes it easier for them if they don’t give the clients any choices.

When we go to some of these place where they (people with an intellectual disability) live all we saw was the training room and if you haven’t seen the place it is hard to visualise what sort of places they are coming from.

Because you know, I always consider I am very lucky. I never had to go into a group home or an institution or anything like that. So I don’t know what it is like but I really really feel sorry for people that do because there are some nasty things that have come out of them.

Ok they closed the institutions down but these cottages and hostels and that — they are exactly like institutions. Lara.
have access to their fair share of jobs and the benefits that flow from work” (Kay Patterson, 2004 pp. 1). I suspected the reality for women with an intellectual disability to be somewhat different and set out to explore this issue.

Research on women with an intellectual disability in the area of work outside of rehabilitation was somewhat sparse. What was available tended to focus on the right to employment issues that included the prevalence of employer discrimination, the extent of the labour market disadvantage, anti-discrimination and equal opportunity laws and attitudes among employers in hiring people who have a disability (see John Morrell, 1990, Neil Lunt and Patricia Thornton, 1994, Sheila Honey, Nigel Meager and M. Williams, 1996, Marta Russell, 2002, Darlene Unger, 2002, Alastair Wilson, 2003). The focus on the shift in economic policy and rationalism as being detrimental to employment opportunities for people with an intellectual disability had also gained attention (see Mark Hyde, 1998, Vashti Gosling and Lesley Cotterill, 2000, Alastair Wilson, Sheila Riddell and Stephen Baron, 2002).

The concentration on researching the implications of market deregulation and micro-policy meant that the experiences of the workers had been overlooked. Two studies that spoke directly with people who have an intellectual disability were Mark Hyde (1998) in the United States and Patricia Reid and Anne Bray (1998) in New Zealand. Mark Hyde's (1998) study on employees of sheltered and employer-supported workplaces focused on the level of satisfaction in relation to changes in social policy. Patricia Reid and Anne Bray's (1998 pp. 238) New Zealand study found that their participants worked part-time in open employment, often in isolation with little chance to socialise with other workers, still valued their jobs and “wanted the chance to progress to more hours or greater challenges”. The New Zealand National Advisory Committee on Health and Disability (Anne Bray, 2003) found that the views and preferences of adults with an intellectual disability about work were not actively sought, nor were they often included in the consultation process of work place support, service planning or evaluation even though they are the central focus. This highlights the way in which people with an intellectual disability are often excluded from
taking an active part in decisions that personally affect them. Although the
Disability Rights Movement has been dominant in changing community
attitudes, a paternalistic approach that views the professional as the holder of
knowledge prevails in the area of intellectual disability.
The evolution of the research design

Asking and then listening to what women had to say became paramount to my design of the project. This perspective, unlike much else about my research, never waned or changed. Within the disability literature, I had begun to read about emancipatory research design. Located within critical social science, at its centre it is a “political commitment to confront disability by changing: the social relations of research production, including ... the relationship between the researchers and those being researched; and the links between research and policy initiatives” (Colin Barnes and Geof Mercer, 1997 pp. 5). This perspective recognises that rather than being objective and neutral, research is inherently political and should be guided by the purposes of emancipation.

There were some researchers interested in intellectual disability who incorporated emancipatory or collaborative and inclusive research practices (see Jan Walmsley, 2001, Malcolm Richardson, 2002, Tim Booth and Wendy Booth, 2003, Jonathan Perry and David Felce, 2004, Annabelle Grundy, et al., 2005). I became passionate about it, as this excerpt from my confirmation of candidature document shows.

The lack of participatory research found in the literature review and the disempowered role women with learning disabilities often occupy in social science and feminist research is of a personal concern. There is little evidence to suggest that women with a learning disability were offered a voice through or had any control over the research being conducted into their lives. Typically it is the researcher who decides the problems addressed, the questions asked to whom and in what manner they are asked (Paul Duckett and David Fryer, 1998). This research project will aim at redressing some of the imbalance and follow the principles as outlined by John Heron (1991 pp. 34-35):

for persons, as autonomous beings, have a moral right to participate in decisions that claim to generate knowledge about them. Such a right...protects them...from being managed and manipulated... the moral principle of respect for persons is most fully honoured when power is shared not only in application... but also in the generation of knowledge...doing research on persons involves an important educational commitment: to provide conditions under which subjects can enhance their capacity for self-determination in acquiring knowledge about the human condition.
The type of research method suggested by John Heron provides the opportunity for participants to collaborate in all stages of a study, including reports or publications. I acknowledged the difficulties of using this style of research, particularly given that I had already chosen the topic, and method of data collection, and that I would control what was written in this thesis. Nevertheless my research would be emancipatory. My primary supervisor’s (Moira Carmody Personal Communication, 23rd February 2005), advice that “the only person you can guarantee to emancipate in any research is your-self” fell on deaf ears, as I began to shave the edges off the principles of emancipatory research to fit my agenda. It was not until after the field work was completed and I began to reflect and examine my research practices, assumptions and position that Moira’s insightful words began to ring true.

Tim Booth and Wendy Booth’s (1994a, 1994b, 1996, 1997, 1998b, 2003) work with parents who have an intellectual disability influenced my initial research design. They had used Photovoice (see Caroline Wang and Mary Ann Burris, 1994) as a research method and it inspired me to do the same. Photovoice is a technique that uses photography as a means of opening a window into another person’s life. Through the use of cameras Photovoice enables participants to control how they represent themselves and see their situation by taking pictures that reflect their place in and experience of the world (Cheryl Killion and Caroline Wang, 2000, Tim Booth and Wendy Booth, 2003, Alice McIntyre, 2003, Richard Woolrych, 2004). The process challenges the established politics of representation by shifting control over the means for “documenting lives from the powerful to the powerless, the expert to the lay-person, the professional to the client, the bureaucrat to the citizen, the observer to the observed” (Tim Booth and Wendy Booth, 2003 pp. 432).

In my research I wanted to work with the women, and for them to have as much control over the process as possible, and I believed at the time that Photovoice was the right method to do this. For a raft of ethical, logistical and legal reasons (that are discussed in chapter 4) it became impossible and impractical to take cameras into the workplace. I had to totally rethink my research design. This
process forced me to refine and develop what it was that I actually wanted to achieve. The fundamental not negotiable principles that shaped my research were:

- The women had to have as much control as possible over the process. For example, negotiating the themes of discussion, and inviting the women to be involved throughout the research. In this way some of the power imbalances within the relationship between the researcher and researched could be reduced.

- Interviewing people with an intellectual disability was well documented as being problematic (Tim Booth and Wendy Booth, 1994b, Paul Duckett and David Fryer, 1998, John Swain, Bob Heyman and Maureen Gillman, 1998, Jackie Rodgers, 1999, Jonathan Perry and David Felce, 2004). Therefore the research had to have a multi-methods approach rather than relying on one-on-one interviews as the main source of data collection.

- Group discussion had to be part of the design.

- The discussion had to be free-flowing and semi-structured around broad themes.

- There had to be time to allow for the women to think, reflect and decide what they wanted to say. People with an intellectual disability’s thought processes are sometimes slower and this had to be a consideration.

- The research process had to be a two-way exchange. This worked on two levels: I would be open and honest with the women and answer any questions they wanted to know about me and my life and the research had to give something back to the women.

- The research had to be a creative and an enjoyable experience.

As fate would have it, I happened to go to Get Over It, an art exhibition by Studio ARTES, a community organisation that provides training programs for people with disabilities, at Hornsby, a northern suburb of Sydney in July 2005. All the artists that exhibited their work in this exhibition had an intellectual disability. The art works included landscape, still life and portrait painting in watercolour, pastels and oil, there were charcoal drawings, pottery, and photography. As I walked around the gallery space and listened to some of the artists speak about their work and what inspired them I realised some of the sanctions I was placing on this research by limiting the participants to
expressing themselves though the use of only one medium — photography. Seeing the range of visual art on display inspired me to think outside the square and introduce creative and alternative ways for the participants to express themselves and tell their stories. As a result, art expression workshops were introduced as part of the research method. These workshops would, I hoped, provide me the opportunity to incorporate all of the above values and guiding principles that underpin this exploratory qualitative research study.

**Using creative arts as a method**
The women and their individual needs were central to the research approach and plan. The workshops were created to use art as a vehicle to communicate thought and were underpinned by a creative arts-based research method that holds its power in the use of language as art (Janette Welsby and Debbie Horsfall, 2006). Visual artworks can commune in ways that words cannot, presenting both simple and complex ideas in a moment, whereas in written text, it may take several pages. Art is a personal and intimate way of expression as it brings into play our senses and connects our thoughts, feelings and perceptions with our life experiences helping us understand who we are. Art provides us with an alternative way to discover insights about ourselves (Cathy Malchiodi, 1998). In using arts-based research the researchers goal is compassionate understanding (Norman Denzin, 2003).

Art making processes in research can take a number of different forms: film (see Michael Rich and Richard Chaflen, 1999, Corrine Glesne, 2006), photography (see Gunilla Holm, 1997, Douglas Harper, 2002, Tim Booth and Wendy Booth, 2003) and art installations have become methods of visual representation of the research findings. Art can also be used as a way to express knowledge (Jocene Vallack, 2005) and can be created as part of the researcher's reflexive practices (see Inkeri Sava and Kari Nuutinen, 2003, Lisa Armitage, 2006, Lisa Armitage and Janette Welsby, 2009).

Analysing the artwork of others has been used to study visual cultures, race, class gender and sexuality (see bell hooks, 1995) and can be used as historical
documents. Susan Sontag (1971) examined the role that photographs play in modern society and how we have come to rely upon them to provide a sense of reality and authority in our lives.

Art practices can also be a means of inquiry. In the research, self-reflection, visual image-making and dialogue were fundamental components of the process. I learnt about the participants’ experiences through their imagery, art creation, and their exchanges in the workshops and interviews. Using art as one method of data collection offered a way “of exploring both the multiplicity and complexity ... of human experience” (Marilyn Guillemin, 2004b pp. 273). Art making was used by both the researcher and the participants to access, convey and illuminate the stories of the women’s lives. Unlike other visual arts or arts-based research methodologies I did not analyse the artwork (see Marilyn Guillemin, 1999, 2004b, 2004a, Barbara Bolt, 2004). Rather, it was up to each participant to interpret and discuss their own artwork through the sharing of stories. This process created an opportunity for them to express themselves through their own images, words and reflections (Alice McIntyre, 2003). As with other social science research, art making in this study was part of an integrated approach that used both visual and word-based research methods to explore the multiplicity and complexity of the women’s experiences (Marilyn Guillemin, 2004b).

For me, the important part was using different art expression exercises to channel the women’s thoughts, rather than the artworks per se. The process of producing the art enabled the women time to reflect, and the completed artworks something to think, feel and speak about. The participants moved in and out of the participant–observer–co-researcher roles asking questions, seeking clarification and relating the other women’s stories to aspects of their own lives, empowering them to be active participants in the research rather than being ‘acted upon’. In this way, art-making became part of the social dialogic production of knowledge, not an introspective process of individual analysis.
A creative arts process provided a window into the women’s lives for themselves, the researcher and now for you, the reader. These processes enabled the women to think visually, see what surfaced, reflect and then decide what they would share. In doing this, an intended sharing of meaning-making took place that opened new spaces for understanding. This research celebrates the stories of these five women.

**What I wanted to know**

My initial research question was: What do women over the age of 21 with an intellectual disability say about their experiences of work? As the research changed this question became less important and was replaced by a number of more pertinent questions. The first of which was: How do women with an intellectual disability live their day-to-day lives?

What became clear from the discussions in the first workshop was that while working took up a significant portion of their day-to-day lives, it became insignificant when talking about what the women valued and cherished. The lack of discussion in the literature in this area, and that the women themselves chose to talk about this required me to ask: What are the things that are important to the participants?

In asking these two questions it quickly became apparent that there was a gap between what the women said was important to them and what they like to do and the reality of their lives. One small example was that Evie loved to spend her money on clothes. Living in a group home, Evie did not have access to her money or public transport. In order for Evie to go shopping she had to wait for her social educator to take her to the bank to make an over-the-counter withdrawal and also to drive her to the shops. Further group discussion about where we like to shop and clothes brands revealed that despite living near three large shopping complexes that offered a range of stores and prices, Evie was only ever taken to one small local shopping centre to shop at Big W, an Australian variety store that offers a low cost limited range of clothing. There were many stories like this that revealed the lack of autonomy and control the
women had in their lives that often resulted in them having few real choices.
When asked why Evie only shopped at this one store she explained that it was
easier as Big W was just near where they did their grocery shopping. This led
me to my final question that centred on constructions of power. How does
having an intellectual disability impact on the women’s autonomy and
life opportunities?

Resolving different expectations
In my need to reduce some of the power imbalance and give the women
opportunities to make decisions about the research, I had planned a brain-
storming activity to facilitate the negotiation of the areas of discussion in the first
art workshop. Naively, I thought this would be empowering for the women. They
thought it was a boring idea and chose not to do it. In fact, just talking about
work was seen as boring and uninteresting.

This was not the response I was expecting. I had read that women with an
intellectual disability were compliant. These women, two in particular — Kay
and Lara — were defiant. They were happy to spend one art workshop and
interview discussing work but now that they were asked, five would be tedious
and out of the question. Nothing I had read about collaborative researching had
discussed or talked about this situation. Why would it? The collaboration usually
started at the very beginning of the process not after consent and at the start of
the fieldwork. This was not the first time that my focus on the process and my
naivety as a first-time researcher were at odds with those of the participants and
the reality of researching.

I had given the women the opportunity to control the topics and I could not
renege. The only option was to go with the flow and just trust in them to lead
me. Work was just one part of their lives and they would rather talk about other
aspects that were more interesting and important to them. This is how Our
stories: Women, Life and Intellectual Disability evolved from My job: My Life:
What women with an intellectual disability have to say about their working lives.
How the Research Changed and Evolved

Although my research focus had shifted, the research aims remained the same. Finding an alternative methodology that did not solely rely on the spoken word was central to the research. It was important that the method presented the women an opportunity to tell their story artistically and in their own words, in an informal, supportive and nurturing environment. What we know and where that information comes from influences our understanding of and interaction in the social world. In our society, language and communication privileges the strongest and most articulate voices. These dominant voices shape our perceptions of reality and inform the basis of our understanding (Mairian Corker and Tom Shakespeare, 2002).

Not often holding positions of power within research, and to a larger extent within society, the voices of women with an intellectual disability have “traditionally gone unheard” (Michelle McCarthy, 1998 pp. 558). As such, their experiences, concerns and what matters to them are muted or suffocated, as they are not part of the dominant communication system (Shirley Ardener cited in Helen Callaway, 1991). Laurel Richardson (1997) asks us to transform culture through new ways of telling and new rituals of sharing stories. In post-modern power relations, where there is power, there is resistance.

I have chosen to move away from this position in the re-telling of the women’s stories. The stories re-told here are not forms of resistance against the dominant stories with the intention aimed at challenging, changing or conserving social relations and institutions (Paul Routledge, 1997). In securing resistance narratives to dominant stories that already have legitimacy it weakens rather than strengthens those stories, as the “dominant is the text and sub-text of the work”. It is through “association, community building, sharing and empathy that we have some hope of repairing and transforming culture” (Laurel Richardson, 1997 pp. 78). This research aims to do this transformation through building communities of the moment where the women stitched together the stories of their lives. In the art expression exercises, in the workshops, and
again in this thesis I have explored different ways of telling and sharing the women’s stories and also mine.

I see this research as exploratory, qualitative, multidisciplinary and feminist. Within feminist literature, women with a disability have often been portrayed as having a double deprivation through sexism and disability, or as Nancy Mairs (1996b) suggests, it is doubly shameful. Instead of challenging cultural norms, this portrayal has reinforced negative stereotypes of women who have a disability as being victims, disadvantaged and oppressed. Although in the last ten years there has been an integration of feminist and disability theory, the focus has largely been on physical disability and has not included or recognised the commonalities and unique experiences of women who have an intellectual disability. Holding to the view that some women are more complete than others, feminist theory has indirectly asserted and expressed a politics of domination (Elizabeth Spelman, 1990).

Through the telling and sharing of alternative stories about the lives of women with an intellectual disability, this research aims to redress some of this imbalance. The intention then is to build upon feminist research by exploring the lived experiences of women with an intellectual disability. This research takes a creative approach to the learning and the experiences that were shared in the dialogic process of the data collection. Within the thesis I have aimed to overlay the identity and experiences of having an intellectual disability and place them within a context of power, agency and history to explore the multiple realities in which we live.

**Why this research is important**

Despite the Disability Rights Movement being active since the 1970s, there has been very little focus on what is important to women with an intellectual disability. The missing contribution of women with an intellectual disability to social policy debates about them is detrimental to their lives and well being. This research sought to make explicit the vast pool of knowledge and experience held by these women. If women with an intellectual disability:
are to be supported to attain and maintain their full adult status with the same rights and respect accorded other women, then it is necessary to understand what does and does not matter to them and why (Michelle McCarthy, 1998 pp. 571).

In providing and opening a discursive space for the women to speak about their lives and what was important to them, this research provides a movement toward understanding the complex experience of having an intellectual disability (Corbett Joan O'Toole, 2004). The research was conducted from outside the field of disability studies and the disability sector. As an outsider, my perspective is different from researchers working within the field of disability. Not having a professional agenda in terms of applying the outcomes of the research made room for new aspects to be revealed and new ways of understanding concepts around intellectual disability.

This research adds to the body of feminist understanding and theorising about women who have been at the margins of feminist theories (bell hooks, 2000a). The stories and analysis within this thesis contributes to filling that gap.

My thesis, *Our stories: Women, Life and Intellectual Disability* seeks to understand and discuss many of the tightly supervised boundaries that restrict and control the women’s lives. It explores how the management of perceived risk takes precedence over the principles of normalisation that advocates self-determination and underpins Australian government disability policy and legislation. It builds onto the work of Sylvia Bercovici (1983), who explored normalisation in practice in residential care settings to reveal how carers and human service systems maintain dependency, passivity, incompetence and fear.

**How Theory Informed My Practice**

In recent years within social science the positivist view of knowledge with its single linear view is declining (Kathryn Church, 1995). Other approaches are increasingly being used that encompass multiple views and voices. Deciding where to position myself theoretically has been a circular process. When I originally wrote my thesis proposal in 2005 I had decided on a post-modern and
feminist approach to the research. I was asked at my confirmation of
candidature not to limit myself and I began to explore disability and feminist
disability theoretical perspectives.

My relationship to theory has been and still remains turbulent. It has been a
continual movement between embracing/resisting and utter frustration from
trying to find an alternative that did not feel like I was trying to force a square
peg into a round hole. While I dabbled in disability theory and fiddled with
feminist disability theory, I found that I kept coming back to a feminism and
post-modernism because I was interested in the how regimes of power were
enacted through an embodied process and having a place/space where the
women could talk about their lives. Although the next chapter positions my
theoretical framework I feel that I need to clarify what I mean by feminism and
how post-modernism has influenced my thinking.

My brand of Feminism
Never being a united body of thought, feminist theory has evolved in opposition
to a “wide range of ‘malestream’ theoretical perspectives, and also from the diverse
experiences of different groups of women” (Valerie Bryson, 1999 pp. 8). First wave
feminism began as a political movement in the early nineteenth and twentieth
centuries and was largely concerned with gaining equal political rights and
economic opportunities for women. Also concerned with women’s oppression,
second wave feminism can be linked to the publication of Simone de Beauvoir’s
(1949) The Second Sex. During this period, feminists argued that the sexual
oppression of women was not just embedded in legal and political rights but
rather, that it permeates every aspect of human social life which is controlled by
men through patriarchy. Rather than trying to reform, second wave feminists
aimed to transform the complete sphere of a woman’s personal and political life.

Feminism during these two periods was dominated by college-educated white
women who rarely questioned their belief that all women are oppressed in the
same way. Criticised for failing to recognise the interplay of race, class,
sexuality and disability, third wave feminism grew out of the need to negotiate a
space for consideration of race related subjectivities (Leslie Heywood and Jennifer Drake, 1997, Stacy Gillis, Gillian Howie and Rebecca Munford, 2007).

Black feminist writers such as bell hooks and Patricia Hill Collins argued that seeing all women as oppressed failed to acknowledge the extent that sexism affected the lives of individual women. By focusing on men as the oppressor, feminism had failed to recognise the ways that women through race, sex and class dominated and exploited other women (bell hooks, 2000a, 2000b). While white women are victimised by sexism, "racism enables them to act as exploiters and oppressors of black people" (bell hooks, 2005 pp. 67) and other marginalised groups. This raises questions of equality and equity for whom? How do feminists work towards equity and equality that incorporates the diversity of experience? How do I take this into my daily practices and the many roles I perform as a woman, activist, advocate? It is very easy from my privileged position to fall into being what I call a chardonnay feminist where the benchmark for equality is pegged at my living standard and life circumstance or above. Would I be prepared to sacrifice principles for practice if I had to lower my standard of living in order to achieve an end to sexism? How many things do I take for granted? What would I be ready to give up?

It is at this point of tension where feminism and post-modern ideas about power and resistance intersect that I position myself in this research. In stating that men and women can be both oppressed and an oppressor at the same time is to acknowledge and question my role in other people’s oppression. Throughout this research journey I have been confronted by these questions and I have had to reconcile holding these two opposing positions at the same time. In recognising that both men and women collude and collaborate in maintaining oppressive regimes of sexism and patriarchy, my definition of feminism is not gender specific. Feminism for me is a political movement aimed at changing existing sexist power relations (Chris Weedon, 1987, bell hooks, 2000b).
Post-modern influences

Seeing myself as a player in other people’s oppression does not sit easily with me. This dual positioning and the interplay of the power dynamic intrigue me. Post-modern ideas of power have been useful in this examination (Michel Foucault, 1972, 1983, Paul Bové, 1995, John Lye, 1999). Seeing power as horizontal rather than vertical provides a platform to explore the power dynamics in the women’s lives and how power and knowledge shape our understanding of intellectual disability. There are a number of dominant discourses that compete, weave and/or join with each other. The discourses I identified within this thesis are gender, medical and therapeutic, normalisation, empowerment, rights, managerialism and risk management discourses. In terms of post-modern ideas about discourse and power I am interested in how discourse is played out through embodied practices.

The post-modern use of multiples — multiple realities, multiple voices and multiple experiences to overcome the privilege of oneness — one reality, one voice and one experience over another — has been influential in my work and I have tried to carry this through into the writing of the thesis. Again, there is a duality: on the one hand trying to write in multiple voices, while at the same time holding a position of power in deciding which voices, experiences and realities are included or excluded. For me, it is important to acknowledge that what is written here is coloured and shaped by my voice, my reality and my experience.

This research is about sharing the stories of women with an intellectual disability and providing a space for them to be heard and shared by others to bring about social change. As my understanding of post-modern power has increased, I have changed my position somewhat from where I began, in saying that this research was about providing a space for people who are silenced to speak. Saying that certain people’s voices are silenced can also be a form of oppression. The women in this research told their stories before this research, and no doubt will continue to speak about their lives long after this thesis is put to bed. The fact that I was not listening before does not mean they were not speaking.
Sisters are doin’ it for themselves

Now this is a song to celebrate
The conscious liberation
of the female state!
Mothers, daughters
and their daughters too.
Woman to woman
We’re sing’ to you…

Sisters are doin’ it for themselves
Standin’ on their own two feet.
And ringin’ on their own bells.
Sisters are doin’ it for themselves.

2. SISTERS ARE DOIN’ IT FOR THEMSELVES — POSITIONING THE RESEARCH

This chapter builds on the Introduction, which set out how this research began and evolved, and the initial brief discussion of feminism and post-modernism. The purpose of this chapter is to explain the theoretical position of the research within a post-modern and feminist framework rather than within a disability framework. The chapter begins with an overview of two different structures of power — the traditional up/down structure and the complex web-like structure of post-modernism. Michael Foucault's (1983, 1972) work on how power is exerted through language and discourse is briefly reviewed as it has been useful in exploring how intellectual disability is constructed.

The second section of the chapter discusses why and how I position ‘others’ in the writing of the thesis as well as a justification of the term intellectual disability, and I explain the use of different font sizes and colours to clearly identify the voices of the participants from my voice and the voices of other academics. The ethical dilemma of being a non-disabled person writing about people with an intellectual disability is also discussed.

The third section of the chapter provides an outline and critique of the medical model, the social model of disability, and the theory of normalisation. These three theoretical models influence and form the basis for disability studies, research, policy, regulation and service provision in Australia, the UK and US. The experiences and criticism of feminist and disability theory to include or recognise the unique issues relating to women who have a disability is also
addressed. The final section of the chapter summarises my position and justification for adopting a post-modern feminist theoretical approach to this research and the writing of this thesis.

**Post-Modern Notions Of Power**

One of the major findings of my study was that the more the participants relied on or used government services and government-funded service providers, the less personal freedom and autonomy they possessed. In order to receive services they require, such as accommodation, they are required to comply with particular rules and regulations and as a result their lives become highly regulated and controlled. In order to examine these regimes of power, I explored post-modern ideas and theories of power.

Power has been traditionally thought of as vertical, pyramidal or an up/down structure (Michel Foucault, 1983). Discourse within this paradigm uses language such as *below*, *under*, *inferior*, *overcome*, and *subordinate* to create hierarchies, and this is reflected within disability discourse and within intellectual disability discourse in particular. Having this rigid ‘abled body oppressor’ versus ‘dis-abled oppressed’ locks discussion into fixed positions that reinforce, rather than destabilise, regimes of power, as it fails to locate sites of power that are held by people with a disability. People with an intellectual disability may have little power over all aspects of their lives: however, they are never powerless all of the time.

Rather than an up-or-down, or top-to-bottom movement, post-modern uses of power see power as a dynamic force that “circulates horizontally, on the lateral and flattened plane” fashioned into a moving, web-like structure (Chela Sandoval, 2000 pp. 73). This has called for a new set of metaphors that represent social actors as moving from the *margin to the centre* or *inside to outside* and in which each experience is a locality or position on the web.

Power in this sense is not just repressive but rather, can be productive and produce knowledge. Never immobilised, power comes from everywhere,
beginning with relations between individuals rather than the sovereign state or one central regulating power structure. All people exercise and are subjected to power through a web-like organisation or capillaries operating on every level of “social practice, social relations and social institutions” (Honi Haber, 1994 pp. 82). This results in many temporary and competing local power struggles that create certain ‘truths’ or ‘discourses’ that either aid or suppress particular political ideals.

Michel Foucault’s work on the genealogy of language and discourse is helpful in clarifying my use and understanding of discourses or truths’. Not only is language and discourse integral to power – it actually is power (Michel Foucault, 1972). For Michel Foucault, discourse is epistemological and it operates by ‘rules of exclusion’ concerning what is prohibited. Specifically, discourse is controlled in terms of objects (what can be said), ritual (how and where one may speak), and the privileged or exclusive right to speak of certain subjects (who may speak). It is the constant interplay of these prohibitions that interrelate, reinforce and complement each other that creates the complex net (John Lye, 1999).

There are two important meanings of discourse that Michel Foucault challenges in his re-conceptualisation of the term. Discourse can refer, on the one hand, to the spoken word or written language, and on the other, it refers to the process of rational thought (Michel Foucault, 1972). The Foucaultian definition of discourse and the one that I use within this thesis departs significantly from these source meanings. Foucault does not understand discourse simply as language-based; rather, discourse is materialised in texts, spoken word, fields of knowledge, social practices, and modes of thought formed in a certain historical moment. Paul Bové (1995 pp. 54-55) asserts that the aim of discourse is “to describe the surface linkages between power, knowledge, institutions, intellectuals, the control of populations, and the modern state as these intersect in the functions of systems of thought”.

From this point forward my use of the words ‘truth’ and ‘discourse’ are interchangeable.
Power and knowledge are joined through discourse and can be used to highlight that every description controls what it describes and reflects power relations (Michel Foucault, 1978). It is this “power/knowledge nexus that renders the Foucaultian approach to history unique” (Gavin Kendall and Gary Wickham, 1999 pp. 48). History in this sense of the word relates to Foucault’s notions of the archaeology and genealogy of knowledge production. David Halperin (1995 pp. 31) interprets Foucault’s discussion of power/knowledge in the following way:

“The effect of Foucault’s political approach to discourse is not to collapse truth into power but to shift the focus of our attention from matters of truth to matters of power”. In this way Foucault prompts us to ask of particular discourses not what does it mean? or is it true? but rather: what does it do? or what makes it possible? or more importantly, who does this discourse serve? These are questions that have been useful in the analysis and writing of this thesis.

Discourse is created and perpetuated by those who have the power and means of communication. Post-modernism allowed me to explore how some discourses have shaped and created the way we define and organise our social world and how they make up the “unconscious and conscious mind and emotional life of the subjects they seek to govern” (Chris Weedon, 1987 pp. 108). Through an examination of the social construction of punishment, sexuality and madness, Foucault found that certain dominant discourses come to be known or seen as ‘truths’, while other alternative discourses or ‘sites of resistance’ are marginalised, subjugated or silenced. ‘Truth’ is grounded in knowledge, which “has never ceased shifting” into “new forms of the will to truth”. It is this will to truth that “exercises a sort of pressure, a power of constraint upon other forms of discourse” (Michel Foucault, 1972 pp. 218-219). Therefore, truth is historically located and a social construction of discourse:

realities are only accessible to us through categories, so our knowledge and representations of the world are not reflections of the reality “out there”, but rather are products of our ways of categorising the world, or, in discursive analytical terms, products of discourse (Kenneth Gergen cited in Louise Phillips and Marianne Jorgensen, 2002 pp. 5).
In this way, it is discourse that shapes reality, not reality that shapes discourse (Michel Foucault, 1972).

The dominance that is given to a particular discourse within a culture masks a specific fear. Discourse is used in a number of different ways: it serves to control that fear; to relieve what is fearful of its most dangerous elements: to organise its disorder. “This logophobia is a fear of the mass of spoken things, the possibility of errant, unrestrained discourse” (John Lye, 1999 pp. 4). Our understanding or knowledge of the world is created through social interaction “in which we construct common truths and compete about what is true and false”. Different social understandings of the world lead to different social actions, and therefore “the social construction of knowledge and truth has social consequences” as the following example illustrates (Louise Phillips and Marianne Jorgensen, 2002 pp. 6).

Every age has a dominant group of discursive elements that can be related to particular beliefs of the time. If we were to look at discourse around racial purity, one of them can be linked to fears about the working class. The idea that feeblemindedness was inherited prevailed in the western world in the 1930s-1940s. This discourse provided the basis for the sterilisation of many women with an intellectual disability who were considered biologically inferior and prolific breeders. As eugenics fell out of favour and our understanding of genetics increased after the Second World War, biological control based on inferiority could no longer be sustained. A new contraceptive discourse emerged that allowed for the continued sterilisation of women with an intellectual disability on the basis of vulnerability and the belief that they could not be trusted to take an oral contraceptive, manage monthly periods or look after a family.

The rise of the human rights and the disability movement in the early 1980s provided a new counter-discursive element that rejected ideas of racial purity, and the mass sterilisation of women with an intellectual disability was abandoned. The control of women with an intellectual disability’s reproduction
continues today, however, and is reflected in protectionist discourses such as duty of care and harm minimisation. For example, women who live in supported accommodation in NSW are required to have their menstrual cycle charted (Department of Ageing, Disability and Home Care, 2007b). While this charting is deemed to be for health reasons a direct consequence is that key staff are able to detect early stages of pregnancy.

Taking the stance that particular interests are served by every theoretical position and in any textual or discursive system (Elizabeth Gross, 1986) discourse does not report the truth; it creates, sustains and reproduces it. Challenging the status quo is then achieved through identifying interests, exposing culturally embedded taken-for-granted beliefs and highlighting the power behind discourse (Norman Fairclough, 1989, Ian Parker, 1992, Ruth Wodak and Michael Meyer, 2001). Viewing power through a post-modern lens has enabled me to explore how power and knowledge shape our understanding of intellectual disability.

Using the same example of racial purity there are a number of dominant discourses that compete, weave and/or join with each other and are played out through the body. In medical discourse this can be seen in the management of medical and therapeutic interventions. The discourses of human rights, self determination and empowerment compete with the medical discourses, however, they are still embodied as people with an intellectual disability are entitled to live their life with the same rights and privileges as intellectually-abled people, including having children. The social model of disability provides a counter discourse. This model constructs social structures such as a lack of parenting support services or sexual education for people with an intellectual disability as oppression, rather than focusing on the individual.

It can be argued that because of strong counter-discourses and civil society’s need to distance itself from the holocaust, the discourse of racial purity has become deeply submerged within our society, making it difficult to locate. Yet fear of the ‘other’ underpins many current discourses that relate to intellectual
disability. In seeking to minimise a perceived risk to the public by a person with an intellectual disability and/or visa-versa, the discourse of risk management comes into play. This discourse is enacted through government policy and practice, disability service providers and employers. Paternalistic attitudes and levels of anxiety held by carers, co-workers, and the general public towards people with an intellectual disability also feed into this discourse. In answering the question ‘who does the discourse of risk management service?’ it services to secure the powerbase of the intellectually-abled through the control and restriction of the intellectually dis-abled.

As people with an intellectual disability become more autonomous, this creates anxiety and fear, as they can be perceived as equal contenders on the grid for the services of power. This can create a ‘double-consciousness of power’ or ‘multiple truths’, with new and old formations working and competing at the same time. Although I draw on post-modern ideas to understand power, I am not interested in providing a discourse analysis in this thesis. Rather, I am interested how discourse is played out through embodied practices that control the lives of the women with an intellectual disability, such as the example of racial purity.

**Positioning ‘Others’ In The Research**
Research is composed of many stories. To write this thesis I have made choices over which words to use. Some words carry with them different and varied meanings and so, require explanation. Making my interpretation of these words clear connects me with feminist concerns about “language as a site of struggle” (Chris Weedon cited in Kathryn Church, 1995 pp. 9) and with post-modern ideas that language is an exercise of power as it produces and constructs certain knowledge (Valerie Bryson, 1999).

Defining the women who took part in this study as having an intellectual disability is in itself an exercise of power. It automatically defines them as other. As a feminist, this is not the intention of my work. As a woman who is intellectually-abled, using this term within my writing makes me awkwardly
conscious of my position of power. Kay, Cindy, Lara, Shirley and Evie very seldom defined themself as a ‘woman with an intellectual disability’; they were/are women — women who had little power or influence over words and images that are used by others to describe them. The names, labels and descriptions of intellectual disability are instead controlled and defined by professionals – who to them, the women, are ‘other’.

It is not important in this research to define the type of intellectual disability each participant had except to state that there are multiple reasons why people have an intellectual disability. The causes can be genetic or related to something that happened before, during or after birth or are unknown. Once a person is labelled as having an intellectual disability it becomes almost impossible to change the image the label creates. Education throughout their lives often becomes simplified. Full or complete information is often omitted in an effort to make it easier for a person with an intellectual disability to understand. This assumes that a person with an intellectual disability is only “capable of limited thinking and knowledge acquisition” (Simone Aspis, 1999 pp. 174). The implications of this assumption are that for most of their lives, people with the label of intellectually disabled are under some form of government, legal, medical or guardianship control.

At the beginning of this research I preferred the term ‘learning difficulties’, as used in the United Kingdom, because it best described the disability of the women who took part in this study; Kay, Cindy, Lara, Shirley and Evie are able to learn, understand and make decisions in their lives. Although the women do learn, understand and make decisions, ‘learning difficulties’ as a way of describing their lives began to appear, to me, as superficial. It glossed over and downplayed the impact that having being labelled as disabled has had on their status as citizens and women in the community. It is for this reason that I have chosen to use the Australian recognised term of ‘intellectual disability’. This label carries with it a history of discrimination and assumed knowledge the depth of which acknowledges the intricate and subtle forms of power that define and control many aspects of these women’s lives.
The political correctness debate in Australia and the United Kingdom, in the 1980s and 1990s was based on the widespread recognition that language communicates attitudes and that inappropriate language encourages negative stereotypes (Jan La Forge, 1991). During this time the People First Movement successfully advocated for use of language that was not reflective of a diagnostic label and/or did not devalue a person (Errol Cocks, 1998, Stephen Greenspan, 1999) such as the terms ‘retarded’, ‘slow’ or ‘crippled’. Disabled person, or in this research, ‘disabled women’ was replaced by ‘woman’ or ‘women with an intellectual disability’. This subtle change of language recognises that having an intellectual disability is only one aspect of a person’s identity and respects the disabled community as first and foremost, a community of people. One of the criticisms of the People First Movement is that writing in this way can be cumbersome and for some people the use of acronyms such as WWID (women with an intellectual disability) has become increasingly popular. I have chosen not to do this within this thesis as I believe it is a form of power aimed at diminishing the position and voices of women.

**Positioning Myself In The Research**

I am innately aware of the paradox that as a researcher, I am in many ways speaking for, about, with and alongside the women who took part in this research. In post-modern terms “I am participating in the construction of their subject-positions” (Linda Alcoff, 2008 pp. 486). Although I have used an oral history approach to gather the stories of these women and present them in their own words taking a feminist post-modern stance recognises that these stories are shaped and re-told through my own particular history and perspective and my voice coos “softly from the background” (Marjorie DeVault, 1999 pp. 189).

A valid criticism made by the disability movement is that research about people with a disability is often made by people without a dis-ability (Corbett Joan O'Toole, 2004). In many ways, this study perpetuates that; it was not participant-driven, the women did not take part in the analysis, nor the writing of the thesis. The women were asked if they would be interested in being involved
in more than the data collection, however, after talking about what would be involved they declined either because they were too busy or not interested.

As a woman, I live in a patriarchal society in which particular structures of oppression and inequality impact directly on my life. At the same time, I acknowledge the privileged position of power I hold as an educated white middle class woman who is intellectually-abled. I am in a unique position where I am able to choose to do research with women who have an intellectual disability and what stories are included or omitted.

I am innately aware that although you may come to know me through my words I nevertheless remain invisible — the academic voice — hidden safely behind text, pictures and artwork. As Shirley, Evie, Cindy, Kay and Lara make themselves known to you through their self-portraits in the next chapter, I feel I should do so here. This is partly because this thesis is about making the invisible visible, and because it serves as another disruption to more traditional forms of academic writing. Also I don’t believe that ethically I should visually present the participants in a way that I am not prepared to do myself.

Figure 2 - Self Portrait, 2005, Janette. Water Colour Pencil, Size A3.

Within this research I have tried not to objectify the participants. I have tried to take into consideration their thoughts and feelings in the research design and writing of the thesis. There is an irony in doing research that looks at the social barriers and I am aware that in presenting these findings I do in many ways
maintain the same regimes of power that I argue against. I do, however, attempt to disrupt them by making them visible.

Through the sharing of the stories and artwork of five women with an intellectual disability I hope to expose some of the barriers that historically and culturally position them as ‘other’. I hope to show their similar and unique experiences as women, moving them ‘from the margin to the centre’ of feminist thought (bell hooks, 2000a). I have taken great care in trying to present Shirley, Kay, Cindy, Lara and Evie and their stories as living, breathing, feeling women while at the same time highlighting some of the complexities that having the label of ‘intellectual disability’ brings.

**Disability Theory**

The word *disabled* is used to cover a large number of people who have little in common with each other, except that they do not function in exactly the same way as those people who are seen as ‘normal’; as such they are considered ‘abnormal’ (Simon Brisenden, 1986). From a disability perspective, having a disability is about disappearing: either into society through passing as ‘normal’ or cast out of society because of being ‘abnormal’ (Bill Hughes and Keven Paterson, 1997, Hilde Zitzelsberger, 2008).

Although some disability theorists would argue that disability studies arose in the 1970s out of the rights movement, others would not (Colin Barnes and Geof Mercer, 2004b). The first recorded journal or periodical devoted to the study and care of the *feebleminded* or the *mentally deficient* was in 1850. The publication *Beobachtungen über den Cretinismus* had three issues and was edited by physicians from Mariaberg, an institution in Germany. In 1881 a new journal, *Zeitschrift für das Idiotenwesen*, began and in 1929 the name changed to *Zeitschrift für die Behandlung Anormaler*. The journal attracted articles from across the professions and was at the forefront of disability thought at the time, for example arguing that not all children belonged in institutions, and covering

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8 English translation ‘Observations over the Cretinismus’
9 English translation ‘Periodical for the idiot being’
10 English translation ‘Periodical for the treatment of the anormal’
issues around exercise, education, and the integration of schools (Leo Kanner, 1964). The journal ceased in 1934.

The most notable English language journal has been *The American Journal of Mental Deficiency*. The first edition began in 1940 and changed its name to the *American Journal of Mental Retardation* in 1987. To reflect more socially acceptable ways to address people with an intellectual disability, the journal changed its name to the *American Journal on Intellectual and Developmental Disabilities* in February 2009. The journal focuses on behavioural and educational research.

In the last thirty years, disability activists have achieved legislation on disability rights, and increased integration and public awareness. Building on the rise of the Disability Rights Movement in the 1970s, current disability theory emerged in the early 1980s (see Vic Finkelstein, 1980, Mike Oliver, 1986, Paul Abberley, 1987, Richard Scotch, 1989, Mike Oliver, 1990, 1996b, Susan Wendell, 1996, Colin Barnes, Geof Mercer and Tom Shakespeare, 1999). Some ten years later, it was criticised for only raising the concerns of young heterosexual white men who had a physical disability (Mairian Corker, 1999, Martha Banks, 2003, Corbett Joan O'Toole, 2004). Although there are a number of different discourses, such as human rights, advocacy and self determination, within current disability studies there are two distinct models. The medical model and the social model of disability currently influence and dominate theory and academic discussion.

**Medical model of disability**
The field of disability continues to be dominated by medical expertise (Irene Esler, Jules Adams, Margaret Reilly, Jo Meyer and Linda Haultain, 2001). At the individual level, the high degree of medical and therapeutic intervention, apart from what is generally required in stabilising any condition or illness, is argued to have resulted in the “colonisation of disabled people’s lives by a vast army of professions” from doctors trying to cure, physical therapists in restoring function,
teachers improving learning and support staff modifying behaviours (Mike Oliver, 1996a pp. 43).

Professional expertise underpins much of the disability industry in Australia and extends into most areas of the life of a person who has an intellectual disability, particularly if they require government services. For example, in Australia eligibility to receive a Disability Support Pension and subsequent reviews require a number of ‘expert opinions’. First and foremost is a doctor’s assessment of a person’s ‘impairment and their capacity to work’. This assessment is used by a Job Capacity Assessor in conjunction with an ‘impairment table’ to decide if an applicant is able to be ‘classified as impaired’.

To be impaired a person has to attract an ‘impairment rating’ of 20 points or over and their ‘impairment’ has to be a fully documented, diagnosed condition that has been investigated, treated and stabilised. Points are attributed to the severity of a person’s medical condition and how it might affect their ability to work (Centrelink, 2007a). Schedule 1B of the Australian Commonwealth’s Social Security Act (1991) has twenty two impairment tables that all relate to different medical conditions (see the table 1 page 51).

The extensive medical list in Table 1 highlights the clinical paradigm or medical model that views disability as a “condition which is essentially within the individual” (Errol Cocks, 1998 pp. 10). As a biological trait, a person with a disability requires rehabilitation or medical assistance to correct or cure the effects of the disability focussing on the individual and how they can overcome their condition. Impairment in this sense is the embodied physical, cognitive or sensory condition. Under the medical model, a person’s disability is their own personal misfortune devoid of social cause or responsibility (Bradley Areheart, 2008).

This belief legitimises professional intervention concerned with maintaining the dependency of people with a disability through ‘cure’ or ‘care’ after birth. When disability is seen as an individual medical problem it “masks the collective oppression of people with a disability” (Mark Priestley, 1999 pp. 49). The general
view of people with a disability within the medical model is a 'personal tragedy' (Mike Oliver, 1986). Here an individual is constructed as 'less than whole' as they are dependant on the abled-bodied and unable to fulfil valued social roles and obligations.

**Table 1 - Impairment Tables used in assessing Impairment for the Disability Support Pension in Australia.**

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
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<tbody>
<tr>
<td>Table 1</td>
<td>Loss of Cardiovascular and/or respiratory function: exercise tolerance.</td>
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<tr>
<td>Table 2</td>
<td>Loss of Respiratory Function: Physiological measurements</td>
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<td>Table 3</td>
<td>Upper Limb Function</td>
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<td>Table 4</td>
<td>Function of Lower Limbs</td>
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<td>Table 5</td>
<td>Spinal Function</td>
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<td>Table 6</td>
<td>Psychiatric Impairment</td>
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<td>Table 7</td>
<td>Alcohol and Drug Dependence</td>
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<tr>
<td>Table 8</td>
<td>Neurological Function: Memory, Problem Solving, decision Making abilities and comprehension</td>
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<tr>
<td>Table 9</td>
<td>Communication Functions – Receptive and Expressive Language Competency</td>
</tr>
<tr>
<td>Table 10</td>
<td>Intellectual Disability</td>
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<tr>
<td>Table 11</td>
<td>Gastrointestinal</td>
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<tr>
<td>Table 12</td>
<td>Hearing Function</td>
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<tr>
<td>Table 13</td>
<td>Visual Acuity in the Better Eyes</td>
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<tr>
<td>Table 14</td>
<td>Miscellaneous Eye Conditions</td>
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<tr>
<td>Table 15</td>
<td>Visual Field</td>
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<tr>
<td>Table 16</td>
<td>Lower Urinary Tract</td>
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<td>Table 17</td>
<td>Renal Function</td>
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<td>Table 18</td>
<td>Skin Disorders</td>
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<tr>
<td>Table 19</td>
<td>Endocrine Disorders</td>
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<tr>
<td>Table 20</td>
<td>Miscellaneous – Malignancy, Hypertension, HIV Infection, Morbid Obesity, Heart/Liver/Kidney Transplants, Miscellaneous Ear/Nose/Throat Conditions and Chronic Fatigue or Pain</td>
</tr>
<tr>
<td>Table 21</td>
<td>Intermittent Conditions</td>
</tr>
<tr>
<td>Table 22</td>
<td>Gynaecological Conditions</td>
</tr>
</tbody>
</table>

The medical model of disability has three key points in how it constructs disability: firstly as a problem that lays with the disabled individual; secondly as
equated with functional limitations or impairments; and thirdly medical knowledge and practice determines treatment options (Colin Barnes and Geof Mercer, 2003). Once a person is diagnosed, a medical label confirms and transforms the public perception of that person and it becomes difficult to challenge or remove the medical label (Freidson cited in Colin Barnes and Geof Mercer, 2003).

This model has largely fallen out of favour with many disability theorists and researchers because of the historical positioning of people with a disability within a personal tragedy discourse that necessitates dependency and the management of their care and protection. It has also been criticised for duplicating patriarchal traditional roles of the doctor/father, nurse/mother, and patient/child (Janet Muff cited in Joe Harrison, 2000). The role the ‘medical family’ assigns to the patient is that of the child subjugating the personal knowledge and experience held by the patient to the knowledge and expertise of the professional (Michele Moore, Sarah Beazley and June Maelzer, 1998). Essentially this model places people with a disability in the position of ‘care recipients’ rather than citizens (Joe Harrison, 2000).

While some forms of intellectual disability have ‘medical’ origins, many do not. The power of the medical discourse and the profession has been crucial in shaping government and community responses to intellectual disability regardless of this fact. Despite the changes resulting from the Disability Rights Movement, normalisation and the social model of disability, professional and medical expertise remain the gatekeepers to diagnosis, and as table 1 shows, determine eligibility for income support. Although these counter-discourses have challenged medical discourse they have not seriously undermined its power over the lives of people with an intellectual disability.

Adopting a medical model of disability leaves little room for participant engagement. Power within this theoretical perspective is dominated by professionals through the construction and control of knowledge production. Power in this sense becomes oppositional and is reflected within the discourse.
Within the medical model people-patients-clients need to *rise up* to *overcome* their personal medical problem, in this case disability. Placed in a *subordinate position* their knowledge is *inferior* to that of the professional (Chela Sandoval, 2000).

While the medical model is useful as a lens to focus on individual stories, its reliance on professional knowledge production and hierarchical power structure is not. This places it at odds with the core beliefs of my research that women with an intellectual disability hold expert and experiential knowledge about their own lives and a commitment to collaborative research design that flattens out the power dynamics rather than the hierarchical structure of the medical model and traditional research.

**Social model of disability**
The individual medical approach to disability has been challenged by understanding the experience of disability as socially mediated with an emphasis on access and inclusion, particularly for people with a physical and/or sensory disability. The social, political and intellectual re-evaluation of the situation of people with a disability has occurred in response to the growth in the field of disability studies in Australia and particularly the United Kingdom in the last 30 years (Helen Meekosha, 2004). Foregrounding the voices of people with a disability and self-representation have been central to re-interpreting disability as a dimension of social difference and identity.

The social model of disability, as originally outlined in ‘Fundamental Principles of Disability’ (Union of the Physically Impaired Against Segregation 1976) and further theorised by Vic Finkelstein (1980) and Mike Oliver (1986) has been central to this re-visioning of disability. The principles of the model have been influential in politicising, educating and empowering the lives of many people with a disability (Alex McClimens, 2003) and were instrumental in challenging the traditional idea of disability as a personal tragedy and the accompanying oppression that this cultural belief creates.
There are several key elements within the social model. It distinguishes between the biological impairment people have, and the social forms of oppression that they experience. It defines ‘impairment’ as the physical, psychological or anatomical aspect of a person’s body that does not function or functions with difficulty. ‘Disability’ is the loss or limitation of opportunity, a form of social oppression rather than a form of impairment (Vic Finkelstein and Sally French, 1993, Nick Watson, 2004). By seeing all people with a disability as one oppressed social group, the social model focuses on the ways social and economic structures create disability through discrimination, prejudice and exclusion.

This model rejects the idea of disability as an individual’s medical problem and places it in the realm of the social. Where ‘impairment’ located within the medical model is seen as biological within the social model, ‘disability’ is a social form of oppression. Social model theorists thus argue that reducing the disadvantage of impairment requires society to make changes — for example changing social structures and attitudes to encourage acceptance, inclusion, and full participation of people with such impairments — rather than to impose physical changes upon the individual (Sara Goering, 2002, Martha Banks, 2003). In our society, disability or dis-abilism is created through the interplay of Western culture and capitalist ideas of production (Carol Thomas and Mairian Corker, 2002). Power is shared or distributed though a caste system that assigns social status to members of society based on able-body-ness, ethnicity, sexuality and gender.

The caste or social system dehumanises the powerless in order to increase the privileges of the powerful. This has resulted in the establishment of social barriers that prevent people with a disability from being full members of an able-body society (Martha Banks, 2003). “The crucial point is that the disabled person, as conceived by the nondisabled world, has no abilities or social function... [and] those who do perform successfully are no longer viewed as disabled” (Michelle Fine and Adrienne Asch, 1988 pp. 12). Stereotyping therefore can only be defined by one exclusive trait. People with a disability, argues Lennard Davis (1995 pp. 10) are
"thought of primarily in terms of their disability just as sexual preference, ethnicity or gender becomes the defining factor in perceiving another person".

Rather than medical limitations, it is social and political decisions that impose able-ist ways of being, and reward the perceived normal population to the detriment of those who are disabled. Within the social model, modes of production are likely to shape and generate different sets of social relationships between what is culturally identified as ‘abled’ and ‘dis-abled’. Therefore, notions of disability or impairment are historically located rather than fixed or universal across time (Carol Thomas and Mairian Corker, 2002). One illustration can be seen in the use of language where terms such as mental retardation or handicap were in use until the mid-1980s. In Australia, these same terms are now seen as politically incorrect and inappropriate and have been replaced by the more socially accepted terms of learning difficulties or intellectual disability. Although the language may have changed, the description of intellectual disability still carries with it culturally located ideas of what it means to have that label.

There has been wide debate of the social model from within and outside of the disability movement. The social model has become the means of explaining why people with a disability are largely excluded in the labour market and in other areas of social life such as education and housing (John Swain, Vic Finkelstein, Sally French and Mike Oliver, 1993, Colin Barnes and Geof Mercer, 1996, 2004a). Much of this research has, however, centred on people with a physical disability. With the need to distance itself from the medical model and its focus on the individual, the social model has failed to address the significant effects that impairment has on the body. Critics and supporters of the social model have argued that there is a large conceptual gap between impairment and disability and have called for a working definition of disability that incorporates impairment (Mike Bury, 1996, Ruth Pinder, 1996, Nick Watson, 2004).
In concentrating on the social there is an over-simplification of the complexity and diversity of disabled people's experience where the social is one part of a much more complex multi-layered picture of a person's life (Ruth Pinder, 1996, Karl Nunkoosing, 2000). Feminists have argued that by not differentiating between men's and women's experiences of disability (Ann Darnbrough, 2003) the model fails to recognise how "social relations carry the imprint of socially constructed gender differences" (Carol Thomas and Mairian Corker, 2002 pp. 19). Being solely concerned with social constructions, theorists using the model have not addressed the multiple or simultaneous layers of oppression that impact on the lives of people who have a disability. As such the model has been ineffective in addressing other social divisions (Mike Oliver, 2004) such as race (O.W. Stuart, 1992, Ayesha Vernon, 1996), age (Michelle Putnam, 2002), sexuality (Tom Shakespeare, Kath Gillespie-Sells and Dominic Davies, 1996, Jane Chivers and Sue Mathieson, 2000) and class (Julia Preece, 1996).

Some supporters of the social model of disability have criticised feminist disability theorists for focusing on the experience of disability as "disablement has nothing to do with the body;" rather, this treats disability and impairment as two separate issues (Mike Oliver, 1996a pp. 48). The pain and/or physical experiences of impairment are seen as secondary or diverting attention away from the political focus of removing the social barriers that create disability (Vic Finkelstein, 1996). Introducing personal experiences is seen to muddy the waters. This response reflects a malestream of theoretical positions where the personal/private is separate from the public/political domains. This type of dualist thinking has resulted in limiting the personal sphere to illness and impairment and fails to acknowledge how personal experiences can clearly and powerfully demonstrate the social.

The almost universal adoption of the social model by western disability theorists has neutralised and devalued any alternative way of interpreting disability (Nick Watson, 2004). The use of social model language by institutions and organisations in their literature, without following the principles, has resulted in sustaining rather than eliminating oppression. As a theoretical model it has
become divorced from the lives of people with a disability and the disability movement (Katy Bailey, 2004). This has created a gap between disability theory and experience. How people deal with differences requires open, engaged dialogue, not silencing (Carol Thomas and Mairian Corker, 2002). The question of which experiential differences matter and how these differences might be conceptualised as a social relation remains unaddressed using the social model. The social model has failed to address the direct physical and emotional effects that specific impairments have on bodily functioning from what is socially construed to be normal or usual:

while environmental barriers and social attitudes are a crucial part of our experience of disability - and do indeed disable us – to suggest that this is all there is to it is to deny the personal experience of physical or intellectual restrictions, of illness, of the fear of dying (Jenny Morris, 1991 pp. 10).

Through the introduction of a political element, the social model has created another dichotomy: in order to be disabled there must be a disabler (Lennard Davis, 1995).

For me one of the fundamental flaws with the social model is the assumption that all people with a disability identify as one universal homogenous group. Although supporters of the social model of disability may argue otherwise, I believe that this model follows the same power structure as the medical model, in which power relations are positioned as oppositional between bodies or environments that ‘able’ or ‘dis-able’. This binary positioning fails to recognise the power dynamics within the group of people who identify as disabled. While it has long been accepted that people who do not have a disability discriminate against those who do, levels of hierarchy among people who have a disability have had little attention. Research by Mark Deal (2003 pp. 898) asked people who use wheelchairs what they found annoying — it was not uncommon for the answer to be “related to being thought of as someone with a learning disability”. A perceived need to distance physical from intellectual disability has indirectly created a situation where people with an intellectual disability have been largely ignored by social model theorists (Anne Louise Chappell, Dan Goodley and Rebecca Lawthom, 2001, Alex Mcclimens, 2003).
The areas in which the social model has been helpful in explaining some of the barriers experienced by people with an intellectual disability are employment and education (Colin Barnes, 1999, Anne Louise Chappell, et al., 2001, Leanne Dowse, 2007). Conceived and developed by activists who had a physical disability, the social model of disability reflects their aims and aspirations and has led to criticisms of the model for failing to address the regimes of social oppression and exclusion that relate to the experiences of people with an intellectual disability. For the most part intellectual disability still remains linked to impairment and the individual. As a result, research about people with an intellectual disability is often undertaken from a medical model perspective rather than from a sociostructural perspective (Jane Campbell and Mike Oliver, 1996, Anne Louise Chappell, et al., 2001).

Given that this research does explore the social structures that surround and position the women in this study it would make sense to use the social model of disability as part of my theoretical underpinning. I am interested, however, in the individual and unique experience of each woman. Therefore, the social model, which relies on a collective view of experience, makes using this model impractical.

In terms of power relationships within my research, the social model of disability fails to recognise the dynamic nature of the structure of those relationships. Adopting a fluid web-like post-modern view of power provides an opportunity to explore a multi-dimensional power dynamic that is fluctuating rather than fixed, and understands people to be both oppressor and oppressed at the same time.

**Normalisation**

Theories of normalisation were developed between the 1950s and the 1970s, predominantly in Scandinavia and the United States (US). Normalisation is the:

utilization of culturally valued means in order to establish and/or maintain personal behaviours, experiences, and characteristics that are culturally normative or valued (Wolf Wolfensberger, 1972 pp. 28).
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The Scandinavian approach is based on quality of life and a rights principle, in which people with an intellectual disability have the right to experience “patterns of life and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society” (Bengt Nirje, 1970 pp. 62). The emphasis in Scandinavia was on individuality and choice, while in the US the focus was on service delivery.

Wolf Wolfensberger (1983 pp. 234) developed the theory of social role valorisation arguing, for the ‘support and defence of valued social roles for people who are at risk of social devaluation’. He believed that enhancing a devalued person’s competencies would enhance their social image and thus increase their cultural value on a number of different social levels (Wolf Wolfensberger and Susan Thomas, 1981). The first level worked directly on individuals’ primary social systems, for example their family and friends. The secondary social systems relates to the local community and service agencies and finally at society as a whole, where values, laws and customs, and language usage is formulated.

Wolf Wolfensberger and Susan Thomas (1981) identified seven core themes, which were the theoretical underpinnings of normalisation, and were to be used by service providers in the management and care of people with a disability:

1. **The role of (un)consciousness in human services.**
   This involved raising the consciousness of people in human services in the areas of discrimination and prejudice towards people who require their services.

2. **The relevance of role expectancy and role circularity to deviance-making and deviancy-unmaking.**
   Eight general negative roles can be applied to members of disadvantaged groups: subhuman organisms; menace; unspeakable objects of dread; objects of pity; holy innocent; diseased organism; objects of ridicule; and eternal child. Social expectations associated with these roles form powerful social influences and control methods. Many people labelled in this way either live ‘up’ or ‘down’ to the roles ascribed to them.
3. The 'conservatism corollary' to the principle of normalisation.
As a person's deviances and stigma increases they tend to have a multiplicative rather than an additive effect upon the observer. The more devalued one is, the less likely they will be to be seen as having positive characteristics. Rather, the focus remains on the increased negative features or behaviours.

4. The developmental model, and personal competency enhancement.
A fundamental belief in normalisation is that all individuals are capable of growth and development. If people are to increase their valued social role they will require skilled training in competencies they are deemed lacking.

5. The power of imitation.
Imitation is considered one of the most powerful learning mechanisms. If devalued people can identify with, imitate and learn from people who have positive values, and use them as role models, they will increase their own social role value.

6. The dynamics and relevance of social imagery.
Images and social symbols transmit and reinforce stereotypes about the characteristics of deviant or undervalued groups. For example in popular culture Frankenstein, Captain Hook and the Hunchback of Notre Dame portray images of people with a physical disability as dangerous.

7. The importance of personal social integration and valued social participation in valued society by people at risk of social devaluation.
Wolf Wolfensberger places at the centre of normalisation a strong emphasis on the integration of devalued individuals into wider society.

To be culturally valued then is a process to improve the public perception of people who are devalued (in this case, people with an intellectual disability), making them more rewarding to be with or at least less aversive to other people. Supporters of the theories of normalisation and social role valorisation advocated community living and inclusion, and were successful in the closure of institutional care of people with an intellectual disability across the Western world. Underpinning both the medical and social model of disability is the concept of normality and an assumption that 'normality' is something that people who have a disability do not have, and therefore either require or want to
achieve (Mike Oliver, 1996a). A post-modern approach would take the position that as a society we need to demonstrate a greater tolerance towards diversity (Mark Deal, 2006). The reliance on normalcy as a benchmark of achievement fails to recognise individuality. These theories have been criticised for suggesting that people with an intellectual disability need to ‘fit into’ society. The ‘deficits’ focus fails to recognise that people with an intellectual disability are respected, valued and contributing members of the community (Michael Bayley, 1991).

The need for education, behaviour management and assistance to modify people with an intellectual disability to fit into society has been instrumental in the growth of the disability and human services sector (Tom Shakespeare, 2006). Professionals adapted to deinstitutionalisation by developing new models of practice that continued to legitimise their authority and intervention into the lives of people with an intellectual disability. Under such models, was their right to live a normal life is earned by conforming to certain norms: norms that are narrowly perceived, defined, instilled and monitored by professionals (Hilary Brown and Helen Smith, 1989, Anne Louise Chappell, 1992, Lindsey Williams and Melanie Nind, 1999). As opposed to self-advocacy, within normalisation an individual’s rights are based on the good-will of others and can be given or taken away (Simone Aspis, 1997). The women in this study were highly aware of certain aspects of their lives where they held precarious positions. There were a number of discussions about living with the fear of services being taken away and also strategies they had developed to circumnavigate the system.

The principle of normalisation is based on a number of assumptions. Firstly, what is ‘normal’ or ‘valued’ is culturally defined rather than open to different interpretations (Michael Bayley, 1991). Secondly, that the able-bodied professional and the dis-abled client/user share the same set of values For example “for professionals, independence refers to self care activities, such as washing and dressing; for disabled people it refers to autonomy and being able to control one’s life” (Mike Oliver cited in Anne Louise Chappell, 1992 pp. 42). Thirdly, that there is
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no power differential between them arising out of their relationship or their relative social positions. Finally, as with the social model of disability, people with a disability are seen as one homogeneous group with “implicit assumptions that men and women have the same experiences” (Lindsey Williams and Melanie Nind, 1999 pp. 659).

**Feminist disability theory**

Gender blindness has implications for women with a disability. The social model of disability and the theory of normalisation have tended to focus on “paid employment and other activities outside of the home” (Jenny Morris, 1996 pp. 10). The gendered role responsibilities that particularly relate to women in the domestic and family domains have been largely ignored, echoing the split between the private and public domains (Carol Thomas, 1999). The women who took part in this research spoke of and made sense of their lives in terms of gendered roles. They were girlfriends, mothers, sisters, lovers, grand mothers and/or aunties. One had been married, divorced and now lived with a man, others hoped to be married and have a family some time in the future, some had had long term relationships and had experienced the death of a partner. Only one woman disclosed that she had not had any romantic relationships although she hoped to meet someone in the future. These women’s lives were rooted in the formal and informal social relationships they had with individuals and groups and “cannot be understood independently of the gendered character of their lives – or of the gendered frameworks impacting upon them” (Carol Thomas, 1999 pp. 29). Although sexuality is a key feature of many people’s lives the women in this study chose not to include this area of their lives as part of the agreed discussion themes and as such it does not form part of this research.

The lives of women with a disability have not been addressed in a positive way by mainstream feminism. Jenny Morris (1996 pp. 6) has argued that the effective silencing of voices of women with a disability from feminist understanding and theory is to “deny their reality by separating them from common humanity”. Other feminists have argued that it is the perception of being helpless, victimised and childlike that has resulted in women with an intellectual
disability being omitted from mainstream feminist literature. This is mainly due
to feminism’s preoccupation with more powerful images of women as being
strong, independent and competent (Margaret Lloyd, 1992, Lindsey Williams
and Melanie Nind, 1999), or alternatively the portrayal of women as carers and
not the cared for (Jenny Morris, 1991).

Where women with a disability have been included in the feminist literature they
are often portrayed as having a double disadvantage through sexism and able-
ism. This only serves to reinforce stereotypes of women with a disability as
being helpless victims and dependent. In recent years there has been an
increased acknowledgement of women who have a disability by non-disabled
feminists, along with issues of race and sexuality.

Within the last ten years an integration of feminist and disability theory has
occurred. Most notable are the works of Margaret Lloyd (1992, 2001), Jenny
(2002, 2005). These works primarily focus on embodiment in terms of physical
dis-ability and through the use of scholarly writing, poetry and narrative make
the personal political and provide a space for the voices of women with a
physical disability to be heard. Although this work highlights how women with a
disability have been overlooked by the disability and feminist movements, they
nevertheless fail to include or recognise the commonalities and unique
experiences of women with an intellectual disability (Debbie Horsfall and
Janette Welsby, 2007).

One of the problems for women with a disability is that they have not yet
“integrated into either the disability movement or the women’s movement” (Ann
Darnbrough, 2003 pp. 158). This position is highlighted when you consider that
the first United Nations Women’s conference was held in Mexico City in 1975.
This conference placed women’s issues high on the agenda of the United
Nations and national governments. It was not until the 1995 Beijing Conference,
however, that the issues of disability or the integrated views of women with a
A Post-Modern Feminist Epistemology.

we
women
laughed
talked
cried
shared, made connections, built rapport
empathised, found common ground
understanding
feminism
gender
oppression
missing voices
diversity, multiplicity
knowledge production
language, discourse, story
colour texture expression creative
embodiment, emotion, ethics of care
authorship, authority, power, representation
female   lesbian
mother   sister
whore     queen
aunty     bitch
wife      lady
woman    spouse
disability gained prominence rather than being consigned to the sub-category of women with special needs (Carol Thomas and Mairian Corker, 2002).

More recently, Rosemarie Garland-Thomson (2004) has called for an integration of feminist and disability theory. “Feminist studies can offer profound insights, methods and perspectives that would deepen disability studies” (Barbara Hillyer, 1993 pp. 11-12). In disrupting the dominant assumptions that there is something wrong or unnatural with a person who has a disability, feminist theory critiques exclusionary and oppressive regimes of power. Feminist disability theorists have particularly focused on em-body-ment and gender.

Em-body-ment
The culture of the body implies that adults are strong and fit both physically and emotionally (Barbara Hillyer, 1993). Western consciousness denies the knowledge of "vulnerability, contingency and mortality" (Rosemarie Garland-Thomson, 2004 pp. 92). Bodies that do not conform to cultural standards are therefore undervalued. For people with a disability, life is constantly depicted as being intolerable. Rather than providing better structural environments and support services, medical technology has traditionally been seen as the way to make their life more tolerable (Evelyn Fox Keller, 1992). This is not to say that medical intervention should not save lives or reduce physical discomfort. It does, however, raise serious questions when certain diseases or disabilities are considered better eliminated than accepted as part of humanity.

The Human Genome Project, prenatal testing of foetuses and selective abortion has created an "eugenics of normalcy" (Susan Wendell, 1996 pp. 156), driven from the current cultural obsession with body perfection. What is considered to be inferior is easily masqueraded as the compassionate desire to prevent or stop suffering (Rosemarie Garland-Thomson, 2004). This desire has seen reconstruction surgery to correct physical disabilities to the point where it is now acceptable to have 'beautiful' women surgically sculptured from top to bottom. Medical procedures remove excess fat, the effects of aging, marks of ethnicity and scarring so that a person does not look different in an effort to 'blend in' to society (Michelle Fine and Adrienne Asch, 1988).
Women with a disability are excluded within the larger social class of women where ideals of femininity, beauty and womanhood culturally stereotype them as dependent, unattractive, and asexual (Rosemarie Garland-Thomson, 2002), or as sexually promiscuous if they have an intellectual disability (Kali Wilde, 1997). Culturally there are few rewards and incentives in being identified as disabled. This is in part due “to a lack of ways to understand or talk about disability that are not oppressive” (Kristin Lindgren, 2004 pp. 150).

Often within feminist disability theory, the disembodied experience hinges on a mind/body dualism where a healthy, normally functioning body disappears from awareness. It is only when the body becomes dysfunctional, for example through pain, that we become conscious of the body as separate from the self. A sense of a stable identity is dependent on an unchanging, taken-for-granted body and that a fracture between the self and body demands a rethinking of the relation between them (Barbara Hillyer, 1993). This fracture has been useful for Susan Wendall (1996) in theorising that the experiences of her body are not the totality of her experience. Through the experience of pain she was able to transcend her body.

Nancy Mairs (1996a), who has multiple sclerosis, rejects this argument, stating that it is not possible to exercise control over the body but rather that illness and disability reveal that the body has a mind of its own. Disease and disability are located within the body. Rather than creating a fracture, identity in this instance is linked to ‘being’ a body rather than ‘having’ one (Kristin Lindgren, 2004).

The difficulty for my research in using embodiment as a theoretical positioning is that much of the literature is based on the effects of physical disability or chronic illness where the manifestation of impairment and pain is located within the body. For me what is interesting in this theoretical discussion on disability is that intellectual disability is not addressed within the literature. This places people with an intellectual disability either outside the discussion altogether or within the discourse as able-bodied. The women who took part in this study did
not identify with women who had a physically disability or chronic illness and although not asked, I would suspect from our conversations that they would place themselves within the abled-bodied discourse.

This research found that the bodies of women with intellectual disabilities are sites of governance and resistance. The social construction of the labels ‘learning difficulties’, ‘intellectual disability’ or ‘mental retardation’ imply a lack of intellectual or behavioural competence or ability (Richard Jenkinson, 1998).

Some disability theorists have argued that a physical disability often extends to an assumption that the person must also have an intellectual disability (Jenny Morris, 1991, Mark Deal, 2007). For people with an intellectual disability, argues Deborah Phillips (2005) the situation is reversed, and perceived intellectual difficulties are transferred onto perceived bodily difficulties. This creates a situation in which the body, in addition to being a site of knowledge and identity, has to be cared for, monitored and governed.

Gender disparity

Traditionally, a women’s role has narrowly been considered to be that of a home-maker and mother; the nurturer and carer of the home and family. The role of women with an intellectual disability, however, is less clear. Women with a disability, either physical or intellectual, are not culturally perceived as being ‘good’ mothers or ‘good’ wives or partners. Often being perceived as ‘dependent’, women with a disability are culturally placed into positions of subordination where they are stereotyped as being ‘cared for’ rather than competent carers (Jenny Morris, 1991, Kali Wilde, 1997). This perception was not borne out in my research, in which certain participants, while in some ways dependent, also held positions in families and relationships where they provided care.

Barbara Hillyer’s (cited in Irene Esler, et al., 2001) study of dependence and interdependence has looked at the relationship between women as carers and women as recipients of care. Women who are carers or who have a disability come into more than average contact with patriarchal institutions through the use of educational, legal, medical, welfare and religious services. Mothers who have a child with a disability experience greater social judgement on the quality
of their care than mothers of children without a disability (Barbara Hillyer, 1993, Susan Wendell, 1996).

The feminist movement has brought to the forefront the traditionally ignored or invisible roles of women as the primary carers of children, the disabled and the elderly (Valerie Bryson, 1999). The decrease of government services and the push for community care in recent years has resulted in more women taking on the role of carer. This has been positioned by some feminists as an 'increased burden' carried by women (Helen Smith, 1991). In wanting to show how difficult and unrecognised the work of a carer is, people who are in need of care are often positioned as "passive, feeble and demanding" (Lois Keith, 1992 pp. 169).

Within the dynamic of the relationship between the carer-giver and care-receiver are relations of power. Whether the care-giver is a government agency or person, often it is their dominant ideas and interests that define the needs of the care-receiver who has little control over how their needs are met or defined (Berenice Fisher and Joan Tronto, 2003 pp. 31). A one-size-fits-all approach to policy design and implementation ensures that recipients have to conform in order to receive services. This situation was reflected within my own research findings.

Research in the area of carer/care receiver has been criticised for focusing on the experiences and needs of carers and largely ignoring the experiences of the care-receivers (Margrit Shildrick and Janet Price, 1996). This has two different ramifications. Firstly, it effectively separates out the person being cared for from the category of 'woman' (Jenny Morris, 1991) or 'man'. Secondly, it hides the reality that many disabled women are frequently denied the right to a family life that most non-disabled women take for granted. This life may include: the desire to marry, take a sexual partner, have children and to carry out maternal and household duties rather than being treated as dependent objects of other people's care. In this case, Jenny Morris (1996) argues housework and childcare are not simply oppressive as some feminists have suggested but rather important activities (and positions of power) from which women with a disability have been excluded.
A Post-Modern Feminist Perspective
Although there is no one universal feminist theory, but rather a number of different feminist theories, there are commonalities among them (Moira Gatens, 1991, Valerie Bryson, 1999, Marysia Zalewski, 2000). Feminist research has at its centre women, gender and a belief in equal rights for women. Historically, these equal rights were in relation to men, however, black feminist theorists such as bell hooks (1997, 2000b, 2000a, 2005) and Patricia Hill Collins (1995) highlighted a fundamental flaw in this universal belief, as not all men possess equal positions of power, and all women do not share an oppressed status. This point is clearly demonstrated in this thesis. Feminist research methods are also sensitive to the differential in the power relationship between the researcher and the researched.

In recognising the importance of maintaining the integrity of the research, the feminist practice of reflexivity has been a continual process throughout my research journey. I have used reflexivity to expose, challenge and confront power structures, roles, influences and assumptions I have held/hold in relation to the participants and the research process.

Unlike modernist feminism (radical, liberal and socialist) ‘the subject’ from a post-modern perspective does not have an inner meaning, and there is no essential subject or fixed idea as to what it is to be a woman (Marysia Zalewski, 2000, Sheila Riddell, Stephen Baron and Alastair Wilson, 2001). Instead of trying to narrow down and find exactly what a woman with an intellectual disability is, post-modern feminists prefer to ask, how do women with an intellectual disability become or get said?

Post-modern feminism acknowledges the agency of individual actors (Elizabeth Spelman, 1990). In this research, the experiences and stories of the women who took part were integral to the work. The social model of disability did not provide me with enough scope, and concentrating only on structures of oppression created an absent subject and alienated knowledge, something that feminist research aims to redress through methods that:
at the outset of inquiry, creates the space for an absent subject, and absent experience, that is to be filled with the presence and spoken experiences of actual women speaking of and in the actualities of their everyday worlds (Dorothy Smith, 1988 pp. 107).

A post-modern approach argues that any attempt to make the identity of being a ‘women with an intellectual disability’ fixed, is an authoritarian practice and a restrictive label. In many ways, as this thesis will show, the lives of the women who took part in this study are restricted and this does lead to oppression. Yet ‘helpless’, ‘dependent’ or ‘victims’ are not ways in which they perceive themselves. Rejecting the notion of a fixed subject, post-modern feminism instead uses a multiplicity approach that allows for many different types of women who are constantly defined and redefined and relevant at particular points in time. The women in this study saw intellectual disability as one of a number of identities or counter-narratives they constructed for themselves that included but were not limited to: women, consumers, girlfriends, workers, voters, dancers and activists.

This ever-changing or fluid idea of women can lead to a transformative approach as it creates a space for new voices/stories to be heard. These unfixed or fluid multiple identities destabilise taken for granted Western cultural beliefs “concerning truth, knowledge, power, the self and language,” about what it means to be a woman and have an intellectual disability (Jane Flax, 1990 pp. 41).

Western feminist thought has been interested in exploring what it means to be a woman, the conditions of women’s lives and forms of privilege and domination (Norman Denzin, 2003). This has often been done through the sharing of stories. Adding a post-modern lens provides multiple ways of re-conceptualising these stories to understand how we experience and explain the complex, dynamic and often contradictory world in which we live. This research has taken the individual experiences of the women who took part in this study to reveal the micro-environment where they live their everyday/everynight lives. I have then extended the women’s stories beyond the local into the macro environment to understand the broader social context of their lives.
The women in this research self-identified as having an intellectual disability. The terms ‘intellectual disability’, ‘learning difficulties’, ‘mentally challenged’, or ‘retarded’ convey a precise meaning within Western society. These labels instantly produce ideas and mental images that are reinforced through powerful cultural stereotypes that reflect an existing social reality in which the dominant position of being ‘able’ is only constructed through and dependent upon the counter positioning of ‘disable’. Through language we create our sense of ourselves and our subjectivity is constructed as such by what is expressed as being more valuable — intellectual ability — and oppresses the other — intellectual disability.

Because of this dualism embedded in our language, facts, ideas, beliefs or concepts are never neutral. Instead meaning becomes an infusion of power and is used to thwart or oppress people’s needs, interests, knowledge and desires. Power produces truth through language. In the language of ability and disability, how disability is said or believed overrides all other able-ness a person may have and effectively removes them from the sphere of what is culturally accepted as being a woman, consumer, worker. Like all labels, the words convey a generalised image that covers a wide and diverse range of conditions, causes, and explanations, so much so that the individual person can become distant, lost or blurred.

The universalisation of life experience does not allow for the diversity of individual women. It is also a form of paternalism or domination that takes away a person’s right of choice. Within post-modern feminist terms it is an illustration of how women with an intellectual disability are constructed and positioned (Susan Wendell, 1996). Through being constructed primarily as vulnerable or childlike or dependent, women with an intellectual disability are placed in a subordinate position to women who are not. This can be seen as a form of power that is used to oppress or prohibit their voices or experiences from being elevated or heard (Marysia Zalewski, 2000). The belief that people with an intellectual disability are unable to think, feel and communicate their opinions, beliefs and experiences, often renders their lives meaningless to others. This
discourse allows for people without an intellectual disability to set the agenda for disability research and policy.

Post-modernist feminists as such are interested in the practices, processes and effects of how women and, in terms of this research, how women with an intellectual disability are constructed. In this way, power and knowledge are linked, as all official knowledge flows from a position of privilege. Questions post-modern feminist researchers ask are:

1. **Who gets to be considered a knower?**
   
   From a review of the literature it appears that carers, parents, state agencies, academics, medical practitioners, social workers — ‘the intellectually-abled’ are the predominate ‘holders of knowledge’ about people with a disability. Within the last 10 years there has been movement towards inclusive research. For examples of research that employs and involves people with an intellectual disability in research design and process (John Morrell, 1990, Jennifer Mactavish, Michael Mahon and Zana Marie Lutfiyya, 2000, Jan Walmsley, 2001, Alex McClimens, 2004, Richard Woolrych, 2004). I considered the women in this study to be experts in their own lives, however, they were not interested in being involved past the data collection phase.

2. **What gets counted as truthful knowledge?**
   
   Within Western culture, generalised assumptions about women who have an intellectual disability tend to be negative and deficit-focused. For example, they are not good mothers, childlike, asexual, are unable to form long term relationships, do not make good witnesses in court, are dependent, cannot manage their money and are not discerning. These statements may be true about some aspects of some women who have an intellectual disability these beliefs were not always true for the women in this study for example **Lara**, **Cindy** and **Evie** had all been involved in long term loving relationships.

Although Australia has human rights and anti-discrimination policies, and legislation, the belief that people with an intellectual disability require constant
protection underpins much of Australia’s government policy and regulation in relation to intellectual disability. While people with an intellectual disability now live in the community and are no longer held in large-scale institutions, power and control over their lives is still exerted through institutional prohibition and restriction.

This is illustrated by the experiences of the women in relation to their employment, finances, residential and living conditions, their social opportunities: in effect, the choices they could make. For example, one issue this research raises is the impact of limited employment options outside of the disability and business service sectors. All of the women were unable to find employment that enabled them to earn a level of income where they are able to move away from the Disability Support Pension and supplementary benefits as their main source of income. Working in an enclosed environment and having a limited income is in itself a form of probation and control. This thesis examines such gaps between policy and practice and the lived experiences of five women.

**Conclusion**

The intention of this chapter was to set out the theoretical perspectives that underpin the study. I have aimed to document the process that required me to reflexively consider the dominant theoretical positions that are influential in the area of disability research. Taking this journey through the medical and social models of disability, normalisation and feminist disability theory has enabled me to clarify and justify my decision to adopt the methodological approach of post-modern feminism in my research. This approach has strongly influenced the design, implementation and presentation of the project.

My research reflects the concerns of feminism to understand the everyday lives of women and acknowledge that the women who took part in this study are experts in their own lives. Post-modern approaches argue that truth is socially constructed and historically located. As such there can be no universal, fixed
identity. This position provides an opportunity for multiple and competing narratives to be heard and explored. In adopting a post-modern feminist position, the research began and flowed from the women’s multiple, diverse and complex lived experiences into the broader social context in which we live. The research method, analysis and interpretation in the subsequent chapters of my thesis explore the tension between the women’s self-narratives and the dominant discourses that surround intellectual disability.

The blending of feminism and post-modernism also requires that the researcher be reflexive, and aware of his/her position of power and influence in the research process — something I have attempted to address in my research journey. In the next chapter, 'I’m coming out', I have used some of the women’s self-narratives and artworks from the workshops to introduce them to you, the reader, before discussing in more detail the processes they took part in. I have done this in an attempt to give the women embodied forms, as I want you to begin to visualise them as living, breathing people rather than snippets and fragments of one-dimensional text on a page.
I'm Coming Out

I'm coming out,
I want the world to know
Got to let it show

The time has come for me
To break out of the shell
I have to shout
That I'm coming out.

I've got to show the world
All that I wanna be
And all my abilities
There's so much more to me
Somehow, I have to make them
Just understand
I got it well in hand
And, oh, how I've planned

3. I'M COMING OUT — THE WOMEN

Chapter two set out the theoretical positioning of the research project. The research design was influenced by feminist, creative arts-based and disability research practices. These viewpoints place the participant at the centre of the research where they are recognised and respected as speaking from a place of authority (Jocelynne Scutt, 1992, Virginia Olesen, 1994).

Before you read any further I would like to introduce you to the women who took part in this research project, so you have a good sense of who they are. Their stories have been presented individually and I have incorporated their self-portraits on the title page so that you, the reader, can put a face to the name. Each small cameo includes two art expression works and something about each individual woman that would perhaps come up if you were meeting her for the first time in person.

The purpose here is to personalise the participants, to make them known, to individualise each woman's story and to foreground their voices throughout this thesis. A different font as well as the participant's favourite colour has been used so that the reader can easily identify who is speaking.
Figure 3 - Self Portrait, 2005, Evie. Pencil and Texta Colour, Size A2.
EVIE’S STORY

I am fifty-two years old and the eldest of seven children. Last year I became a great aunty to K A. I am close to my nephew B who is twenty-two. We always go to his house for Christmas. Everyone gets together and we have tea, talk and drink and eat lots of chocolate.

Mum is getting old now and she has bad arthritis so it’s hard for her to do things. My sister had a talk to me and now I have to decide if I want to move back home and look after her. I love where I live but she’s my Mum. Someone has to help.

The reason I work is for the money. I am a good worker. The main thing we do at work is fold handkerchiefs and put pencils into packets. It’s very boring.

My dream is to work with children. I told my supervisor a long time ago that I want to get another job. I have to wait until they sort something out. I don’t like working there as no one is allowed to talk and they yell at you.

Lately we haven’t had any work so we have to sit at our table and either read or watch TV or do activities. I bought a new pair of sandals and wore them to work last Thursday. They sent me home because you have to wear enclosed shoes. There is no work and they still sent me home. It’s silly.
Figure 4 - Ink Wash, 2005, Evie. Ink and Paint, Size A3.
Evie’s Story

James and Paul share the house with me. I have the large bedroom at the front. They are really nice men and we look out for one another. Helen is our carer.

I have a boyfriend his name is A. He’s a bit of lady’s man. We have a good laugh.

C is my best friend. We sit next to one another at work, we talk on the phone and sometimes we can see each other on the weekends.

I like to read romantic books. The ones by Barbara Cartland are the best. I like to go shopping and buy clothes and go out with my friends.

On Monday nights I go to craft. I enjoy making things so doing this art is fun.

I have a lot of patience and I hardly ever get cranky. I’m pretty happy most of the time.
Figure 5 - Friends 1, 2005, Evie. Poster Paint, Size A3.
Figure 6 - Self Portrait, 2005, Lara. Pencil, Size A2.
LARA’S STORY

I am forty-eight years old and the eldest of five children. It was hard being the eldest. You always had to set the example. I emigrated from England when I was small. I remember coming on the boat. You know — one of those ten pound Poms that emigrated in the fifties.

I have one son. He is married and lives down the coast. Every second weekend I catch the train into Central11 and then catch the train to N from the country train platform and pick up my grandchildren. It is a long trip but I take food and books and colouring in with me and we make it into an adventure. I love having them.

I live with my partner of 8 years and I have a dog.

I didn’t get diagnosed until I was forty-two that I had an intellectual disability. I wish I had been diagnosed earlier.

Each morning I take the time to reflect on my life. When I first went to work at the book binding company12 I started feeling sorry for myself. I made myself stop and look around at the other people working here. There were a lot of people far worse off than me. Now I never feel sorry for myself because there are always others around who are worse off.

That company was a good place to work. They encouraged me and I became the union rep and then the state rep13. I was the first person with an intellectual disability to do that — loved the power.

11 Central Station is the main train station in Sydney where city, intra- and interstate trains leave from.
12 The Book Binding Company was a Business Services Company. These companies are historically Sheltered Workshops.
13 Shop floor Union Delegate for the blue collar workers at the Book Binding Company.
Figure 7 - Reflections, 2005, Lara. Acrylic Paint, Size A3.
Lara’s Story

Now I teach self-advocacy and interview staff for workplace audits. I really love listening to people’s stories. I have my Training and Assessment – Certificate IV from TAFE and I am working towards my Computer Applications for the Office — Certificate II. I enjoy using the computer — particularly Microsoft Messenger when you can type back to one another.

When I move to the country, I want to be able to do what I’m doing now. I absolutely love to do training. Remember that time I went to ….. and remember how I got caught in the rain and I didn’t really want to go. You know the feedback from that session was fantastic. A lady the next day rung up and said “Lara is marvellous. Lara is fantastic”. I didn’t ask them to do that. Now we have more training as well. I just go in there and be myself and if they don’t like it, well…

I work to shop. I love clothes shopping and I get my hair done every six weeks. It’s important when you deal with people and train that you look your best. No-one likes to look at a frump all day.

When I train I tell people if I can so can you. It’s important to have role models. If they know that I can do it then it makes them think ‘hey maybe I can’. It’s hard for lots of people with an intellectual disability; people always think that they know better and they tell you what you should do and make decisions for you.

You go to meetings and you have all these ‘normals’ standing up telling us what we should and shouldn’t do. If someone just asked they’d find out we actually know a lot.

Figure 8 - Untitled, 2005, Lara. Crayon, Size A2.
Figure 9 - How I See Me, 2005, Cindy. Texta Colour and Pencil, Size A3.
CINDY’S STORY

My thing’s not art — it’s music. I love to go in my room and lie on my bed with my headphones on and just listen to the music. I just want to stay there.

My parents live in a long way from where I live now. I’m the middle sister. I don’t see Mum and Dad any more. I had to get away. My Sister said Mum might call me for my birthday. That will be good.

I had to work on my birthday. I don’t mind ‘cause at morning tea time, when we have our break. Everyone stood around and sang me ‘happy birthday’. There was a big cake with ‘happy birthday’ on it and I blew out the candles and we all had a piece of cake for morning tea.

I have a young face and no-one believes me when I tell them “I am twenty-eight years old”. I don’t mind except when I have trouble getting into the club with my friends to go dancing or listening to a band. The man at the door doesn’t believe me when I say “I’m older than eighteen”…I suppose it could be worse people could think I’m really, really old, you know, 40 or something like that!
Figure 10 - Untitled, 2005, Cindy. Collage, Paper and Pencil, Size A3.
Cindy’s Story

I want to colour my hair purple but my carer says I would look stupid so I can’t. I don’t care if it looks stupid. I will one day.

I don’t go to work for the money. It’s the only way I get to see my friends.

I remember the first day I went to work in Sydney. Do you remember Evie? You asked me to sit at your table. You were so friendly. You introduced me to everyone and I felt really happy. I’m always in trouble at work for talking. You’re not allowed to talk at work, only in breaks. The supervisors always shout at us, don’t they Evie. I like working there because I get to be with my friends.

The best job I had was working in Target\textsuperscript{15} for work experience. I stayed for a while there. I loved that job. Everyone was happy and nice. I could talk to the customers and the people that worked there.

My boss called me a social butterfly. I like that. I like to think of myself as a butterfly. When I moved to… I had to leave. It’s hard to make friends in a new place.

\textsuperscript{15} Target refers to Target Australia Pty Ltd a general nationwide retail store.
Figure 11 - Butterfly, 2005, Cindy. Ink, Size A3.
Figure 12 - Self Portrait, 2005, Kay. Pen and Ink, Size A2.
KAY’S STORY

I don’t really know why you want to know about my life — it’s very boring. I get up, I go to work and one day a week I go to TAFE, on the weekends I visit my Mum. That’s about it.

I had meningitis at fifty days. That’s how I have an intellectual disability. Mum, Dad and I moved here from Hong Kong when I was eight. I am an only child and my parents were very strict when I was little.

After I finished school I did a Fine Arts Diploma. Ceramics is what I enjoy doing best. We just had an art exhibition at P last week and I sold a pot. I am so happy. I would like to do more but it is difficult for me to go unless I can catch a bus or train. There are things at night, I can’t afford taxis and I don’t like to travel on the train by myself late at night.

I work three days a week: Monday, Wednesday and Friday. I pick up the phone, I go to get the mail and I help the staff with what they need, like the information packs. I do office work and to try to learn some skills like fax and e-mail. On Tuesday I go to TAFE. I am studying Business Administration — Certificate IV.

My first job was in a sheltered workshop. I am so glad to be where I am now. I started in 2000 and I’m an Administration Assistant in our office. Before I lived with my Mum. It was a long way from here so now I live by myself. It’s good. It’s close to work and the train station and I can go to Mum’s on the weekend if I want to.
Figure 13 - Free form self expression, 2005, Kay. Poster Paint, Size A2.
Kay’s Story

Sometimes people to say to me “you don't look like you have an intellectual disability” and I say to them “what am I supposed to look like?”

I love to shop for shoes, clothes and make up. Mum looks after my money 'cause I am not good with numbers. I am doing Microsoft Excel at TAFE this term, so I can learn to do the petty cash and my time sheet. I am not good at maths.

I really love going to the women’s group on Friday. Last year we painted a mural in the community centre. It was very beautiful and colourful. It’s good to have a nice place to go to. Before it was just plain walls. You know, young women come with their babies.

This year we did nutrition. Learning about healthy eating. We have to plan for next year now. We might do car maintenance. I don’t have a car but I would like to learn.

I couldn’t make an ugly face. I put things that I like. Beautiful pink lips, lovely white skin and curly hair. You are so lucky you have beautiful white skin like the women in the picture. I can’t believe you straighten your hair, Lara. I would love curly hair my hair is so straight you can’t do a thing with it!
Figure 14 - Untitled, 2005, Kay. Collage Paper, Size A4.
Figure 15 - That's me, 2005, Shirley. Pencil, Size A3.
SHIRLEY’S STORY

That’s me! I look in the mirror I see my long eyelashes and my crooked teeth. Well… I do. That’s me! That’s what I see.

I’m forty-four years old and I live at home with my Mum and Dad.

I’m in the middle. I have a brother and sister older and a brother and a sister younger than me. We just went to my sister’s fortieth birthday party. She had visitors and nice food. After that we went to my brother’s place to spend the night. He is a good barman and poured drinks for everyone.

I am an Aunty. When we went to the party I saw my J. She used to, she used to wack me on my knee when she was little. Probably she loves me!

On Wednesday I learn my money skills from half past three and to about four o’clock. We just count notes like five dollar notes and you count five cents its not pretending money it’s the real packet money.

In the morning I go to gym and do the treadmill and stretching with Mum. Sometimes I go for a walk around the block. I play CDs. Sometimes I help Mum and Dad set the table.

When I go to my sister’s house we go outside and look up at all the stars. There are so many stars. This is a picture of the stars in the sky and the flowers in the paddock.
Figure 16 - A Starry Night, 2005, Shirley. Poster Paint, Size A3.
Shirley’s story

I had my birthday on the 15th November. My parents took me out. They took me to the RSL Club for lunch. I had schnitzel, beef schnitzel with salad and chips and coke and a cup of tea.

I love music. The Rat Pack and Tom Jones are my favourites.

Last year I went and saw John Paul Young. We had dinner first and danced all night. At the end he signed a poster for me. “To Shirley, my greatest fan love JPY”. It’s on the wall in my bedroom.

I can cook. I cook lots of things. My favourite recipes are beef casserole, lasagne, spaghetti bolognaise, meat loaf, chicken marinade and chicken apricot. I have a recipe book that the Centacare people helped me put together. They taught me at home on the stove in the kitchen. See, the pictures are of me in the kitchen. That’s our stove.

I didn’t think I could do art but it’s not that hard really!

16 Centacare Catholic Community Services is the official welfare arm of the Catholic Church in the Archdiocese of Sydney.
Figure 17 - Untitled, 2005, Shirley. Ink and Crayon, Size A3.
MY WAY

REGrets, I'VE had a FEw;
BUT then again,
too FEw to mention.

I did what I had to do
And saw it through without exemption.

I planned each charted course;
Each careful step along the byway,
But more, much more than this,
I did it my way.

4. MY WAY — RESEARCH METHODS

‘m coming out was designed to make the participants, Evie, Lara, Cindy, Kay and Shirley more visible by introducing them to you, the reader, in a more personal way. As witnesses to the re-telling of their stories and art expression work, some of those barriers in research that fragment participants’ lives become broken down, and as we begin to visualise and think about them as real people, the distance between our lives closes.

This chapter outlines the methods used to gather the data. It provides details about the location of the study, how the participants were recruited and how the initial idea of using Photovoice as a method of collecting data evolved into art expression workshops. The multiple methods of the data generation are also discussed. The chapter will also include ethical, logistical and occupational health and safety considerations that specifically relate to the women having an intellectual disability and that needed to be resolved to it make possible for them to participate in the research. The final section includes a discussion on analysing, interpreting and presenting the data as well as more formal details on the women.

RESEARCH DESIGN
The main requirements of participation in this study was for the participants to be female and have an intellectual disability, be over the age of twenty-one and have some working experience. The term ‘intellectual disability’ covers a wide range of diagnoses from Down’s Syndrome, Autism, and Prader-Willi Syndrome, through to illness or head injury. The nature of the research and
fieldwork was more suitable for women with mild or moderate intellectual disabilities, however, the type and severity of the intellectual disability was not stipulated.

**Location of the study**
This study was conducted in the North West suburbs of Sydney, New South Wales, Australia — an area that consists of mainly residential housing and light industry. The Sydney regional area has a population of approximately 4.2 million people and covers an area of 12,144.65 square kilometres (Australian Bureau of Statistics, 2006). In order to cause the least inconvenience to those who volunteered to be a part of this research, transportation was supplied. Therefore the recruitment area had to be reduced to enable car pooling. Additional transport-related issues are revisited in the section below on transportation.

**Recruitment**
A number of dilemmas were experienced in recruiting participants with an intellectual disability. The nature of this research involved more than just asking people for an interview. I was asking them to open their private lives to scrutiny on a number of levels: with me in the one-on-one interview, to the other participants at the art workshops, and eventually to you the reader. So it was important to establish contact in such a way that left the initiative with a potential participant.

The most difficult aspect of the recruiting process was gaining access to potential participants, as I had no current connections to people with an intellectual disability or their social networks. As my initial focus was on work, in order to recruit a range of participants with different work experiences, I made contact with twenty-one already established disability networks within the research site. These included four self-advocacy services, five supported employment agencies, four supported accommodation agencies and seven business service organisations. The largest target area was the business
services\textsuperscript{17} sector as it is the main employer of people with an intellectual disability.

Prior to the 1980s, most people with an intellectual disability worked in sheltered workshops. These workshops were primarily subsidised by local, state and federal governments. Between 1983 and 1985, a review of the sector by the Australian Federal Government resulted in the introduction of the \textit{Disability Services Act (1986)} and changes to pre-existing funding arrangements. Sheltered workshops were phased out and replaced by business services. These organisations were expected to be competitive in the open market and provide support and training to employees in their transition onto the open employment market.

I also targeted designated disability employment agencies as they have contact with potential full or part-time participants in the open employment market. The Disability Employment Network provides specialist employment services to any person with disability who requires assistance in finding a job or ongoing on-the-job support. To find a mix of participants, networks other than those involved in the employment sector were also contacted. Four local supported accommodation agencies were contacted to generate interest in the research study. Within the site location of this study, supported accommodation is predominately in group homes or in home support.

A strong emphasis within the disability movement is placed on individual rights and self determination (Simone Aspis, 1997, Patricia Noonan Walsh, 2003, Marcia Rioux and Anne Carbert, 2003). As a result, disability advocacy agencies have been established to assist people with a disability to overcome barriers that impact on their daily lives and restrict them from participating in community life. These services are often run by and for people with an intellectual disability. Although they are government funded, they work

\textsuperscript{17} Renamed Australian Disability Enterprises on the 28\textsuperscript{th} November, 2008. The name was changed to help build a stronger corporate image for the supported employment sector. I have continued to use Business Services in this thesis as at the time of writing the sector and literature had not adopted the change in name.
independently and at a community level. In using advocacy services as part of the recruitment process, it was hoped that I would be able to access women who worked and/or lived independently. This target group would be less likely to be recruited through business services, supported accommodation or employment agencies.

I made the initial contact by telephone to the manager of each organisation. If a manager felt that it was something that their members would be interested in, an appointment was made to meet with the manager to discuss the project. In the interim a detailed letter was sent to him/her outlining the study (see Appendix A). At the face-to-face meeting with the organisation’s representative I outlined the study’s aims and methods and what each participant would be asked to contribute. Copies of the participant information sheet and consent forms were left if there was an agreement to proceed further (see Appendix B). As each organisation has different methods of contact, it was left up to them to approach potential participants to see if they would be interested in being part of this research project. It was only after potential participants had expressed an interest in being involved that their contact details were forwarded to me.

There are a number of advantages when a person known to the women introduces them to the research project. It becomes easier for the women to decline to take part. The potential possibility of compliancy was therefore reduced, as by the time I came to speak to any potential participant, she already had some idea about the project and had agreed to speak with me. Finally, it addressed the statutory law *Privacy and Personal Information Protection Act (1998)* requirements placed on organisations in regards to privacy and confidentiality of personal information of any employees, clients or members (Tim Booth and Wendy Booth, 1994b).

There were, however, a number of disadvantages in using this method of recruitment. One of the major issues for me having to rely on other people to approach potential participants was that I had no control over the process. Twenty different organisations were initially contacted by telephone. From that
group, twelve organisations (see table 2 below second cycle of contact) agreed to meet with me to discuss the project and the possibility of them distributing the information within their network. After speaking with a manager from each of the twelve organisations five proved to be unsuitable.

<table>
<thead>
<tr>
<th>Table 2 - Recruitment contact cycle.</th>
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<tbody>
<tr>
<td>Business Type</td>
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<td>----------------</td>
</tr>
<tr>
<td>Business Services</td>
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<tr>
<td>Self-Advocacy Agencies</td>
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<td>Employment Agencies</td>
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<tr>
<td>Supported Accommodation</td>
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<td>Totals</td>
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The reasons for these five organisations not proceeding were varied. Although one advocacy organisation was very interested in the research and its findings they withdrew, as the majority of women they were in contact with were victims of sexual assault or abuse or other violent crimes. Upon reflection they felt that it was inappropriate for them to ask their clients to be involved as many were still traumatised from their experience.

All the managers in the Business Service sector that I approached raised different concerns about authenticity and the need to vet the transcripts of any interviews. Others insisted that a non-intellectually disabled staff member be present at the interviews to clarify and/or correct information. This raised serious questions about privacy and confidentiality and it may have prevented participants from speaking freely, thus negatively affecting the research. These concerns ruled out the possibility of using some Business Service organisations from the recruiting process for this research project.

The other main reasons for not proceeding was that although a manager may have been interested in being part of the project, when I came to speak with an employee who had the responsibility for recruiting, they advised me they had no suitable candidates. Of the seven organisations that remained interested in the
second cycle of discussions, only three were able to provide me with the names of potential participants. The recruiting process took six to eight weeks and resulted in four interested women.

This was a very labour-intensive process for so few recruits. The most difficult problem was communication. There were a number of changes in staff, people going on holidays and a general lack of communication within the organisations. This meant that I often had to restart the recruitment process with a different person. For example, a manager of one organisation telephoned me to say that they had the names of two women who were interested in being part of the study. The staff member who was in contact with the women in the meantime went on holidays and had left no details. By the time they got back and I was able to make contact with the women to gain their consent, they had missed the first two workshops.

In recruiting this way I had to rely on the discretion of a staff member who initially screened potential participants. Rather than the researcher, it was the staff member who controlled the flow of information. This type of recruitment is difficult, as the researcher and the staff member have different criteria for screening participants and many potential participants may be unnecessarily ruled out. In discussing the project a number of the organisations approached expressed concerns that their clients were not artists. Care was taken to explain that the research was not about producing works of art; rather, art was a method of collecting data. It may have been that for some staff members the association of creating works of art rather than art as a tool of expression and a perceived lack of ability in their female clients may have been another reason why few women were recruited using this method.

Alternatively for the women who were approached there was a risk that any potential participant may be influenced by their relationship with a staff member, and as a result the research might come to be too closely identified with authority. Having no control over how the study is initially presented and
explained to the women may have been influential in the few women being recruited through these organisations.

Upon reflection, as well as using this form of recruitment, I should have also attended social gatherings such as Friday Night Coffee Club or monthly skills training meetings that are held by a number of self-advocacy agencies. In conjunction with a staff member I would have spoken about the study and left the information sheets. If any women were interested they would be directed to speak to that staff member who with their permission would forward me their contact details. This would have been a far better approach as I would have been on hand to answer any questions and had some control over how the study was presented.

One of the participants, Shirley, was recruited outside of this process through a colleague who heard about the study. This approach has been documented as being effective and ethically sound (Tim Booth and Wendy Booth, 1994b). The major difficulty with recruiting people with an intellectual disability is that often where they live, socialise and work is within a closed environment. As an outsider this makes accessing their networks difficult.

Using other methods such as the local newspaper or computer internet sites would have been an ineffective way of recruitment. Although all the women in this study were able to read, none of them read the local community newspapers. In regard to access to the internet, Lara and Kay used computers at work, however only Lara had a personal computer. The other three women, Shirley, Cindy and Evie, had never used a computer. What this study brought to light was that the women who lived in group homes were not allowed to use or give out their telephone number without first gaining permission. If they had read about the study in newspapers, on posters or flyers they may not have been able to make telephone contact to express an interest in the study.

‘Snowballing’ or ‘snowball sampling’ a technique where existing participants recruit other participants from among their acquaintances, has been suggested
as another way of accessing hard to reach population bases (Rowland Atkinson and John Flint, 2001). After our discussion on confidentiality, however, the women were all very proud about how they had managed, although it was difficult at times, not to discuss what we had talked about in the interview and art workshops. Snowballing may have been useful for me in accessing other participants; however, as the women all took confidentiality extremely seriously, I believed it to be inappropriate as it would have undermined the trust process we had built up. Given the nature of this research, having a large number of participants was not crucial. Even though there were difficulties with the method of recruitment that I adopted, it was important to best address the needs of the participants and their carers or support workers.

**From Photovoice to art expression workshops.**

At the beginning of my doctoral research, I had envisaged that the aim of my research was to gain an understanding about the workplace experiences of women with an intellectual disability from their perspective. An important part of my research was to use a collaborative design that gave the participants control over some of the research process. As previously discussed in chapter one, my initial proposal was to use Photovoice as developed by Caroline Wang and Mary Ann Burris (1994). As a research method, Photovoice was devised as a catalyst for change and to affect social policy and justice.

The aim was to give each participant a disposable camera to be used to take photographs of what was important to them in their working lives, the idea being that each photograph prompted conversation and stories about their experiences of work. These conversations, it was envisaged, would lead to further understandings of their working lives. Due to the extended ethical considerations for the participant, employer and co-workers that come from taking cameras into the workplace, the process of using Photovoice in the research design proved problematic. In the initial discussions with employers in the business services sector, concerns were raised over the vetting and ownership of the photographs.
In this instance using Photovoice was not the best method as it reduced the autonomy and confidentiality of the participants and left them open to possible risk. As a technique, Photovoice also restricted the participants to only one style of expression and would have stopped two of the women, Evie and Lara from being involved. They both had some difficulties with fine motor skills and were very hesitant about using a camera, fearing that the photographs would be blurred or ‘not turn out’.

**Figure 18 - Using art as a stimulus.**

The decision to change the research design to a series of art workshops occurred after attending the Studio ARTES Northside Inc July 2005 ‘Get Over It!’ art exhibition. Studio ARTES Northside runs community-based programs designed to “increase independence, employability and community involvement through the arts, recreational and vocational training programs” for people with disabilities (Studio ARTES Northside, 2005 pp. 3). This exhibition inspired the design of the fieldwork to be art workshops where the participants could experience a range of different forms of art expression. The idea behind the workshops was to use art as a vehicle to communicate thought. Visual art is able to commune in ways that words cannot. Art invokes our senses and can connect our thoughts, feelings and perceptions with our life experiences helping us understand who
we are. Through art we can discover insights about ourselves (Cathy Malchiodi, 1998).

Figure 18 on the previous page, illustrates how art can trigger our senses into providing us with either a physical or an emotional response that in turn, awakens a memory. For example, every time I see Andy Warhol’s 1962 painting of *Campbell’s Soup Cans*, (figure 19 below) it triggers a memory of myself as a child of around ten years old. It was one of those occasions when Mum didn’t feel like cooking and we had Campbell’s tomato soup for dinner. My nostrils immediately fill with the pungent aroma of tomato soup, my stomach starts churning and I begin to feel sick. I can remember being made to sit at the dining table until the bowl of soup in front of me was empty. More than thirty years later, I still can’t bring myself to eat tomato soup, whether it is fresh or from a can. In the moment I begin to reflect and thoughts of my mother flood in: having to cook for a family of eight each day, the running of the household, Mum colouring black and white photographs on the back veranda to supplement our income, and the Vacola bottling production line in the kitchen each summer to preserve fruit for winter.

![Campbell's Soup Cans, 1962, Andy Warhol.](image)

As I sit and write this thesis my thoughts shift, move and settle on my life now and the different life Mum had when she was my age. Our lives could not be more different and yet they are intertwined. The women who participated in this study touched my life, enlarged and enriched it, and took me on an unexpected
path of self-discovery. The women’s discussion and reflection made it possible for me to uncover insights about them. As a participant in the expression workshops, the same processes allowed me to make sense and connections within my own life (Cathy Malchiodi, 1998).

**Ethics**
This research study commenced after university ethics approval was gained. Ethical considerations followed the feminist ethic of research that calls for the researcher to have empathy, emotionality, personal accountability, to take care and value individual expressiveness (Michelle Fine, 1992, Caroline Ramazanoglu and Janet Holland, 2002). These feminist principles are the founding blocks of what Norman Denzin and Yvonna Lincoln (1994 pp. 21-22) call the “contextualized-consequentialist model” of ethical research. This requires the researcher to build “relationships of respect and trust that are noncoercive and that are not based on deception”. It recognises that it is impossible to suspend yourself from making judgements and that “every research act implies moral and ethical decisions ... Every ethical decision, that is, effects others, with immediate and long-range consequences” (Norman Denzin and Yvonna Lincoln, 1994 pp. 21-22).

This study adopted the guiding principle from the self-advocacy and disability rights movements that people with an intellectual disability are people first, have the same value, rights and responsibility and are entitled to the same ethical treatment as other research participants (Tim Booth and Wendy Booth, 1994b).

**Informed consent**
It is commonly accepted that participants should be fully informed about the nature of the research in which they are participating (Virginia Olesen, 1994, Tom Shakespeare, 1996). To overcome any participant having different expectations of the research project, they were given clear details about the research, the goals, aims and how the information would be disseminated. Informed consent includes both verbal explanations and a written agreement between the researcher and the participant (Celia Fisher, 2003). As all the participants had prior information about the study and had already indicated their interest, my first meeting with them was then to introduce myself, explain
the purpose of the research, what was involved and my responsibilities to them. An important part of this research involved treating Kay, Cindy, Shirley, Evie and Lara with respect and dignity. It was important to me that the women fully understood what being involved with this study entailed.

Informed consent and ongoing ethics was an important part of gaining ethics approval through the University of Western Sydney to undertake this study. In some ways, striking a balance between respecting the women’s autonomy and the need to fulfil my ethical obligations to the university was difficult. People who have an intellectual disability are seen as a ‘vulnerable’ group by the academy (National Health and Medical Research Council, Australian Research Council and Australian Vice-Chancellors’ Committee, 2007). To undertake research with this group of people, ethics committees require the researcher to demonstrate how they will ensure that the participants’ physical and emotional welfare will not be placed in jeopardy and that they have the capacity to consent and make informed choice (Ruth Freedman, 2001). Unfortunately, there are no empirically-based guidelines on how to do this.

In preparing the information sheet and the consent form, I sought advice from the Intellectual Disability Rights Service (IDRS). IDRS is a community legal centre that works with people who have an intellectual disability by supporting them to exercise and advance their rights. Part of their service is to produce a variety of fact sheets and publications about Australian Law that are specifically written for people who have an intellectual disability. Their practical advice on making documents easier for people with an intellectual disability to read included: using a clear and easy-to-read font such as arial in either a 14 or 16 point font; keeping the sentences short; and write the information in plain, straightforward English. These small considerations allowed the women to independently read the information.

The suggestions made by IDRS also helped me to better communicate with the women, particularly in regards to consent. It was important to me to ensure that the women who took part in this study clearly understood what they were
consenting to. In the recruitment process a number of organisations had commented that some of their women ‘loved to do craft’ so it was important that the participants recognised that they were involved in a research project and not art classes. The consent process was broken down into a number of small steps as indicated in Figure 20 - Stepping out the consent process.

**Figure 20 - Stepping out the consent process.**

A criticism of information given to people with an intellectual disability is that in an effort to keep the language simple and jargon-free, important points are omitted. The language of omission only serves to reinforce ignorance and is in itself a form of oppression and disempowerment that deprives people with an intellectual disability of the right to make informed choices (Simone Aspis, 1999). A plain English style was adopted to discuss and explain each step of the consent process. No information about the research was omitted, however, and concepts and words were explained. For example the women were told that the primary purpose of the research was part of my PhD and to produce general
knowledge about their experiences of working life. What, why and how I was doing my PhD was included in the discussion.

At the end of going through the consent steps, I asked each participant the same two questions to confirm their understanding of the research process and their consent to take part. The reasons for asking these questions were explained as being confirmation that they understood what the study was about and what was involved.

Question 1: What is this study about?
All the women were able to answer that it was ‘talking about work’.

Question 2: Would you tell me some of things that you will be doing?
‘Having interviews’ or ‘meeting on Saturday’ or ‘going to the workshops’ or ‘doing art’ were the main answers given to this question. After going through the consent process, written consent was gained.

In health care decisions, people with an intellectual disability may be asked to select a family member, friend or trusted person to be present during an informed consent discussion to help review the information and aid them in the decision-making process (Celia Fisher, 2003). In the initial telephone conversation all the participants were asked if they would like to have a support person present during the ethics and consent process. Cindy, Evie and Shirley indicated that they would like someone to be with them and so I met them at their home. Kay and Lara, however, declined the invitation and consent was gained during their lunch hour at their place of work.

On-going ethics
Ethics in this research was an ongoing process that was renegotiated each time I met with a participant (Virginia Olesen, 1994). Within disability research, people with an intellectual disability are often seen as acquiescent (Tim Booth and Wendy Booth, 1996). This is said to be related to their cognitive functions, a defence mechanism (Leena Matikka and Hannu Vesala, 1997); and the social
practice of not asking them their opinion. At the beginning of each workshop and interview together, we would go over what we were going to do. I would also talk about confidentiality and the voluntary nature of the research. This included reassuring the participants that it was okay for them to say no to answering any question or participating in anything they felt uncomfortable doing.

Privacy and confidentiality

In asking the women to share the stories of their lives, I was concerned with the risks associated with revealing intimate matters of a personal nature. With this at the forefront of the research design, to reduce the risk of breaking confidentiality, scrupulous attention was given to record-handling and concealing identifying information (Juliet Corbin and Janice Morse, 2003). In line with feminist research practices and the disability rights movement, in order for the reader to easily identity with the participants as women first, and then as someone who happens to have a disability, the women were asked to choose a female pseudonym. Any audiocassette tapes, transcripts, files etc were labelled using the women’s pseudonym. No reference to their real name was used outside of the consent forms.

My fear of participant identification was heightened after a third person, who was part of my initial supervision panel identified a participant. It happened just after completing my fieldwork during a supervision meeting between Moira, Debbie, a third supervisor and myself. The aim of all research is to circulate the results to audiences that are often far removed from the participants, but as my experience taught me, participants can also be recognised by audiences much closer to home. Like many research participants, one of the reasons for participation in this research was my commitment to ensure that they would not be identified. With some of the sensitive data and acts of resistance against authority some of the women had developed, I held fears and concern about the imaginable audience closer to them rather than from far away. Although

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18 Due to different philosophical beliefs about disability research and services as well as research in general, it was agreed that in the best interests of this research that this person would not be part of my Higher Research Degree Supervisory Panel.
permission has been granted to reproduce photography, to further protect the identity of the participants, any identifying features have been obscured.

Do the least harm
In this study I adopted a feminist ethics of care to the research design that advocates the use of personal support as a resource of research (Claire Tregaskis and Dan Goodley, 2005). Asking the women to reflect and then share stories of their lives had the potential to raise memories that could produce a strong emotional response. Many people with an intellectual disability are survivors of physical and/or emotional violence (Moira Carmody, 1990, Moira Carmody and Joan Bratel, 1992, Roeher Institute, 1995, Marcia Rioux, Cameron Crawford, Miriam Ticoll and Michael Each, 1997, Joan Petersilia, 2000, Darja Zavirsek, 2002). The women in this study were no different. One of my major concerns was that I am not a counsellor, so I needed to allay my own fears and have in place a range of strategies of what to do if a situation arose in which I felt I was beyond my expertise. To better deal with a situation if it arose I attended training on how to provide effective communication and support to individuals with an intellectual disability who disclosed that they have been abused or sexually assaulted. This highlighted the need for access to a fully comprehensive list and a broad range of information and services that were available for the participants in the local and regional area (see Appendix C).

An extensive list of women’s agencies and disability resource services was compiled, which covered a wide range of topics: sexual assault; abuse and domestic violence; general health and counselling; consumer and advocacy services; government departments and complaints; workplace, financial and legal advice; court; and victim support services. This list has now been used as a template by a number of postgraduate candidates who are researching with participant groups who are deemed ‘vulnerable’. The resources list (Appendix C) contained each organisation’s name, contact details and a brief outline of the service, and was attached to the participants’ copy of the consent form. Copies were also taken with me to all the interviews and workshops.
Throughout the fieldwork I had on hand the mobile telephone number of a female private psychologist who was experienced in counselling people with intellectual disability. This person was recommended by the NSW Council for Intellectual Disability and had agreed to be available to offer counselling if required. Her name and contact details were also included in the resource list.

Giving a participant the telephone number of a counsellor and a resource list are practical strategies. If a situation had arisen where a participant became very distressed or angry, however, this would not solve the immediate problem. If this situation had happened, or if one of the participants became ill or had an accident, part of the consent form included the name and telephone number of a family member, friend or trusted person that was on hand and could be called in an emergency during the fieldwork process. This person also served as a support person during the consent process and someone who the participants could speak to about any matters that arose out of the study. The women chose either a parent, a support worker or a partner. Having support on hand proved to be useful as on one occasion a participant had forgotten to bring her medication and she was able to telephone her carer to see if she was able to take her medication at a later time.

One of the concerns about using art workshops as a form of data collection was the informal atmosphere and how this can blur the lines between researcher and friend. Asking the women to select a support person was an indirect way of reminding them that I was a researcher and not a friend (this will be discussed in more depth later in this chapter).

_A word on power_

Throughout the fieldwork I was aware of the power imbalance between me as the researcher and the women as the participants. The potential to exploit women in research has been a concern of feminist researchers (Patti Lather, 1988, Regina Scheyvens and Helen Leslie, 2000). Often in research, people with an intellectual disability occupy a disempowered role, and there is little evidence that this section of the population have been offered a voice or control.
I Get So Angry!

I want to go dancing but when I get to go they won’t let me in because they think I’m not 18. I tell them I am 28 but they say I look young and without identification, they won’t let me in.

We phoned up the RTA and they said I could get a proof of age card but I had to have my birth certificate. So I wrote to my mum and dad to send me my birth certificate. They couldn’t find mine so they had to write and get me a new one. I don’t have any identification so I can’t get it. They have to ‘cause they are my mum and dad. That took a long time and then they finally sent it to me in the mail. I was so happy.

Then I had to wait for a time my carer could drive me to the RTA. Finally we went last Saturday morning. The RTA was full of people and we had to sit and wait for our number to be called. That took about an hour. Finally we get to the counter and the woman said that they don’t do it any more.

I was so angry I started shouting at her. I waited all that time, all those months and they don’t do it. I got so angry and lost my temper that I’m back in anger management classes. Cindy
To apply for a copy of a birth certificate in NSW you are required to produce three forms of formal identification. Cindy only had two: a Medicare and Centrelink card. She did not have a passport or a driver licence. Nor did she have a recent utility account that showed her current residential address, as the rental lease and the electricity were in the name of her accommodation support provider. Also, Cindy was unable to produce a bank statement that showed her address as she used a passbook and statements are not issued on this type of bank account. Without proof of identity, Cindy required her parents to obtain her birth certificate for her.

The RTA does issue these cards. The person behind the counter had made a mistake. By the time the field work had ended some 10 weeks later Cindy had not been taken back to the RTA to get her photo ID. The meant that Cindy could not go out dancing as she looked under the age for being allowed onto a licensed premises.

What this story illustrates is Cindy’s lack of autonomy and the lack of respect for her requests. Having this card was important to Cindy as it was a way to connect with friends and the community. Yet it took some months for her parents to send her birth certificate and her support worker to take her to the RTA. I can understand how Cindy would have been angry and upset, I believe that many people would have acted in the same manner; however, the repercussions for people without an intellectual disability is that they do not end up in anger management classes. This highlights how Cindy was not allowed to have the same range of emotions.
Research has found that people with intellectual disabilities can have issues with anger (Betsey Benson and Carola Fuchs, 1999, James Harris, 2006). Anger is commonly associated with aggressive behaviour. In women with intellectual disabilities, challenging behaviour has been linked to internal biological problems (Jo Bromley and Eric Emerson, 1995). Anger can, however, be a reaction to frustration, unmet physical and emotional needs (Raymond Novaco and John Taylor, 2004) or related to poor problem-solving skills (Betsey Benson and Carola Fuchs, 1999). Some suggestions to decrease aggressive behaviour included conflict resolutions skills, intervention strategies, anger management and assertiveness training. These strategies are seen as ways to interact with peer and authority figures at home and at work. The position taken within the literature reviewed reflects the discourse of the medical model of disability, where the problem is caused by their disability and as such, the responsibility lies with the individual who requires diagnoses, intervention, and treatment by a profession.

Issues of power were seldom addressed, yet it is often direct support staff who first assess a person with an intellectual disability’s level of aggression and decides what action should or should not be taken, such as in the case of Cindy. Research that uses both observer and self-rated anger scales have found that the perception between the two groups are different. Staff tended to rate their clients as being more angry than the clients rated themselves, with staff often including irritability as a sign of anger (John Rose and Danielle Gerson, 2009).
over the research being conducted into their lives (Paul Duckett and David Fryer, 1998, Anne Louise Chappell, 2000, Dorothy Atkinson, 2004).

The belief that women are experts in their own lives is one of the cornerstones of feminist research (Patti Lather, 1997, Marysia Zalewski, 2000). This philosophy lends itself towards a research design that aims to reduce the power imbalance between the researcher and the researched. Having a two-way exchange helped to build a relationship of trust. The hierarchical nature of the interviews was a stark contrast to the informal nature of the workshops, and will be discussed later in this chapter.

The unstructured free-form style of discussion in the workshops allowed the participants to exercise control over what stories they chose to share, and how they shared them. While the workshops had to be loosely designed to gain university ethics approval, not controlling the topic of conversation or having prepared questions served to minimise some of my power as a researcher.

Feminist research not only sets out to describe women's lives and realities but also improve them. A concern with using art workshops was the potentially damaging affects that creating friendship or friendliness can have on the participants. Trying to move the power imbalance in the research process towards a more equal relationship may paradoxically become exploitation. Although the participants were advised that they could withdraw from the research or not answer any question, it has been found that participants rarely exercise these rights (Gesa Kirsch, 2005). I was concerned that the participation in the research had more to do with creating art and enjoying company than contributing to knowledge production. In future, wherever possible I would invite participants to re-negotiate the relationship after the fieldwork and introduce the right to co-interpret, or provide participants with emerging interpretations of the research data for their review and comments. This type of collaboration can provide the researcher with a different point of view in interpreting the data (Gesa Kirsch, 2005).
Part of being a participant in any research is the educative effects it may have. Power comes from knowledge and within disability discourse this often equates to ‘what they don’t know can’t harm them’ or the fear that people will act on their newly acquired knowledge (Simone Aspis, 1999). The risk that people may learn something either about themselves, others, or practices that do not sit comfortably with them, is always a risk in any research project. It could be argued that the women were co-researchers during the data collection stage of this research in that they asked questions and sought clarification. They also gave advice, particularly around rights and regulations.

It is acceptable practice now to have the participants as co-researchers throughout the whole process (Malcolm Richardson, 2000, Jan Walmsley, 2001, Dan Goodley, 2004, Alex McClimens, 2004, Annabelle Grundy, et al., 2005). In future research, and in particular researching with people who have an intellectual disability, I would do this. This research project is a direct result of my desire to obtain my Doctor of Philosophy. There were no industry partnerships nor did the research topic come from people within the community. I made a decision at the beginning of the project that the interpretation of the data and the writing of this thesis were my responsibility, as the research was principally for my benefit and career. Although I believe ethically I made the correct decision I have had to wrestle with conflict between research as a collaborative process and my power as the researcher. To overcome this dilemma and to address a gap in my research design, I have begun working in collaboration with three of the participants to publish some of their experiences in poetry and disability journals.

**Logistics**

In order for the research to proceed there were statutory requirements such as occupational health and safety and personal requirements such as health care issues, limited financial resources and/or restricted access to transport that had to be addressed. This made planning the workshops logistically challenging.
Catering
Morning, afternoon tea and lunch were supplied for the workshops. The two main reasons were: some of the women were on medication that had to be taken at strict times during the day; and the reliance on a Disability Support Pension as a main source of income. As the women had a limited income I believed that it was unfair to expect them to attend interviews and workshops, and provide their own food and drink. This was a small gesture to thank them for giving up their time.

Transportation
Some people with an intellectual disability are able to drive a car, although none of the women who participated in this study had her drivers licence:

*I could drive if I wanted to but I would be too nervous driving in all the traffic. Lara*

Therefore they all had to rely on public transport, taxis or someone to drive them to and from each workshop. It was first envisaged that the participants would be transported by taxi; however, the costs involved made this option impossible.

All the participants and/or their carers raised different issues about transport. Providing door-to-door transport removed a major obstacle that would have potentially prevented them from attending. For Shirley’s parents, catching taxis posed safety questions. Kay and Lara were able to catch public transport if I provided them with detailed timetables, maps and instructions. The time taken to travel to the venue was inconvenient, however, and involved a number of transport changes. Cindy and Evie, on the other hand, completely relied on their support workers for transport to all activities and appointments outside of work. The time of the workshops clashed with the hours their support workers worked, and without transportation, they would have been unable to attend.

During the consent process, transportation was discussed and it was resolved that I would provide transport. This included arranging a time that was
convenient for the participant for me to telephone them the Friday night before the workshop to let them know the time and person who would pick them up the following morning. Transportation was shared between my partner Chris and myself.

**Room Set-up**
A large, light-filled room with a high ceiling and large windows was selected to hold the art workshops on a University Campus. If the women chose to work outside, the room opened directly onto a grass quadrangle that had large shade trees on one side and a wide veranda with a ramp and hand rail access on the other. The drop-off and pick-up access place was a flat few metres walk to the ramp. The room was adjacent to a telephone that linked directly to the security office in case of an emergency, and was next door to the toilets and kitchen facilities. There was also a large clock in the room so we were all aware of the time.

To facilitate the smooth running of the day’s work, and to adhere to occupational health and safety standards, the room was divided into five distinct areas, as described below. As the floor had to be covered with plastic sheets to protect the carpet, bright blue tarpaulins were used that contrasted with the grey carpet to define the space. Where possible these were anchored down to stop us from tripping over.

**Computer Area**
All the workshops were photographed as a pictorial data representation of the research process. A laptop computer and colour printer were set up so that photographs could be downloaded directly from the digital camera. At the end of each workshop that day’s photographs were downloaded and saved. As previously discussed all the participants had the opportunity to edit and delete any photograph they did not want to be published.

**Eating Area**
Tea, coffee, and water were laid out so participants were able to help themselves at any time. A number of the women had to take medication at
certain times of the day, so it was important to keep refreshments on hand. Lunch, morning and afternoon tea were served and eaten in this area.

_Art Materials_
All the resources required for the day’s different activities were set out within easy access of the communal workspace. This kept the workspace clear, and enabled the smooth and quick flow from one activity to another.

_Drying Areas_
As a number of art expression works were completed in each workshop, a large area for drying was required. In addition, a storage and mounting area was required for work that was completed or in progress.

_Work Area_
One large work area was set up so that the group could work together on their individual pieces. Occasionally a second space workspace was set up when one activity interfered with the work of another.

**Collecting And Using The Data**
In this section, I provide an overview of the workshops, one by one, in order to give a snapshot of the process, and discuss how the ideas in programming played out in reality. I show how an arts-based approach creates dialogic opportunities to gain deeper insight into the women’s lives from their perspective.

Within disability literature, concerns have been raised about the validity of data when directly interviewing people with an intellectual disability (Dorothy Atkinson, 1989). To overcome this problem, it has been suggested that people without an intellectual disability can be used to cross-check the data (Jackie Rodgers, 1999). I chose not to do this as it undermines the feminist principles that women are experts in their own lives. There is a perception among some researchers that people with an intellectual disability are not reliable, trustworthy or capable research participants. When discussing my research at conferences, colloquia and workshops, the question of data validity has usually been raised.
In this research project I began with the conscious decision that all “perspectives on an issue or event are inherently valuable and equally useful” (Jennifer Mactavish, et al., 2000 pp. 216). As the researcher, this placed an obligation on me to find, document and analyse the lived experiences of the participants, who for various reasons, may not otherwise be considered as worthy participants (Steven Taylor and Robert Bogdan, 1998). In order for the women to participate in this study my data collection procedures, at times, had to be modified to accommodate their individual needs.

Data were collected, in this study, over a four-month period through a series of art expression workshops, interviews, observations and field notes. Supplementary data were obtained from both Australian Federal and State Government Workplace and Disability policies during and subsequent to the period of field data collection.

**Undertaking the research: Art expression workshops**

The research design focussed on the notion that the art that was produced was a by-product, a means to an end, a form of self-expression, and not a ‘work of art’ to be analysed. To plan and facilitate the workshops, I engaged the services of an experienced artist and art teacher, Moi, who has for many years incorporated arts-based educational practices in teaching students from Kindergarten to Year 11. Moi’s participation in the research was to run the art workshops this included planning and facilitating the workshops. This meant that the activities could be instantly varied or adapted to meet the individual needs and skill level of each participant.

Moi’s expertise in art enabled her to problem-solve and respond in a variety of situations. For example *Lara’s* difficulty with fine motor skills undermined her confidence in her ability to be creative. Working with thicker crayons, brushes and pencils reduced the effects of her tremor and made it possible for her to make the fluid lines that were important to her in her artistic expression. After each workshop Moi and I discussed each art activity in terms of what did and did not work. From our reflections and based on the women’s individual
requests or needs any additional art resources were procured and activities were adjusted for the next workshop. Moi’s contribution to the evolution and implementation of the arts-based method used in this research was profound influenced the visual data, however, as this data was not analysed by the researcher the impact was seen as minimal. Moi did at times contribute to the discussion of our art work and in the telling of our stories but she was not involved in analysis of any of the verbal data.

Figure 21 - Workshop Collage, 2006 Janette & Moi, Size A1.¹⁹

Having Moi on hand throughout the process to advise on colour, design and techniques built the confidence of the women, who except for Kay had not ‘done art’ since leaving school. For some of the women this was over twenty years ago, so naturally they experienced a mixture of excitement and anxiety:

¹⁹ Moi and I met three times at the beginning of 2006 to reflect on the art expression workshops. Over the meetings, we worked around my kitchen table, creating the collage in figure 21 as we talked about the process of making art in the workshops. This collage was made from photographs, original artworks and off-cuts, Moi’s and my art expression works, and left over craft materials. As in the workshops, creating this collage gave us time to reflect and decide what stories we wanted to share about the art workshop process.
I didn’t think I could do art but it’s not hard really! Shirley

To overcome some of their concern, each art expression process was approached with the philosophy that there are no mistakes in art; every line, colour or texture can be changed or coloured over. It was hoped that this would free the women from getting bogged down in perfect artistic representations and to experiment and express themselves in new, bold and different ways.

A series of five art workshops were planned, with the option of having one workshop at the Art Gallery of NSW. Each workshop was designed as a stand-alone unit so if one of the women missed a week or decided not to continue, the research process would not fall apart. Committing twelve weeks to a research project is fairly difficult for most people, as life has a tendency to take over. As it turned out, none of the women were able to attend all the workshops, so having independent modules meant that particular discussion threads from the workshops could be followed up or introduced in the subsequent interviews.

Table 3 outlines the date of each workshop, the theme, art medium and the participants who attended. All the workshops, except for the Art Gallery of NSW visit, were held on a Saturday between 10am and 3pm. The first workshop was held on the 15th of October, 2005 and a workshop was held each subsequent fortnight until the 10th December, 2005. The fieldwork ran during this period to accommodate Moi’s teaching schedule which was less demanding at this time of year.

Table 3 - Workshop attendance and dates

<table>
<thead>
<tr>
<th>Date</th>
<th>Workshop 1</th>
<th>Workshop 2</th>
<th>Workshop 3</th>
<th>Workshop 4</th>
<th>Workshop 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Theme</td>
<td>Who I am</td>
<td>Art Gallery of NSW</td>
<td>Friendship</td>
<td>My Work</td>
<td>Collage</td>
</tr>
<tr>
<td>Participant</td>
<td>Self Portrait</td>
<td>Art Gallery of NSW</td>
<td>Movement</td>
<td>Sculpture</td>
<td>Still Life</td>
</tr>
</tbody>
</table>
Each workshop was planned around a theme, and introduced new artistic media. The participants had control over what stories they chose to tell and also an opportunity to gain something from the process. It was important that the research design incorporated a two-way exchange (David Fetterman, 1998, Angie Titchen and Joy Higgs, 2001). By this I mean that I was not the only person who gained knowledge; rather in exchange for information about their lives the participants were given the opportunity to tell their stories in their own way, listen to the stories of the other women, experience different styles of expression and learn some new skills in return.

What this opening up of the research design achieved was that work was only one topic of conversation the women chose to talk about. They spoke of love, food, and friendship. They did talk of work, but only as one part of their lives (Debbie Horsfall and Janette Welsby, 2007). Evie, for example, spoke about having Christmas day with her nephew. When her family celebrated Christmas at his home, all her siblings, nieces and nephews came. Evie loved Christmas when her family was all together and this year was more exciting as she had become a great aunt.

As with any group, not all the women found certain art media to be a sympathetic form of expression; therefore, it was important to provide a range of activities where the women could work at their own pace and level of interest. Having a variety of creative arts activities and the informal nature of the group created a space that made it possible for the women to exercise choice over the conversation and topics of discussion (Janette Welsby and Debbie Horsfall, 2006). The gentle nature of the process provided greater opportunity for rich and intensely personal insights into the lives of these women that may have been lost through a more formalised process.
We worked around a large communal space and there is something quite symbolic, familiar and ritualistic about the process of eating, talking and sharing around a table. When we moved away from this collective space the conversation, instead of a steady flow, waned and stifled. It could be argued that the art expression workshops were informal group interviews. The conversations were unstructured and usually flowed from the day’s theme and the artwork stories. In this way, they differed from traditional focus groups, a more common form of group interview, that asks specific questions about a particular topic or event. The free-flow form of the art expression workshops provided a snowballing and elaborating platform of discussion and aided in producing rich data (Andrea Fontana and James Frey, 2003). To ensure that every person spoke, we would move around the table talking about our individual art expression pieces. Throughout the workshops we would first listen to each woman’s individual story, and then we would have a group discussion. All the women were very respectful of each others’ stories, and tended to listen without interrupting.

In talking about our art we spoke individually and collectively about our lived experiences. This gave each woman the space to be heard and to be witnessed by the other women in the group. While each woman’s story was unique to her, we found that collectively we shared many commonalities and as we spoke we gained new insights and understanding about ourselves and each other. The gaining of knowledge through sharing experiences has also been documented by other researchers (Mary Field Belenky, Blythe McVicker Clinchy, Nancy Rule Goldberger and Jill Mattuck Tarule, 1997). The process highlighted that the women in this study were reflexive, had clear and definite opinions and a depth of understanding about who they were and their lives, making them interesting, valid and legitimate research participants.

Each workshop would begin with morning tea and a quick chat about what had happened over the fortnight since we had seen one another. Ongoing ethics, confidentiality and the reason for the research was also discussed. Moi outlined the day’s theme, what we would be doing during the day and the different art
media/techniques used in the expression exercises. See Appendix D for a daily plan and checklist for each workshop.

**Workshop one: Who I am**
The underlying principle of this research project, as discussed in the previous chapter, was to incorporate an inclusive design. Therefore the first process of this day was a brainstorming activity. This was designed so that the women were individually and collectively able to choose the topics of discussion for the next four workshops. The plan was that the topics selected would then have been grouped into different themes that would be explored in subsequent workshops.

The idea was that brainstorming would stimulate conversation and start the women thinking about what they would like to discuss. The reality was somewhat different, and highlighted some of different expectations between the researcher and the researched, and what happens when participants exercise their right to say no. Although I was focussed on ensuring that the participants had control over the content, believing this to be an empowering exercise, they had no interest or desire in brainstorming — they just wanted to start being creative. Instead of a collaborative discussion where we negotiated topics for exploration, there was a quick discussion around the themes of family, friendship and work, and an agreement to go where our conversations took us.

The central pre-planned theme of the first workshop was ‘Who I am’. Reflecting this theme, the day’s workshop involved a number of different self-portrait activities that focused on our identity and self perception. The wording of this workshop as a statement rather than a question was important to me as I wanted to reinforce the idea that the participants knew who they were. Having a clear, concise statement reaffirmed and reflected this belief. In contrast the theme ‘Who am I?’ seemed to imply that they did not know themselves and questioned their personal identity. Working and living in different areas it was highly unlikely that the women would know one another. At one level the art expression activities were designed to allow them to build rapport and get to know one another.
For many artists, having a large blank canvas placed in front of them can be daunting (Moi, Personal Communication, October 2, 2005). So as not to intimidate or scare the women, the first activity would often be worked on A4 paper, with the size of the canvas increasing for subsequent activities. The first activity ‘what makes a face’ used pictures from magazines to make a face collage. Each woman was given an A4 sheet of paper and a number of different magazines, which they could look through, select and cut out from. These pictures were then glued in place to construct a face. The pictures below in figure 23 are the faces constructed by Moi, Shirley and Lara. Kay’s face is included in her artwork in the chapter ‘I’m coming out’ (see page 96).

![Collage of faces created by Moi, Shirley, and Lara.](image)

**Figure 22 - It’s in her look, 2005, Moi, Shirley, Lara. Collage Paper Size A4.**

This initial activity had a number of different purposes. Apart from being an ‘ice breaker’ it was designed to build rapport and gently ease the women into using creativity as a way of combining reflection and storytelling to explore shared lived experiences (Rene Geanellos, 1996). This was done in a non-threatening way by focusing the discussion on the face they had created rather than talking about themselves. Starting with Moi we each spoke about what in particular had drawn us to select its different characteristics. In this group discussion our conversation revealed that we had all selected qualities that we admired in others.

*Kay:* I love curly hair. My hair is so straight you can't do anything with it.

*Moi:* Yes mine too.
Lara:  My hair goes frizzy. I hate it. Every morning I have to wash it and blow-dry it straight. I would love to have hair like you.
Shirley:  Me too! My hair is so thick I keep it cut short so it’s easy to manage.
Lara:  We all want what we don’t have. It’s funny but look we’ve all picked things that we find beautiful like my red thick lips.
Kay:  Do you like red lips?
Lara:  No. I can’t wear it. My lips are too thin.
Shirley:  I love lipstick. Look [opening her handbag and placing the tubs of lipstick on the table] one, two, three, four… I always have lots in my handbag.
Kay:  My lips are dark so I have to wear dark colour otherwise you can’t see it. I would love to wear pink lipstick. You could wear red.
Lara:  No way!

This simple activity promoted a huge amount of conversation and laughter, and helped us to get to know each other on a more intimate level. The process gently eased the women into telling stories about themselves. These general conversations gave me insight into the lives and personalities of each woman. Although the setting was part of the research process, it was a comfortable relaxed environment in which to talk and chat over food and art — more akin to friends meeting for coffee than the formal environment of a one-to-one interview.

Although Moi and I had discussed whether or not to have examples of each activity we decided against it as we did not want to influence the outcome. This soon emerged as a mistake on our part. Not being sure of what to do Kay and Lara held back and took some time to begin in the first activity. It wasn’t until our group discussion that Lara disclosed:

I wasn’t exactly sure of what I was supposed to be doing. I didn’t want to get it wrong so I waited to see what you did before I started.

Not having visual examples overlooked the basic ways in which many people learn and the need for both visual and verbal clues (Demetrios Sampson and Charalampos Karagiannidis, 2002). Some of the women needed a visual point of reference before they were able to start their own work. We readjusted our approach, and although we did not provide examples Moi demonstrated the
activity. This way the women could ask questions and watch until they felt confident to begin their own work.

The second activity of the day (see figure 23) was a profile self-portrait, first using pencil and then adding water colour pencils, texta colours and pens. This involved a deal of trust as one woman knelt on the floor and laid her head, shoulders and hands as flat as possible onto A2 paper while another woman traced around her outline onto the paper. We then used the sense of touch to understand the shapes of our faces and filled our features into the outline on the page. For example, to draw in the length of your ear, the top is usually in line with the corner of your eye and the bottom is near the corner of your mouth. We measured these distances physically before drawing.

Figure 23 - Self Portrait, 2005, Kay. Pencil, Size A3.

This was a difficult activity, as most of us had not explored our own faces in such detail. Other body features that we could see along with jewellery, glasses, and hair fasteners were added to complete the picture. The topic of conversation over this activity moved from where we were born, our position in our families, what we like to do in our spare time, to holidays — who we are.

The final activity of the day involved using a mirror to draw our own portrait (see Figures 24 and 25). The mirrors varied in size and shape, and using water colour or lead pencils we drew ourselves. Taking the instructions literally, both Shirley and Lara first drew around the mirror and then drew their self-portrait.
inside. As I came to know the women during the fieldwork, I found that they tended to take things on face value, so it was important that I communicated in a clear and concise way.

Figure 24 - Shirley's mirror self portrait. The artwork is titled Me in the mirror, 2005, Shirley. Pencil, Size A3.

Well that's me. My big eyes, long eyelashes and crooked teeth. That's me! What more can I say? Shirley

During this workshop a large amount of personal data and observations about the women were gathered and recorded in my field notes. Who they were, their families, their intellectual disability, what was important to them, how they liked to be treated, what annoyed them and how they spent their leisure time. From the general conversations a more complete picture of the women began to emerge, where having an intellectual disability no longer overshadowed other possible identities such as: sister, traveller, consumer, friend.

Figure 25 - Lara working on her Self Portrait, 2005 Lara. Pencil on Paper, Size A4.
See I added red lips for you Kay. I like how my straight hair it curls around my face. I get my hair done every six weeks. It’s important to look your best when you’re a trainer. I wear stockings to work every day and make up and have to blow wave my hair. Lara

Workshop two: The Art Gallery of NSW

In the first workshop it was suggested to the women that they might like to include a visit to the Art Gallery of NSW. In our conversations about the research project both Shirley and Lara disclosed that they had never been to the Art Gallery. Although Kay had been a number of times some years prior while she was studying for her Diploma in Fine Arts, she felt it was a good idea as “the exhibitions change all the time”.

The purpose of going to the Gallery was not just for an outing. Throughout Moi’s years of teaching art she had discovered that when many people start to use art media they often feel that they have to have picture perfect representations. The fear of ‘getting it wrong’ often stifles the creative process and these women, as we discovered in the first workshop, were no different. By providing an opportunity for the participants to experience different styles and media: sculpture, photographic, abstract, modern, Indigenous, collage, print, paint and water colour it was hoped that the women would overcome any preconceived ideas about what ‘real art’ was. To reinforce the idea of art as an expression, we limited ourselves to the 20th and 21st Century Australian and International Galleries and the Yiribana Aboriginal and Torres Strait Islander Gallery. We purposely avoided the 15th to 19th Century, where the works of art tend to be a true representation of life.

One of the central components of the research method was to provoke personal and group discussion through various art expression exercises. In order for the process to work, it was critical to have the participants begin to critique the artwork they were viewing. As we walked through the Gallery, we stopped at different pieces selected by the participants. From the title and any notation we discussed why we did or did not like that particular work, what story the artist was trying to tell, how he/she did this, if the artist was successful and if the work...
triggered the same or a different emotion or story in us. This simple process made us conscious of how art can trigger a memory, a train of thought or an association of ideas.

In planning this workshop, in addition to a general critique of artwork at the gallery, Moi and I selected seven works of art that we would discuss to communicate different techniques and styles that the women may consider using in their own work that incorporated dots, words and assemblages. These selected works of art are illustrated and discussed over the next five pages.

**Morning Underground.**

![Morning Underground](image)

**Figure 26 - Morning Underground, 1922, Weaver Hawkins. Oil on Canvas**

This painting is of people travelling to work on a train. The people are doing a variety of every day things, such as reading the paper. The idea was to examine the relationship between an artwork and our own personal experience, such as how we travel to work. It also encouraged the women to notice the everydayness of their lives — the things they do automatically without thinking. The idea of taking moments in time was incorporated in workshop four, which looked at the women’s daily routines.
Conflict.

The idea behind selecting this particular abstract canvas was to introduce the women to how meaning and emotion can be conveyed through the use of shape and colour, and that sometimes we have to search for meaning in art, and working out what the artist is saying can be challenging. The discussion around this canvas looked at whether the artist had succeeded in conveying to us his interpretation of conflict, if so, how was it achieved, and if it did not convey that message, what feeling did it convey.

Beast.

This large 1967 work of Calligraphy by Teshigawara Sôfû (no photograph available) was selected to demonstrate how art can convey different meanings and interpretations to different people. Here the artist uses what can only be described as a series of black ink splats to depict the abstract image of a beast. In this large-scale work the shape, size, form and number of beast/s is left up to the viewer to discover. This work demonstrates how the viewer is drawn into the artwork to interpret and experience the work for themselves, while at the same time leaving the artist open to misinterpretation when the reading of the story is left up to the viewer. We also wanted to show the women how to create large-scale works by fusing together a number of small canvases to create one large work, and that their artwork was not limited to the size of piece of paper they were working on.
The Artist and his model.

Figure 28 - The Artist and his model, 1938, Grace Crowley. Oil on Hardboard.

I wanted to look at some of the work by a female artist to explore how other women express themselves through art. This is an abstract painting and I felt that it was useful in demonstrating how the artist uses a series of overlapping rectangles, circles and patterns, rather than a picture-perfect representation. Although the painting is abstract, the viewer can clearly see that the canvas is of an artist painting a female model.

Glad Family Picnic.

Figure 29 - Glad Family Picnic, 1961-1962, Colin Lanceley. Oil, mixed media on plywood
Both Moi and I were interested in producing a piece of work that had been built up each fortnight and culminated at the final workshop in a collage. This work would represent the multi-dimensional personalities and lives of the participants. The collage used broken plates, eating utensils and other everyday manmade and natural items to depict people and food laid out on a picnic blanket. This collage was worked on over a period of time and as we stood in front of the ‘Glad Family Picnic’ we used the work to demonstrate what we were going to do and how a work of art does not have to be completed in one sitting.

Fruit bats.

*Figure 30 - Fruit bats, 1991, Lin Onus. Installation Polychromed fibreglass sculptures, polychromed wooden disks, Hills Hoist clothesline.*

*Fruit bats* on a clothes line is one of my favourite pieces at the Gallery. In the summer months in Sydney the calls of fruit bats can often be heard as they fly through the night sky in search of food. Lin Onus uses one of Australia’s icons, the Hills Hoist or clothesline in an installation that is filled with irony, whimsy and humour. Beneath the clothesline are little wood disks that represent the fruit bats droppings. Drawing on his Indigenous and Scottish heritage, Lin Onus brings together the sacred and the mundane. What we were interested in here was the use of multiple meanings that reflect ourselves and our culture. Art does not have to be serious; it can be silly and frivolous and still provoke a
response. It is often in the everyday mundane rituals of our lives, like hanging out the washing, that as women we share a common bond.

Three studies from the Temeraire.

![Figure 31 - Three Studies from the Temeraire, 1998-1999, Cy Twombly. Oil on Canvas](image)

*Three studies from the Temeraire* is a series of three canvases that were inspired by Turner’s famed painting *The Fighting Temeraire* painted in 1839, depicted the boat, the *Temeraire* being tugged to her last berth in 1838. Cy Twombly’s canvases were stylised and symbolic in its use of simple brush strokes to portray a boat. Although it is not a perfect representation of a boat, the viewer nevertheless understands that the picture is of a boat. The simplicity of this series of canvases illustrates how we use and read stylised symbols to convey meaning to someone else.

For a number of different reasons it took some time for the participants to feel comfortable enough to begin giving their opinion. For Kay, Shirley and Lara, viewing, interpreting and talking about art was a completely new experience. It became important to gently reassure them that both Moi and I valued and were interested in their opinion and that there was no right or wrong answers as each work of art triggers a response that is unique to them. Having the pre-selected art works helped to stimulate conversation as did asking each woman individually what they thought or felt about a particular work that they had stopped to look at.
At different times throughout the workshop some of the women disclosed that they were not often asked their opinion and in particular how they felt. They found that being asked to do so was sometimes quite confronting and difficult, particularly when they were concerned about ‘getting it wrong’. Another challenge for the participants was trusting the space that they were in.

*I thought this was like a library. Shirley*

*It’s really strange talking in a place like this. I keep thinking that someone will ask us to be quiet. Lara*

The painting that stimulated the most conversation and was **Rhythmic Composition in yellow, green minor**. In planning the visit, both Moi and I had completely overlooked this picture yet it was this artwork and the discussion around it where the women ‘clicked’ into what we were trying to achieve. The women were able to experience the story that the artist had tried to convey and importantly, they had selected the picture.

![Figure 32 - Rhythmic Composition in yellow, green minor, 1919, Roy de Maistre. Oil on paperboard.](image)

*Lara: I can see it! I can see the rhythm. Look it’s in the way the colour moved around the purple centre. See the swirl? Can you see it? Shirley: Yes I can see it.*

*Moi: If the swirl represents rhythm what might the different colours be? Kay: They could be the keys on a piano. The shapes. Moi: Yes so we have rhythm and…*
Shirley: Sound. You play music on a piano.
Moi: How is the sound represented?
Janette: In the movement. It reminds me of a whirlpool.
Shirley: That’s not a piano sound.
Lara: The notes on a piano. Like a scale?
Moi: What is it about the picture that makes you think of a scale?
Lara: The colours. They go from dark to light. See they’re dark down here and lighter up the top.
Shirley: You know like how men sing low and women sing high.
Kay: Tenors and sopranos.

When a boat is not a boat

The discussions that arose from the above painting helped to promote discussion at the Gallery. Lara in particular started to critique and express her personal interpretation of many of the major works in the gallery. Her enthusiasm inspired Shirley and Kay to join in and enable all of us to build rapport. As we spoke, we began to feel comfortable, enjoy the company and take interest in each others’ opinions. By the time we came to Cy Twombly’s painting ‘Three studies from the Temeraire’ (see page 136), which we used to discuss the idea of how symbols can be used to draw out meaning, Moi could not convince Lara that the pictures were of a boat.

Moi: See how the artist has used a symbol to represent a boat. Yet in only a few brush strokes we can see clearly that the picture is of a boat.
Lara: That’s not a boat.
Moi: Here are the oars and the mast.
Lara: I don’t think it’s a boat.
Moi: The artist tells us it is a boat because the series of paintings are inspired by a famous painting by an artist called Turner. The original painting is of a boat called the Temeraire and there is a photograph of Turner’s original painting.
Lara: That picture may be a boat but this isn’t.
Moi: Well it is very stylised……
Lara: Even I could do better than that. It’s not very good because it doesn’t look like a boat at all.

Janette: Can we just say for the purpose of the exercise that this represents a boat?
Lara: Ok… but it’s not a boat.

Managing the group dynamics proved challenging at times and a discussion of this follows at the end of this section.
Workshop three: Friends and family

For the first time all of the five participants came together. In this workshop, art and movement were used as a way to express friendships, family and community. The techniques introduced were photography, shadow drawing and charcoal rubbings.

A Maori gathering was being held in the next room and we were invited to attend the Welcoming Ceremony and to learn weaving later on that morning. This workshop became very disjointed with some of the women learning weaving next door and others inside working on different art expression works and the cohesion became lost. In my need to give the women choice and not exert my power in terms of the aims of the research process this was successful, however it made collecting comprehensive data impossible. It was not until after lunch that we were able to gather ourselves, begin to work around the communal space and began to share.

The afternoon’s most popular activity chosen by the women was rubbings, and instead of using charcoal they decided on coloured crayons. This process involved arranging different items on the table such as leaves, bark, cut-out figures or letters, placing a white piece of artist paper on top and then rubbing different coloured crayons over the paper to produce different relief effects. Once the first colour was rubbed over the paper, other colour crayons were applied as shown in Figure 33 -above. Some of the items underneath, such as the body shapes, were moved slightly to introduce movement into the work.
Rubbing the crayon over the ridges of the items underneath deepened the colour of the outline and introduced texture.

An optional final step was to finish the work by spraying different coloured dye to produce a splattered paint effect as in Figure 34. The reaction of the dye with some of the crayons turned the colour iridescent and translucent see figure 36. The women became very involved in this activity, producing a number of different works as interesting effects were quickly achieved and they could easily start again if they were unhappy with the results. During this time we talked about workplace friendships.

![Image of spray bottle and paper](image)

**Figure 34 - Spraying water based dye for an iridescent effect.**

To build multi-textural works and provide new interpretations of expression, three different activities were incorporated into the workshop design and worked on each fortnight. These works also provided some continuity and links between the workshops.

One of these activities, which incorporated movement, was a style of stain-glass windowing. This involved placing a small amount of watery dye and/or paint on the paper and then either blowing through a straw as demonstrated in figure 35 or moving the paper to roll the liquid to create a pattern. When the women where happy with the results they were left to dry, ready to be built up through hand painting or collage in the later workshops.
Other activities that were available involved shadow casting. Using an overhead projector to project light onto paper stuck on a wall, an individual or group of women are arranged to stand in the light to cast their shadow. Once the arranger is happy with the cast shadow they draw around the outline with a thick felt pen. Alternatively the shadows are cast on the ground then photographed, downloaded, printed and enlarged using a photocopier. While the women enjoyed casting the shadows and photographing them they chose not to continue with the second step of the activity that day.

![Shadow Casting](image)

**Figure 35 - Blowing Ink through a straw.**

The main topic of conversation in workshop three revolved around the importance of friendship and family, the people we worked with and the different friends that we had made through work:

_L will ring me up and say hello... but she doesn’t talk much...you know, she does talk to me. I understand what she is saying — how’s your dog and this and that and this and that...Yes she is my best friend.... We go to respite together with my dear friend A and my friend K. Sometime we go outside and have picnics or going to the café, shops or somewhere...we have a good time together._

*Shirley*

_On the weekends I often meet with my friends. We get together and cook and laugh and talk about lots of things. Last week we made wontons together. It was really good fun._

*Kay*
Workshop four: A typical working day

The theme of discussion in this workshop centred on our working lives. Free form clay sculpture and paint were added to the range of art media. The plan of this workshop was to work in the third dimension. We had a number of sculpture activities using clay. The first was to free- or hand-form a sculpture that related to our work. Alternatively, items that we used at work or things that we did could be modelled in clay, for example, a telephone, computer, screw driver, packing boxes, hands, kettle or pencils. These could then be formed into a larger sculpture to represent our working lives.

In this workshop, Moi and I had wanted to introduce colour through still life painting. We had planned that some of the small sculptures could be arranged in a group and then painted as a still life. In another activity we were going to reflect about our work. Then using A1 paper and a range of house paint brushes from 2cm to 10cm in large broad strokes, use colour to express the emotion we were feeling. Only two participants, Cindy and Evie, attended this workshop. Lara, Shirley and Kay were unable to attend due to family commitments: Laras son’s family had planned a birthday celebrate for her some months prior to Lara’s commitment to the research and Kay had a family function she had to attend. Shirley was away in the country staying with her
brother and it was this trip that influenced her painting *Starry Night* see Figure 16 on page 99.

At this workshop Cindy and Evie elected not to do what we had planned. Instead they chose to do two of the self-portrait activities from the first workshop that they had missed. This allowed me to get to know the two women and we discussed much the same things as we had done in the first workshop, such as our families and our likes and dislikes.

Both of the women decided that they would like to do the second activity of the first workshop where their outline was drawn around and they in filled the details. The two women worked at very different paces, with Evie being extremely meticulous, and thinking about each colour and stroke before committing to paper. While Evie would have been happy to work on one activity each day Cindy worked at a much faster pace, quickly finishing each exercise, eager and ready to move onto the next. Although we only had two participants, they were at the extreme ends of the spectrum. Moi concentrated on working with Cindy, adapting each exercise so Cindy had a number of different options and variations to keep her focused and interested, allowing Evie to work at her own pace.

Having Moi on hand proved invaluable as the women decided that they did not really want to do what we had planned. Moi was able to change the workshop format and still keep within the broad themes. Cindy and Evie decided to complete a story board with the theme of ‘a day in the life’. For many people with an intellectual disability, time is a difficult concept to grasp. A story board is therefore useful in that each board breaks the day down into a small section. For example, the first story explored what we did prior to leaving for work. The second how we travelled to work; the third what we did when we first arrived at work; the fourth what we did up until morning tea etc, until we had completed the day. Linking each story board to an activity helped to anchor time. This unplanned activity was invaluable and brought up a number of issues such as workplace bullying, the large periods of down time the women in business
services experienced, how work was their main access to meeting and seeing friends, and the levels of job dissatisfaction they felt.

Figure 37 is a page from Cindy’s story board. Although there are only five pictures, these images represent a number of valuable insights into Cindy’s life. For example, Cindy has few opportunities for social interaction in her life, so work is one way in which she is able to keep contact with her friends:

I don’t work just for the money. It’s the only way I get to see my friends. Cindy

The lack of disposable income makes purchasing morning tea a rare treat:

I love chocolate éclairs. You know the ones with chocolate icing and lots of cream inside. I love ‘em. I save up and then I buy one for morning tea from the tuck truck. Oh they’re so good. I’d have one every day if I could. Cindy

As a technique the art expression workshops provided a way of talking about the “everyday happenings that didn’t seem to count” and were valuable in gaining small intimate glimpses into the lives of the women (Jocelynne Scutt, 1992 pp. 2). The story boards were put up on a white board and each woman went through each board and told us the story of her typical day (figure 38).

As indicated in the first workshop by Kay, Shirley and Lara, work was a small part of their lives. After spending some hours discussing Cindy and Evie’s work
day in detail, they were not inclined to chat about the matter further, however, they did want to make something with the clay. This shows how data, and lives, cannot be defined by any simple element and that they often overlap.

Although we had talked about our friends and the importance of friendship in the previous workshop, the significance of work had not been explored. The two main reasons these two women went to work were for money and then as a way to see their friends. It is generally recognised that people often make friends at work, and these women were no different. What was important was that they had little opportunity to see or speak with their friends outside of work. Moi improvised and came up with the idea of making a wall plaque of three of the women’s work friends that they could make and then take home.

Figure 38 - Evie telling the story of her typical day at work.

Figure 39 is of Moi showing us how to construct noses with paddle pop sticks and lips with a skewer. To make the curly hair on the face we forced clay through a sink strainer to the required length. While we worked, the women talked about the friends that were of particular importance to them at work.
Figure 39 - Moi demonstrating the techniques of how to make clay faces.
The plaque below shows the three people that sit around Evie at work. The first face on the left is of her closest girlfriend who has beautiful curly hair. As with most friends, they like to get together and talk at lunch time. The middle figure is of her boyfriend who likes to keep his hair short and spikey.

Figure 40 - Work Mates, 2005, Evie, Clay

He’s always joking and great company to be with. It helps make the day go quicker. Evie

At work he sits opposite her and K, the third figure on the plaque, sits on Evie’s the other side. K has thick eye brows, wears thick glasses that make her eyes look very large and always wears a beanie to work as she doesn’t like her hair. Evie captured the essences of her friends and what emerged was that while Evie considered them to be her closest companions and confidants she seldom had the opportunity to socialise with them outside of work. Evie talked about how they had recently had their Christmas work party at the local sports club and this was one of the rare occasions she got to dance with her boyfriend.
Although they had been going out for some time, it was only at work or work functions that they were able to see one another.

Changing the art expression exercises to something that interested and stimulated the women enabled me to gain deeper insights and an appreciation of the women themselves and their lives. The discussion in this workshop highlighted the level of control these two women experienced and more importantly, how they accept the high level of control and surveillance as a normal part of their day-to-day lives. Overt challenges often resulted in threats that they will lose their place in supported accommodation, or punishment such as the withholding of privileges and/or behaviour intervention such as anger management classes.

Workshop five: Reflections

The final workshop used collage to highlight the multi-layers and complexity of the participants. The art expression exercises that we had built up over a number of weeks were to be completed and some of the previous artworks would be used to construct new interpretations of expression. Also on hand were photographs, photocopies of the body shadows we had cast in the third workshop, magazines, paint, colour and tissue paper plus all the art expression works and art materials from the previous workshop. During this workshop we mounted the art expression works the participants wanted to keep.

Of all the workshops Moi and I were the most excited about creating a collage. We were interested in multi-textural layers and the exploration of the self through ripping up or cutting previous works and then rearranging the pieces to provide new interpretations and stories. All the five women were, however,
absolutely mortified at the suggestion of cutting or ripping their art work. They flatly refused to ‘destroy’ their work and there was no negotiation or discussion. This was really not the response we had expected. We ended up having a free-form workshop where the women chose what they would like to do as they reflected over the workshop process.

Some of the women did make a collage, however, it was constructed with new materials. For example, friendship was an important part of Evie’s life and a common theme in her art work (see figure 41). Others chose to paint, and some remade the crayon rubbings that we had done in the third workshop.

Providing the women with choice and the option to exercise their right to say ‘no’ worked within this small group. In workshops three and five when all the five women were present it was difficult for me to be an active participant as I spent most of my time facilitating and helping Moi run the different art exercises.
The reaction of the women to the original collage activity demonstrates that they did exercise their rights, however, it also highlights the different expectations held by the participants and myself in relation to the purpose of the workshops. The women viewed the work they had done as ‘works of art’ and were very proud of them. I, on the other hand, was focused on the discussion and the artwork as a means to an end.

**Limitations and problem-solving**

When I started to talk about this research just after the field work in 2006, and I re-told some of the women’s stories, and showed pictures of their artwork, some comments have been about the simplicity of the art work and that they have a ‘childlike quality’. This raised serious concerns and highlighted the need for me to clearly articulate the purpose of the workshops. My failure to do this may reinforce the stereotype that people with an intellectual disability are childlike, simple and not good research participants, rather than the complex women who took part in the research, who knew who they were and had clear and definite opinions about their lives and communities.

Whether research participants have an intellectual disability or not, sometimes it is challenging for people to say what matters to them and why. Using the art workshops and traditional interviews provided different spaces for the participants about speaking their own truths.

**Group dynamics and collaboration**

One of the most challenging parts of the workshop design was facilitating the group dynamics and collaborative processes. Even though there were only five participants there was a wide range of skills and cognitive abilities. Coupled with each woman’s individual personality and idiosyncrasies, this made running the workshops challenging at times. While the women seemed able to express their needs, thoughts and ideas, Moi and I learnt that we needed speak to them in clear, direct, specific terms, making sure that we gave them all the information and nothing was implied. We found that the women took what was said literally and usually did not pick up the subtle nuances or social cues of conversation.
For example, at one of the workshops, Lara talked about her move to the country. Kay began to tease her in a friendly way by saying things such as “she doesn’t love me any more, that is why she is going” and “if you go Lara I know you don’t like me any more”. Although Lara and Kay were familiar with one another through working in self-advocacy Lara, unable to pick up the clues that Kay was teasing her from Kay’s facial expressions, the tone and inflection of her speech, became distressed at what Kay was saying. Lara tried to explain that moving to the country was a ‘life change’ decision and that she did not mean to hurt Kay by her actions. Kay in turn could not see the effect her teasing had on Lara and the other women present who responded by becoming silent and withdrawn. Asking Kay to stop only served to intensify her focus. What did work however was to divert Kay’s attention away from the situation onto something else.

Finding different ways to shift the women’s attention back to the workshop process or discussion proved difficult at times. At the end of the first workshop, when we were reflecting over the day, Shirley suggested that it would be nice to have music playing in the background. We all agreed that this was a good idea and Shirley volunteered to bring the music. As you will remember from Shirley’s story, one of her passions in life was music, so once the music began to play it became the focus of Shirley’s attention rather than the art expression exercises and the conversation around the table. Our chatting made it difficult for Shirley to hear the music so she quietly picked up her chair and moved next to the CD player with her back to the group. When we asked her if she would like to re-join the group she would just politely say, “no I’m fine here thanks but you keep talking”. It was only when lunch was served that we were able to coax her away from the music. Towards the end of lunch, I asked if it would be OK if we could turn off the music for a while and Moi talked to Shirley about what sort of art exercise she would be interested in doing to bring her attention back to the group.

Collaborating with the women meant that things did not necessarily go the way I planned, and often took much longer than anticipated. Including the women in
decision-making processes usually involved lengthy discussions, as the women took time to consider each others’ needs and talk about what would be the best options. The discussion around what they would like to eat for lunch at the workshops is a good example of this, as it took over half an hour to come to a decision. To begin with there was a long discussion on whether or not to have hot food. This raised concerns that the food may be cold by the time it was delivered and that there were no facilities to reheat the food if this happened. Some time later, a decision was made that a selection of sandwiches and a fruit platter would be the best option. The discussion then moved onto ensuring that everyone’s tastes were catered for: Kay and Moi were vegetarians: Cindy, Shirley, Lara and I liked cheese and tomato: and Evie preferred ham, cheese and tomato. As the food had to be ordered the day before, it was agreed that other sandwiches apart from these should be included; as Shirley suggested it was “nice to have a variety”.

Overall, the workshops had few real problems and we spent most of the time just talking, enjoying each others’ company, eating, drinking and expressing ourselves through art. This embodied process of telling stories and producing art created a relationship where we were able to make connections in our everyday lives, agree, disagree, and discuss what was important to us.

**Undertaking the research: Interviews**

The second form of data collection within this study was face-to-face interviews. Semi-structured interviews are one of the most popular strategies used by feminist researchers (Yvonne Darlington and Dorothy Scott, 2002). The specific aim of interviewing is to gain a greater understanding of the personal experiences and interpretations of an individual’s reality (Victor Minichiello, Rosalie Aroni, Eric Timewell and Loris Alexander, 1995). Semi-structured interviews have also been documented as being an appropriate way to collect data from “women with an intellectual disability, as they allow both sufficient flexibility and structure” (Michelle McCarthy, 2002 pp. 282).

In this research, semi-structured interviews provided another opportunity for me to listen to the life stories of the women in their own words and from their own
perspective, and to gain a more indepth knowledge about their lives that was sometimes missed within a group discussion. Semi-structured interviews also provided the opportunity for the women to introduce topics of discussion that they felt were important, which they may not wish to share in the more public space of the workshops. Providing a place for the women to speak collectively in the art workshops and individually in the interviews recognised them as experts in their own lives and active participants in the creation of knowledge (Yvonne Darlington and Dorothy Scott, 2002).

I chose semi-structured interviews in an attempt to reduce the hierarchical, inequitable interaction that often places the participant in a subordinate passive position in the researcher-researched relationship, in line with feminist theory (Pamela Cotterill and Gayle Letherby, 1993, Juliet Corbin and Janice Morse, 2003) and this was of particular concern to me in researching in the area of intellectual disability. Following Ann Oakley’s (1981) proposition that interviews should be mutual and reciprocal exchanges of information between the researcher and the participant, I answered questions and shared the stories of my life with the women in the interviews.

Table 4 - Schedule of Interviews

<table>
<thead>
<tr>
<th>Interview</th>
<th>Cycle</th>
<th>Week 2</th>
<th>Week 4</th>
<th>Week 6</th>
<th>Week 8</th>
<th>Week 10</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>3rd wk</td>
<td>1st wk</td>
<td>3rd wk</td>
<td>1st wk</td>
<td>3rd wk</td>
</tr>
<tr>
<td>Shirley</td>
<td>Oct 05</td>
<td>k</td>
<td>k</td>
<td>k</td>
<td>k</td>
<td>k</td>
</tr>
<tr>
<td>Lara</td>
<td>Nov 05</td>
<td>k</td>
<td>k</td>
<td>k</td>
<td>k</td>
<td>k</td>
</tr>
<tr>
<td>Kay</td>
<td>Nov 05</td>
<td>k</td>
<td>k</td>
<td>k</td>
<td>k</td>
<td>k</td>
</tr>
<tr>
<td>Cindy</td>
<td>Dec 05</td>
<td>k</td>
<td>k</td>
<td>k</td>
<td>k</td>
<td>k</td>
</tr>
<tr>
<td>Evie</td>
<td>Dec 05</td>
<td>k</td>
<td>k</td>
<td>k</td>
<td>k</td>
<td>k</td>
</tr>
</tbody>
</table>

The process of the semi-structured interviews was guided by the broad negotiated themes and discussions in the workshops and a limited number of pre-determined questions. Within the themes of workshops and the interviews the women were encouraged to follow their own thought processes and explore ideas and life stories in their own way and in their own time (Andrea Fontana...
and James Frey, 1998). This principle followed through to my approach in the individual interviews.

The difficulties of interviewing people with intellectual disabilities

The interviews, as with the workshops, had their own set of unique difficulties. Prior to an interview, I would telephone the participant and confirm the time that I would either meet or pick them up. At this time I would also tell them the themes that we would be talking about so that they were able to begin thinking about what they may like to discuss (Jennifer Mactavish, et al., 2000). Unlike the workshops, where the women were stimulated and the conversation flowed, the interviews at times were hard work. Drawing on previous research with people with an intellectual disability (Tim Booth and Wendy Booth, 1996), I found that asking a number of direct questions that could be answered with a yes/no answer to start a conversation, at times worked best. Following the advice from the Intellectual Disability Rights Service (IDRS) in relation to providing information and consent sheets and asking short single questions using simple language, also proved to be useful.

Often, rephrasing or asking questions in more than one way helped to simplify or refine questions when the women became unsure of what they were being asked, or appeared to be telling me what they thought I wanted to hear (Jackie Rodgers, 1999). At times, paraphrasing the women’s stories back to them helped me to clarify that I had correctly heard and understood what the women were telling me.

These strategies, however, were not effective in all the interviews. Some of the problems appeared to be related to restricted language skills; however, it can be argued that being inarticulate goes beyond this and is compounded through a "lack of self-esteem, learnt habits of compliance, social isolation or loneliness, and the experience of oppression" (Tim Booth and Wendy Booth, 1996 pp. 56). These factors are certainly the case in Evie’s and Cindy’s lives and, to a somewhat lesser extent, Shirley’s. These three women tended to speak only when they were asked and then in few words. Consequently, drawing information from them in the interviews was a slow process. Open-ended or abstract questions,
that are usual in narrative styles of research (Victor Minichiello, et al., 1995, Jane Elliott, 2005), proved to be ineffective as the following excerpt from an interview transcript demonstrates:

Janette: Would you tell me what is good about work?
Evie: Nothing
Janette: There’s not one thing you can think of that you like about work?
Evie: (long period of silence) No
Janette: What happens at work on your birthday?
Evie: Nothing
Janette: You don’t get sung happy birthday?
Evie: Yes
Janette: What about a birthday cake?
Evie: Yes
Janette: Do you have to buy the cake or does work?
Evie: Work
Janette: So on your birthday work supplies a cake and everyone sings happy birthday
Evie: Yes
Janette: Could you say that this might be a good thing?
Evie: Yes but there is nothing else good.

There may have been a number of reasons why Evie chose not to answer the questions in more than one word, such as she did not understand the question. In the final art workshop as the women were reflecting over the process, however, a more pertinent reason was mentioned and most of the women agreed that:

_It’s hard to think about things that are good. I don’t get asked that; it’s always about what problems I’m having. You know, ‘what’s wrong?’_ Cindy

While acquiescence is well documented within the disability literature (see Tim Booth and Wendy Booth, 1994b, John Swain, et al., 1998, Jonathan Perry and David Felce, 2004), I discovered within this research that acquiescence did not always equal compliance. This was highlighted in the interviews. In particular, when the topic of conversation shifted into areas that some of the women were not interested in or did not want to talk about, they would become quiet or reply only in yes/no answers. These resistance strategies are rarely discussed within the literature (see Mark Rapley, 2004).
At these times, the established method of interviewing fell short of enabling multiple voices in society to be heard. In interviewing there is a Western cultural assumption that “people are prepared to speak and that it is regarded as legitimate for them to speak, usually to relative strangers, about most topics” including those of a sensitive and private nature (Mary Maynard, 2002 pp. 36). The interview privileges a particular type of spoken word and with it, those who are able to speak in a particular way. In combining interviews with a creative arts approach, I sought to work against this privileging by opening up the discursive space for women not often asked to speak.

Through my inexperience as an interviewer and the drive to be collaborative, I allowed the women to choose where and when to meet for the interviews. As a result of this decision, the interviews were held in a variety of places, varied in length from one to four hours, and often included morning tea, lunch and shopping, depending on the amount of time each woman had to spare. A breakdown of the approximate length and location of each interview is outlined in the following table.

<table>
<thead>
<tr>
<th>Person</th>
<th>Interview</th>
<th>Place</th>
<th>Approximate Length</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cindy</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shirley</td>
<td>1</td>
<td>In her home</td>
<td>2 hours</td>
</tr>
<tr>
<td>Kay</td>
<td>1</td>
<td>TAFE Library</td>
<td>1 hour</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>At work in the lunch</td>
<td>1 hour</td>
</tr>
<tr>
<td></td>
<td></td>
<td>room</td>
<td></td>
</tr>
<tr>
<td>Lara</td>
<td>1</td>
<td>Café in large shopping</td>
<td>4 hours</td>
</tr>
<tr>
<td></td>
<td></td>
<td>mall</td>
<td>4 hours</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Café in large</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>shopping mall</td>
<td></td>
</tr>
<tr>
<td>Evie</td>
<td>1</td>
<td>Local coffee shop 1</td>
<td>2 hours</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Local coffee shop 2</td>
<td>3 hours</td>
</tr>
</tbody>
</table>

All the interviews were audio recorded with the consent of the participants, except for Kay, as she declined to have her first interview taped. Having interviews in coffee shops in large shopping malls and different local cafés proved problematic. Apart from a lack of privacy, at times the background noise on the audio-tapes made parts of the interviews inaudible, which made the
interviews difficult to transcribe. Other difficulties with audio taping the interviews was that although the women had agreed to have the interview taped, often when the tape was first turned on some of the women would stop talking. If the tape disturbed the flow of conversation, it was turned off. At other times throughout the interview process, the women would either request that the tape recorder be turned off or the conversation erased. Naturally I respected the women’s right to vet the interviews and those conversations were omitted from the data and not written about in the field notes.

Sometimes in the interviews, often after the tape was turned off, the women told me intimate moments of their lives that they had not shared with the group. I believe that from the workshops a deeper level of trust, respect and empathy grew and this allowed the women to disclose very personal feelings and stories that may have otherwise been withheld.

**Supplementary data generation**

Within this research supplementary forms of data were generated in different ways. The interview transcripts and tapes combined with MY research diaries, photography, artwork and government policy documents enabled me to explore the lives of the participants and the structural features of their social world. Using a variety of data sources I was able to listen beyond the words to find common elements in their stories to reveal how these women’s lives are “shaped by the wider society and throw light on the network of social relations to which they belong” (Tim Booth and Wendy Booth, 1994b pp. 415).

**Research diaries**

Laurel Richardson (1994b pp. 524) argues that “writing as a creative form is a method of knowing”. Research diaries or field notes have been used extensively throughout this study and have become additional sources of data. As none of the workshops were recorded, field notes were used to document what we did, the discussion, and what happened. After each contact with a participant, field notes were used to capture observations, points for clarification, insights into the participant and anything I thought might have had an impact on the data. For example, I would note things of particular importance to a participant, such as their favourite colour.
My research diaries record my own thoughts, feelings and reflections, and are a historical record of the research journey. They have been the foundation of the experimental writing that forms this thesis and they include notes on methodology, theory, influential texts, and data analysis.

**Pictorial data**

Photographs are a way of documenting a hidden reality and make a moment eternal (Susan Sontag, 1971). Within this research, there are two forms of pictorial data. Firstly there are the photographs taken in the art workshops to document the fieldwork process. The original artworks form the second source of data.

**Workshop photographs**

The purpose of photographing the workshops was to have a pictorial representation of the process. Photographs can be used as social documents to furnish evidence, provide authority and transcend language (Susan Sontag, 1971). As such, the photographs used in this thesis provide validity and are used to highlight importance within the written text.

Apart from confirming the authenticity of the fieldwork, the photography used in this text makes "everyone a tourist in other people’s reality and eventually in one’s own" (Susan Sontag, 1971 pp. 57). The photographs used in this text are one way of moving the women’s experiences from the margins to the centre, by creating a space for the stories of Kay, Shirley, Lara, Cindy and Evie to be heard and seen.

Permission to pictorially document the workshops was gained during the consent process and at the beginning of each workshop. Photographs were taken throughout each workshop and at the end of the day the photographs were downloaded to my laptop computer. The women then had the opportunity to edit and delete any picture that they did not want to be included in the study. All the photographs were made available to the women at every workshop so they could review the process and make further deletions. Like most people I know, the photographs that the women chose to delete were mainly of
themselves, in particular the ones where they did not feel that they looked their best.

The photographs also served to refresh our memories of previous workshops and what we did. As part of a thank you the women were given the opportunity to select photographs to put in a small album as a memento. The photographs that can identify any of the women have not been used in any publication other than this thesis, to protect their identity and maintain confidentiality.

**The art expression works**
The art expression works in this research are secondary sources of data. Although they are integral to the gathering of data, none of the artwork has been analysed by anyone other than the artist. As previously discussed, the art expression works were a conduit in the narrative process and are best viewed in conjunction with the women’s stories.

All the original artworks were mounted and given back to the participants. Any work they did not want to take home, I have kept. With permission, the artworks have been photographed for my records to be used in this thesis and other publications.

**Government policy and guidelines**
Not having any experience in the disability sector when I began this research meant that I had to familiarise myself and gain an understanding of the different disability funding models and responsibilities of both the Commonwealth and State Governments. These additional sources of secondary data included Australian Commonwealth and NSW Acts of Parliament; *Disability Services Act (1986)*, *Social Security Act (1991)*, *Disability Discrimination Act (1992)*, and the review of the same Act by the Productivity Commission (2004), the *Privacy, Personal Information Protection Act (1998)*, and the *Disability Services Act (1993)* NSW, *Health Records and Information Privacy Act (2002)*. A review of the Australian disability statistical and census data was also undertaken (ABS, 2003, 2004, 2006, Department of Family and Community Services, 2003,
Department of Families, Housing, Community Services and Indigenous Affairs, 2007).


A review of the government documents and reports in relation to disability and public housing was undertaken (Australian Institute of Health and Welfare, 2006b, Housing NSW, 2008a, 2008b, NSW Department of Housing, 2006, 2007). Policy, procedures and reports that were associated with the women who lived in supported accommodation in New South Wales were also appraised (Centre for Developmental Disability Studies, 2004, DADHC, 2005b,

Interpreting the data
Feminist epistemological and methodological frameworks and the stated aims of the research guided the analysis and interpretation of my research data. I began my interpretation of the data by exploring the threads of the women’s stories, the things that connected them and how they differed, in an attempt to understand the lives of these five women. I immersed myself in the data by reading, re-reading, listening, reflexive critique and interpretation. I spent time playing around with the data noting the ideas, going over the transcripts, field notes and audio tapes, and creating names for chunks of data that were coded and categorised into flexible themes, allowing the data to speak for themselves. Different shaped, sized and coloured post-it notes were used to code the themes, ideas and patterns that emerged from the data (Judith Davidson, 2004). In this way, interpreting the data became an embodied and highly visual process as I wrote and moved post-it notes, and drew and erased connecting themes or ideas in different coloured textas on the mirrored wardrobe in the spare bedroom at home.

During the interpreting phase of the research I found that gaps in the data began to appear. At times during the art expression workshops and the interviews, through my inexperience as a researcher, I thought I understood what the participants were telling me and missed opportunities that would have provided rich data had I delved deeper into the women’s stories. At times I had
to go back and ask the participants for further information but often it was not until after the field work was completed and the writing had begun that I realised that further questioning would have given me a deeper level of understanding. For example, in looking at the pro-rata wage system for people with a disability in the Chapter 6 (see page 200), it would have been useful to ask if any of the women had been assessed, how they felt about this and their experiences of the process.

At other times, being an outsider and not holding specialised knowledge about the disability sector or people with an intellectual disability prompted me to ask questions when I was not sure I had understood or I needed further clarification. This provided more density and depth to the data. Having a combination of sensitivity, knowledge and life experience helped me as a researcher to move between subjectivity and objectivity and find a balance between interpreting the data (being subjective) and allowing the data to speak for themselves (being objective) (Charles Higgs and Lindy McAllister, 2001).

**Dominant narratives**

In allowing the data to speak for themselves a number of inconsistencies began to emerge between the women’s stories, my observations and the dominant disability discourse of ‘autonomy’. In planning the fieldwork, I had read about emancipatory disability research with its theoretical human rights and advocacy underpinnings. The dominant discourse in government, disability employment, advocacy agencies, Business Service employers and accommodation support service websites was of ‘autonomy’, and used such words as empowering people, self-advocacy, valued, independent, recognised and participation. Yet many of the daily practices that I had observed, and that the women spoke of, worked against their ‘autonomy’.

Looking at state and federal government policy I found that although it spoke of ‘autonomy’, many of the policies were about ‘risk management’. The discourse of ‘risk management’ morphed into ‘duty of care’ within the business services sector and group accommodation services.
One of the most influential texts in the data analysis phase of this research was Sylvia Bercovici’s (1983) ‘Barriers to Normalization: The restrictive Management of Retarded Persons’. Sylvia Bercovici discusses the exploitation and oppression experienced by people with an intellectual disability living in community and institutional care in California in the 1970s. This study draws on the principles of normalisation (see Bengt Nirje, 1970, Wolf Wolfensberger, 1972) that recognises the dignity all people with a disability and their right to live in mainstream society and to receive care and treatment that maximises their potential for growth.

Sylvia Bercovici’s (1983) research highlights the ways in which caregivers, service providers and the welfare system systematically employ practices that establish and maintain dependency, passivity, incompetence and fear. The study uncovered that moving from large institutional care to small homelike settings in the community did not necessarily improve an individual’s right to autonomy. I started tracking the ‘autonomy’ narratives that were emerging in my own data source and in particular within government policy and regulation. What soon became apparent was that the findings of my study mirrored many of the benevolent exclusionary and restrictive practices that were uncovered by Sylvia Bercovici’s (1983) earlier study.

This primary analysis called for a re-exploration of the women’s data separately and against one another. Exploring the discourses within them to uncover regimes of power, I used the questions Foucault prompts us to ask: What does this discourse do? How is this discourse made possible? Or whom does this discourse serve? Asking these questions, I found that the discourse of ‘risk management’ had the greatest influence the further the women were drawn into the welfare system. This discourse often over rode or cancelled out the discourse of ‘autonomy’.

A simple example of this is making a telephone call — a taken-for-granted social practice for many people in our society. In order for Cindy to make a
telephone call from her home telephone she must do so during the hours her support worker is on the premises. Cindy has to advise her support worker whom she would like to speak with in order to gain permission to use the telephone. Cindy’s autonomy is over ridden as her support worker makes the decision who Cindy can speak with and when. The reason given to Cindy is that a support worker needs to know whom they are speaking with because “it could be anyone”. The unknown person is perceived as a potential risk, and in order to reduce the threat, rules are made that inhibit Cindy from making her own decisions. Ironically, Cindy has not been taught how to judge people’s actions and characters, and this heightens her risk of being a victim of crime or abuse, the very thing these rules are designed to evade.

This example highlights how the discourse of ‘risk management’ controls Cindy’s behaviour and social contact in the community. One way it is made possible is that it is presented to Cindy as being for her own good. The discourse serves the organisation that provides Cindy’s supported accommodation, by reducing their risk of litigation through controlling her behaviour.

Cindy’s telephone call story is also an example of how moving between data and theory enabled me to see beyond the stories to a deeper understanding of the complex social world in which the women live. This iterative, creative process of interpreting the data evolved over a period of time and has permeated the entire research endeavour (Caroline Ramazanoglu and Janet Holland, 2002).

Presenting the data
Although I have tried not to objectify Kay, Cindy, Lara, Shirley and Evie, I accept that taking their stories, summarising their lives and placing them within the wider social context is an act of objectification (Joan Acker, Kate Barry and Johanna Esseveld, 1991). What was important for me in writing this thesis was to find a way to re-capture the experiences as they were for each participant, and to present their lives without violating their reality. An integral part of this
research then is to foreground the voices of the women and to present them as they see themselves as women. One of many parts of their identity as women is that they happen to have an intellectual disability. I spent some months exploring the best way to present the data. To write this thesis in a traditional Australian academic format left the women flat and submerged within the text. Their stories became lost within the academic discourse and the examination of the restrictive practices, oppression, power and resistance that I saw impacting on their lives.

I started by using a different font to distinguish their voices within the sea of text, but it felt like their presence was symbolic, something akin to the boats in Cy Twombly's oil on canvas painting *Three studies from the Temeraire* you only know they are boats because of the stylised shape and the title of the painting. Throughout the art expression workshops, we had spoken about the visual impact that using different colours can have, and I have carried this thought into the thesis by integrating colour into the text to bring their voices to life. Cindy's favourite colour was pink, Lara's was blue, Kay liked the colour of jade, Evie like blue and purple and Shirley loved red.

Using an Arial font and making the quotes of Cindy pink, Lara blue, Kay green, Evie purple and Shirley red helped to make their voices 'seen'. To value and privilege the women's voices their stories had to be re-told. To only tell their stories, however, as interesting as they were, did not present the complex and ambiguous world in which they lived. I hit a crisis of representation that only raised more questions. How should I write about the tightly controlled spaces that the women lived and worked within without diminishing their stories? They had not spoken about social construction, being oppressed or restricted. They had entrusted me with their stories, and in doing so, exposed their vulnerability. I believe that I had/have an ethical and moral obligation to tell their stories as closely as they were told to me. In saying this I again acknowledge that I come to this research with my own frames of reference. This quandary brought me to

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20 A photograph of this painting can be seen in this chapter under Workshop Two: The Art Gallery of NSW.
a cross-road where I could take out the different font colours and write a traditional academic thesis where the women’s voices could be seen within my academic voice or I could find an alternative way that allowed for multiple voices and versions of reality (Mary Field Belenky, et al., 1997, Patti Lather, 1997) to be more vividly represented in the text.

The way in which this thesis was written, therefore had to fulfil a number of aims: to tell the women’s stories in a way that honoured them; and to bring to light the complexities of the world in which they live; and from my point of view, keeps them isolated from the wider community. It also has two different audiences: the academic community; and the wider general community. So writing in a simultaneously plain English and scholarly fashion became another challenge. I had started exploring alternative forms of academic writing such as new ethnography (see H. Lloyd Goodall, 2000, Norman Denzin, 2003) and reading the work of Laurel Richardson (Laurel Richardson, 1990, 1992, 1994b, 1994a, 1997, 1999, 2000, 2008). This lead me onto Carloyin Ellis and Arthur Bocher’s (1996) book Composing Ethnography: Alternative Forms of Qualitative Writing. The work presented in these publications influenced the layout and presentation of the multiple voices within the research, and gave me ideas on how to incorporate the women’s stories and chapters in a variety of different formats, including: autobiography; narrative poetry; story; and fiction.

Music was Shirley and Cindy’s passion, and to honour that passion each chapter title is a popular contemporary song where the lyrics reflect the narrative within the chapter. Within the thesis each chapter is referred to by its song title and number. Where applicable, I have included the art expression works of the women. Although I cannot guarantee that I have empowered (Dorothy Atkinson, 2004) the lives of Cindy, Evie, Shirley, Kay and Lara through the telling of their stories, I have endeavoured to provide a space for their stories to be documented (Laurel Richardson, 1997). I have used multi-textual forms of writing to understand the women’s lives, and move beyond their individual stories to expose some of the tightly controlled boundaries in which they live, in an attempt to deepen my understanding of their lives, thus adding to
the body of feminist theory in an attempt to refashion and renew constructions of women’s identities (Angie Titchen and Joy Higgs, 2001, William Tierney, 2003).

**Conclusion**
The purpose of this chapter was to present how the research design developed, its relevance to the research focus, and how the procedures engaged in this study followed the aims of feminist post-modern qualitative research. It also brought to light some of the complexities and ethical considerations of researching with women who have an intellectual disability, how the participants were recruited, and the multiple methods used to collect the data. Included was a discussion on how the data were analysed, interpreted and presented, and the incorporation of creative writing as a vehicle to move the voices and stories of Cindy, Lara, Kay, Shirley and Evie from the margins to the centre, and the reflexive processes that developed my thinking about the purpose and nature of this research, my voice and position within it. Further information about the participants has been mentioned to provide social context and comparison among the participants. In writing this chapter, I have touched on some of the ‘messiness’ of research rather than the clear distant linear process that is so often written about in academic writing.

Feminist research principles, in particular reflexivity, constructions of power and presentation, have guided and influenced this study. Although some of their stories may be representative of women’s experiences and/or women who have an intellectual disability, the voices presented here are the voices of five women, and are not representative of all women or all women who have an intellectual disability. The next Chapter — Chapter five —— *Show Some Emotion* — is a discussion on the epistemological stance I have taken in my research.
Show some emotion
Put expression in your eyes
Light up
If you’re feeling happy
But if it’s bad
Then let those tears roll down

Come on try
Learn to bleed
When you get a bad fall

Light up
Light up
Light up
If it’s nice
But if it’s bad
Then let those tears roll down

5. SHOW SOME EMOTION — KNOWLEDGE PRODUCTION

When I started to write this, it was to be part of an eighth chapter about naming and honouring the position that my emotions had in this research. As I wrote, however, I found that my emotions were so tightly bound to my epistemological stance that it was impossible to separate the two. Of all the chapters in this thesis, this chapter has been the most difficult to write. I am envious of colleagues who chose to use methodologies that have a clearly defined stance on knowledge production. Feminism unfortunately doesn’t. Like feminist theory, feminist epistemology has no one view on knowledge production. Rather it has epistemologies that create a paradox, as feminism has similar, distinct, and contradictory perspectives on how knowledge is created and expressed. Therefore, the term ‘feminist epistemology’ is a means of summarising, to some extent, and integrating women’s knowledge and experiences. This perspective forces the reader to consider something other than traditional beliefs, attitudes and values (Louise Johnson, 1987).

Like my theoretical perspective, how I perceived knowledge as being produced is influenced by feminist and post-modern thought and oral story telling traditions. Knowledge production for feminists is situated within the lived experience, within post-modernism it is textual located, and in oral traditions knowledge production is through the telling of stories. These ideas flow from an interpretive paradigm in which knowledge production is not “simply a one dimensional act of discovery” but in which layers of meaning exist that allow for multiple ways of understanding and viewing the lives of women with an intellectual disability (Donna Bridges and Joy Higgs, 2009 pp. 51).
The poem on the opposite page was taken from Shirley’s interview transcripts when she spoke about her boyfriend. The frame is a small section of Shirley’s artwork enlarged. The complete original can be seen in Figure 20.
I had a boy friend
he's gone now.
There's no one else.
The love of my life

We met at coffee club
one Friday night
a long time ago.
I have a photograph.
We're going to
the fancy ball
at the club.
We danced.
He danced with me.
He was so handsome.

He went home one day
and died in his sleep.
I miss him a lot.
I haven't met anyone else
That's the way it goes.

That's the way the cookie crumbles
He was the love of my life
I miss him still.

Shirley (2005)
I suppose you are wondering why I have this chapter after my theory and research methods chapters when it might normally be located closer to the front of a thesis. I wanted to re-create how my thought processes and formulation of ideas developed, and then try to put that into a timeline. Of course, the process of learning and writing wasn’t linear; it was more like a constant state of flux: re-visiting, re-working, re-finining, adding in new ideas, editing and deleting the old, but like most narratives, it can be plotted against time in the re-telling.

Working from a post-modern perspective is a metanarrative in itself, and I enjoyed the process of unpacking and disrupting the certainty of my knowing and believing about intellectual disability, power and the production of knowledge. People who don’t like, or maybe don’t understand post-modernism would argue that this way of thinking means you never have to take a stance.

This is the paradox of post-modernism — you have to take a discursive stance in order to disrupt another. The difference is in accepting that whatever discursive stance you take, it is located within a particular historical moment in time. In this way, research is contextually situated and inherently political. Taking the position that there is no “one full and unique truth” (Lynn Hankinson Nelson, 1993 pp. 131), knowledge can then be seen as multiplicity – there are multiple realities, and multiple perspectives that are in a constant state of flux and influenced by gender, culture, race, sexuality and class (among other things).

Trying to present the contradictions and juxtaposition of post-modern ideas textually challenged me to be creative and take risks. Moving between traditional and non-traditional forms of writing, and pushing the boundaries of black text and white paper into coloured text and textured paper was an embodied way of creatively exploring “new ways of thinking and framing knowledge construction” (Sharlene Nagy Hesse-Biber and Patricia Leavy, 2006 pp. xi). Taking a non-traditional approach to research gave me a certain level of freedom to “present texts in a variety of forms to diverse audiences” (Laurel
Richardson, 1994b pp. 523) prompting me to think about authorship and ask, who am I writing for? What is my intention?

This thesis is only one of a number of different ways to consider the lives of women with an intellectual disability, and to confront and/or displace privileged discourses that surround intellectual disability and the interests they serve. As Patti Lather (1991 pp. 8) maintains, “like all discursive politics, this book (or thesis) is positioned in the language/power nexus. To position my own discourse is to mark a place from which to speak”. This chapter makes explicit the places that I speak from.

**Marking a Place to Speak From**

In the early stages of the research, and long before I had begun to write, the theoretical position I wanted to take was very clear to me. My methods were guided by my moral stance; I worked intuitively and I wanted us, the participants and myself, to have fun. My greenness as a researcher, and lack of knowledge about the women’s lives, gave me the freedom to follow where the women wanted to take me in the data collection phase of the research. I was not led by the concerns of a ‘disability professional’. At that time, I was interested in the process — what the women had to say — and not how knowledge about gender and intellectual disability is constructed and re-produced. I wasn’t really thinking about epistemology.

After completing the fieldwork and the analysis, the emotional impact of the research hit me. Working through the emotions forced me to re-examine my morals and ethics in relation to power, knowledge production, representation and voice at a much deeper and more personal level than I had ever done before.

**A place for emotion**

Like post-modernism, feminist research challenges the objective, detached researcher and recognises contradictory readings (Valerie Bryson, 1999, 21)

21 I hyphenated this to emphasise the word ‘exam’, because the process was both a test and a trial.
Adopting a feminist methodological approach acknowledges that research is an embodied process, and as such it acknowledges the presence of emotion within the research process. Despite positivist criticisms, feminist scholars have been interested in the link between feelings and research (Patti Lather, 1988, Marjorie DeVault, 1999, Rebecca Campbell, 2001, Kathleen Gilbert, 2001, Janet Holland, 2007).

There is a growing discursive space in which, people are willing to admit the impact their research has had on them personally (Kristin Blakely, 2007, Rebecca Campbell, 2001). The reluctance to disclose this impact has been linked to the influence of a positivist research paradigm and the idea of a neutral, objective, detached, dispassionate, truth-seeking researcher.

Conventional accounts of research often hide the “complexities of knowledge production and yield deceptively tidy accounts of research” (Laura Ellingson, 2006 pp. 299), and separate the researcher’s mind and body from the research process. I believe that there is an obligation for researchers to begin to acknowledge the emotional impact that doing research has on them. The failure of journals to publish deeply personal accounts of research, and many researchers to be open and frank about their personal experiences in the field leaves all researchers (but perhaps more crucially new researchers) often unprepared to deal with any emotional impact they may experience. The taboo of speaking about the emotional impact of research is compounded by the sanitised version of research found in many theses, journal articles and academic books.

Research ethics committees place importance upon ethical research practices, the use of personal support as a resource for participants, and recognition that research can raise strong emotional responses in participants. When a part of research practice is to engage both our intellect and emotion — to view the world through the eyes of the participant — it raises questions as to why the same considerations have not been extended to researchers. Where this is mentioned, it has been associated with concerns about maintaining the integrity of the data and researcher objectivity (Andrea Fontana and James Frey, 1998).
Another reason put forward as to why the emotional impact of research on the researcher is not raised as a concern is that there is an assumption that researchers tend to screen themselves out of projects they consider would pose a danger to themselves (Gill Hubbard, Kathryn Backett-Milburn and Debbie Kemmer, 2001). Within social science research, the personal voice gives way to the authority of the academic voice that places value on theory, detachment and control rather than story, involvement and ambiguity, and leaves little room for emotion in research (Carolyn Ellis and Arthur Bochner, 1999). Revealing emotions that bring out our vulnerability and fragility as researchers is akin to opening 'Pandora’s box'. This box holds the secrets of fieldwork.

Towards the end of my candidature, I became involved in postgraduate advocacy and support. This work brought me into contact with a large number of postgraduate students and the feelings of insecurity and emotional experiences they often disclosed were similar to my own. The silence around the emotional impact of research is often only broken when things have hit a crisis. For many candidates, it is enough to hear that what they are experiencing is a normal part of research. Some required examples of academic references, particularly those students whose supervisors have dismissed their feelings, while others joined writing circles or formed support networks. Others used the free counselling services that are available for all staff and students through the university. The building and maintaining of support networks for the researcher/s is an important yet frequently unacknowledged part of postgraduate research (Emma Wincup, 2001, Laura Ellingson, 2006).

While I had done a large amount of preparation on the effect that this research may have on the participants, I was unprepared for the emotional and physical effect this research had on me, and in turn on my family. Having no support network in place, I suffered from insomnia, which left me feeling exhausted, I gained a large amount of weight, had frequent migraine and spent a lot of time crying in the shower or late at night when everyone else in the house was asleep. At other times I felt sorrow, guilt, betrayal and fear. While my supervisors were very supportive, I tended to contact them with technical and
theoretical dilemmas rather than questions around emotion. At research seminars, nothing was mentioned about the emotional impact of research. This omission only added to my isolation as I tried to come to grips with the emotional consequences of doing this research.

In addition to these issues I felt, and still feel, ongoing concern for the participants. Some of the things I observed and that were disclosed have had a significant and continuing influence on my life. Transcribing the interviews and analysing the data proved to be both a happy and painful exercise, as it was a constant reminder of the women’s lives, the difficulties they encountered, their dreams and hopes, and the emotion they felt in sharing their stories. While most of the participants were happy to end our relationship at the end of the fieldwork, two of the participants remained in contact with me for over twelve months after the fieldwork ended. Apart from enjoying the women’s company, I felt it was necessary and a part of my ethical responsibility to respect the women who attached their own terms and conditions of participation to this research (Wendy Booth, 1998).

Anger, frustration, joy, grief, guilt, concern, obligation and helplessness were all feelings that I experienced during the fieldwork and data analysis processes. When the women spoke about their experiences of verbal abuse and/or being spat at walking down the street, I became angry and dismayed. I felt joy when we celebrated, one woman’s birthday, took pleasure in singing Happy Birthday, and cutting the cake, and in our mischievous laughter and hushed tones as we confessed the best and worst gifts we had ever received, with the person with the worst gift story receiving the last piece of cake.

My observations when I sat waiting for the women or dropped them home after interviews and the art workshops left me feeling perplexed. When some of the women spoke about the high levels of control they experienced in their lives I felt helpless as to what I should do, and later guilty for not directly intervening

22 None of these subsequent conversations or meeting have been included in the data.
even though I had not been asked. For example, Cindy had said that she would like to dye her hair purple but her support worker thought Cindy would look stupid and refused to give her the money to buy the dye or go to the hairdresser. When talking about the incident with a colleague, who was also researching with people who had an intellectual disability, she disclosed that she would have just taken Cindy to the hairdresser and not have worried about the support worker. While I understand and agree with my colleague that it is Cindy’s right to dye her hair whatever colour she likes, I felt sure that my actions would have been seen as an inappropriate interference. For Cindy, however, I believe it would have been viewed as an act of wilfulness and noncompliance that would have resulted in some form of intervention.

I hit a crisis point. Even though I was using a feminist post-modern lens to explore regimes of power, I had unquestionably taken on the belief that emotion in research was a sign of weakness and had no place in good research design and analysis (Emma Wincup, 2001). Rather than keeping a ‘social distance’ I had exceeded the boundaries of rapport and had ‘gone native:’ over-identifying with the participants. I couldn’t work out how to split myself between the emotional experience of the art workshops, my observations and data analysis, and writing in the neutral voice of a social scientist where the discussion of feelings and subjectivity is actively discouraged (Carolyn Ellis and Arthur Bochner, 1999). I became overwhelmed, and felt voiceless and powerless.

Some months later in a joint supervision meeting, Moira and Debbie raised their concerns that I wasn’t writing. I won’t forget that meeting. It was a Thursday around 1.00pm, and we were in Moira’s office. Like most academics’ offices, one wall was filled with floor-to-ceiling book cases. Moira’s desk faced into the room, and on the desk-return near the wall was a desktop computer. Her desk was empty except for a stack of document trays and a pile of coloured manilla pocket folders on the far right. Beside the desk along the back wall was a bank of four black four-draw filing cabinets and a picture above them on the wall. A red rug was on the floor and we sat at a small round table next to the door. On
the round table was a plain, somewhat thin-looking manilla folder with my name written on it. There was a place for everything, and everything was in its place.

I had e-mailed Moira and Debbie the week before an updated table of contents but had failed to send them a first draft of my methodology chapter as promised. Meeting at 1.00pm had given me the morning to work myself up into a nervous wreck. I entered the room wracked with guilt, flush-faced, nervous, feeling nauseous and extremely stressed, having run out of excuses as to why I was continually missing my own self-imposed writing deadlines. I had no option but to do the Catholic thing: confess my guilt and take my punishment on the chin. Unfortunately, Moira and Debbie are not Catholics, so they don’t know the rules of confession — I confess, they tell me how bad I am, invoke punishment and we all move on with the assurance that to my best ability I will never miss a deadline again.

It was more like — raised eyebrows and wily smiles exchanged between Moira and Debbie. “We’ve both done a PhD, apology accepted but lets get real here we know you will miss deadlines, things happen but that’s not the issue is it Janette? The issue is that you’re not writing — what’s happening?” Each time I tried to deflect the question one of them would bring the conversation back and ask me “what’s going on?” I would hate to give the impression here that this was some sort of storm trooper interrogation with one of them sitting on me and the other shining a bright light in my eyes. Not at all! They’re far more subtle than that, but their endurance and genuine concern in the end meant that I had nowhere to hide. They sat, handed me tissues and just listened as the emotional reactions to my research findings I had been keeping silent, submerged, tumbled out and were laid bare amongst the humiliation and self retribution for breaking down and admitting that I felt overwhelmed, desolate and immobilised.

I prepared myself to be suitably chastised but instead I was surprised and confused; they didn’t admonish me, laugh or tell me I was the first person to experience a reaction to fieldwork in the history of research. Rather, they
explained they had both felt emotional reactions to their research; how could you not, listening to people’s stories? They challenged me to recognise that what was important was what I did with those emotions. I could choose to ignore them and pretend that they did not influence the research process, or as I was using a feminist epistemology that contested objectivity and distance in the researcher/researched relationship, I could channel them into my research and use them to bring me closer to the data. The latter was a much riskier and less traditional option than the first.

Debbie asked why I hadn’t used my research method on myself as it was designed as a reflexive practice, and Moira suggested that I just start writing about how I was feeling. Acting on their advice, that weekend I began an embodied process of creative writing and painting small\textsuperscript{23} canvasses. I used this technique throughout the writing process as a way to work through emotion, to channel my thoughts, reflect, and express myself both visually and verbally. The painting on the next page and the prelude to this thesis are two different examples of that process. I have at times been tempted to delete the prelude. In post-modern terms it signifies a particular moment in time that encapsulates how I was feeling. I made a conscious decision that weekend that I would write this thesis in a way that is emotive and evocative.

I would incorporate emotional reflection as part of my research, and be prepared to acknowledge the emotional impact, both positive and negative, that this research was having on my life. I had used my research journal to write down any perceptions I had or that the participants had voiced during the fieldwork. I went back over my research journal, interview transcripts and tapes, adding more detailed notes about my emotions and areas that needed a deeper understanding. For example when something provoked an emotional response in me, I would make a time to sit quietly, write, reflect, read and do something creative to explore my reaction and what had triggered it. I joined a thesis

\textsuperscript{23} I used A4 size canvases as I tend to do art expression exercises rather than works of art, as I am not an artist and I have no formal art training. If I feel the need for a larger working space, I use a series of small canvases and join them together to make a larger work.
writing circle where we critiqued each others’ writing and discussed research-related problems. I also created two very different networks that provided a nurturing and creative space in which we supported each other by being available to discuss ideas, talk, read or just listen. I now had a more honest and open relationship with my supervisors where I could talk to them about any problems I was having that may impact on my progression. Finally, I sought professional help to talk through the emotional impact this research had on me and the flow-on effect it had on my family. During these counselling sessions, I gained a deeper understanding of myself and I learnt different techniques to reduce the effects of stress and channel my emotions.

Figure 43 - Awash, 2006, Janette. Poster Paint, Size A3. In this art expression exercise I attempted to suspend any conscious thoughts and head chatter. I didn't think about the aesthetic of the work. Rather, I found a quiet space and let the emotion and tension I was feeling wash over me.

As a knowledge production tool, emotional reflection has helped me to re-live my data, to listen more closely to the accounts of the women in this research, and honour the women’s stories. Incorporating emotional reflection into my research has assisted me to develop intellectual clarity and a deeper understanding of the complex issues that impact on the women’s lives. It has been instrumental in enabling me to find creative ways to present multiple voices that re-tell the women’s stories, my story and interpretations of their lives that incorporate other voices of the academe. As I write I imagine you to be a thinker, open to new ways of seeing and ready to challenge taken-for-granted
knowledge. Upon reflection, even though the data collection finished some years ago and the participants have moved on with their lives, I still haven't left the field. In writing the chapters of this thesis I continue to re-live the data and although they can still create an emotional response in me, particularly around issues of social justice and abuses of power, they no longer overwhelm and debilitate me.

As I am being honest here about my emotions, I need to say that at times during the fieldwork I had negative feelings towards one of the participants. Apart from teasing Lara, Kay would make derogatory remarks in front of the other women as if they were not there. She would say, for example, “business services is a horrible place to work but it is good for some people like them — people who aren’t so smart”. The women knew she was speaking about them, but they never said anything. Shirley and Cindy would put their heads down as if they didn’t hear, whereas Evie would quietly catch my eye and give me a smile and wink. One act of resistance that Evie spoke about was to keep quiet and say nothing. That way, people in positions of power tended to either underestimate or over-look her. Slipping under the radar enabled Evie to exert more personal freedom whereas people, such as Cindy, who resisted by challenging authority, were placed under constant surveillance. At an intellectual level I could understand the reasons for Kay’s actions and inability to see the emotional distress some of the things she said had on the other women. On an emotional level this proved to be more difficult. I often felt embarrassed and frustrated with her behaviour and this made it difficult at times to establish and maintain an open, honest and connected relationship with her.

Participating in the research also had an emotional effect on the participants. Like mine, their emotional responses were both positive and negative. Using methods such as semi-structured interviews and workshops provides the participants the opportunity to set the agenda and decide what stories they would like to share about their lives. The topics of discussion can, however, unintentionally cause the participants to re-live painful memories and create emotional stress (Emma Wincup, 2001) particularly when they stray into areas
that are too personal, the question is too direct or there is not enough distance between the event and speaking about it (Gesa Kirsch, 2005). I tended to blame myself when the women became sad, upset or cried, yet when I asked the women if they would like to stop, they often said “no”. So I sat, listened and handed them tissues; occasionally I cried with them. I found grief and sadness were emotions that were easier for me to deal with than anger. There were a few times when a woman became angry in telling or listening to a story. This was the case, for example when Cindy recounted her experience at the Road Traffic Authority Office (see Interlude I Get So Angry). Anger and frustration were two emotions that tended to flare up and disappear just as quickly. The anger expressed was embodied within the person who expressed the emotion, for example by their going red in the face, breathing quicker and/or shaking; it was never directed at any other participant or manifested into physical violence. Anger was often a response to an injustice or feeling powerless. For the story teller, having a safe space for that emotion to happen and be acknowledged sometimes helped them to move on. A number of the women spoke about how anger was a ‘bad thing’ and not an emotion they were often allowed to express. We talked about getting angry, losing our tempers and how we felt when we experienced anger in other people. Like me, the women often cried instead of getting angry. For Cindy, the consequences of losing her temper, stamping her feet, shouting or yelling often resulted in being placed back into behaviour modification classes or punishment such as not being allowed to go out.

A place of care
In acknowledging emotions in research, feminist methodology draws attention to the researcher’s experiences, “particularly in the field, and to issues of ethics that permeate all research” (Janet Holland, 2007 pp. 196). This research is based on an interpretivist paradigm that takes a holistic approach to the people involved to gain an understanding of the world view of the research participants. A key part of feminist methodology challenges the issue of objectivity and the detached relationship between the researcher and the researched (Joan Acker, et al., 1991).
An ethic of care places an emphasis on individual uniqueness, personal expression and empathy. A part of seeing every person as unique accepts that we all come with our own baggage. Experiencing life is not done in a vacuum; it’s an interactive process that’s shaped by our personal history, biography, social class, age, race, ethnicity and gender. What adds texture and colour to experience is our personality. Rather than viewing personality as a form of bias and separating it from ideas, a feminist ethics of care sees personality as “connected knowing” (Patricia Hill Collins, 1995 pp. 537). As such our personality influences our ideas and view of the world. Although rapport makes a connection between people, it takes empathy to gain an understanding of and respect for another person’s feelings and point of view. In using a collaborative approach to the method and topics of discussion the research was shaped by Kay, Lara, Shirley, Evie, Cindy and myself. This co-created space provided the opportunity for us to develop, express and share parts of our lives and lived reality. When we connect with people the blending of our uniqueness and personalities creates diversity and can enrich our understanding of ourselves and our world.

Part of my holistic approach to research accepts that we are all vulnerable at times (Ruth Behar, 1996), not just certain groups of people. One of the most important things I have learnt from undertaking this research is that as a researcher I have no guaranteed way of knowing that any question I ask will not trigger an emotional response or painful memory in a participant or myself. I understand that there are topic areas which you have a greater chance of doing so, such as rape, abuse, death, illness or suicide. When undertaking this type of research, or research with people who are seen as vulnerable, disadvantaged or marginalised there is often a call to use ‘sensitive research methods’ as outlined in the methods section of this thesis. These types of methodological considerations focus on participants who disclose behaviours or attitudes that are kept private or are socially unacceptable or illegal, or research that might cause the participant distress or have direct implications for a particular group of people (Pranee Liamputtong, 2007). Whether you require extra ethical and emotional care is based on a perception of risk. Under that criterion this
research is deemed ‘sensitive’ because my research participants have an intellectual disability. While at the beginning of the research journey I agreed with the literature, now I have a broader perspective that encompasses all people involved in research.

For a researcher to adopt a belief that one group of people or one topic of research should have a greater ethics of care over another is taking a positivist or quasi-positivist stance, depending on your epistemology. It is also an exercise of power and other-ing of research participants. Such a stance pushes researchers, supervisors and ethics committees into making moral judgements about participants who are ‘worthy’ or ‘unworthy’ of extra care and consideration. I will try to illustrate what I mean by this. Consider two different research projects that ask mothers how they communicate with their children. The first asked mothers how they told their child that they had a serious illness. The second project asks mothers how they negotiated with their children the after-school and/or weekend group sports they could play.

I think that we can agree that there is a marked difference between the two topics. The first topic about illness is viewed as being of a highly personal nature and therefore the research has the potential to unleash painful memories. As such this research would be considered as requiring ‘sensitive research methods’ (Michelle Ramos, 1989, Pranee Liamputtong, 2007). The second topic about negotiating sport although it deals with children, lies within the leisure field, so it may be assumed that it would not have the same emotional impact as the first and therefore would not require the same level of sensitivity. If it were disclosed that the group of mothers taking part in research with the topic of sport had a seriously ill child, then the research moves back into the realm of ‘sensitive research’.

What this research has taught me is that as a researcher you are a brief encounter in another person’s life. While you may have an area or topic you want to gain information on, you actually have no idea how or what a participant will say when they open their lives to you. Part of my research praxis
acknowledges that personal life has both a private and emotional dimension. As such, any area of research has the potential to cause distress. This raises the question for me that shouldn't all research participants be afforded the same ethics of care as those who are deemed ‘vulnerable’? For me the answer will always be yes; however, when I add an ethical and moral dimension the answer is not so clear cut. In adopting a holistic approach to research there is an expectation that I will confront my moral and ethical boundaries and move into those uncomfortable spaces where life is not so black and white. When disclosure moves into areas of socially unacceptable or illegal behaviour, who and what am I prepared to protect or expose becomes more difficult to define. Does an assurance of confidentiality cover every disclosure?

There were things that were discussed in this research where the participant asked me not to break confidentiality and most of the time it has been easy to agree to. It would have made for an interesting discussion but erasing it from an interview tape and transcript and maintaining confidentiality really wasn’t a problem. Other promises of confidentiality that conflict with my own belief systems have not been so easy to keep. These ethical dilemmas have been far more difficult to resolve, particularly when disclosure may fix a current problem but the solution has the potential to place the participant in a far worse situation. Having to live with some of the moral decisions I had to make in this research is not easy, and it made walking away from it very difficult.

There have been feminists who have queried whether ethical research is ever possible in "situations governed by inequalities and hierarchies" (Laura Lengel, 1998 pp. 233). In presenting stories of dis-empowerment and oppression in this thesis have I become what I seek to expose – one of the oppressors? It's easy to fall into the reductionist domain of ‘self-other’ and take a generalist stance that positions all women with an intellectual disability as submissive and oppressed. As I have mentioned before this thesis doesn't speak for all women with an intellectual disability and I have fought against adopting this duality by taking a post-modern stance. Understanding positions as places on a web and
power as fluid and constantly moving rather than fixed, offers me a way of re-
visioning the women in this study as they move in and out of these positions.

**A place for telling stories**

In this thesis so far I have spoken about ‘stories’ and ‘narratives’ — for me these words are interchangeable. This research is not narrative inquiry, as I am not interested in narrative as a discrete unit of discourse that uses linguistics to identify scientific rules within each line of transcribed text (Catherine Kohler Riessman, 2008). This research does however, draw its use of story telling from oral or life traditions. Within intellectual disability literature, oral or life history research is a growing field (see Dorothy Atkinson and Fiona Williams, 1990, Dorothy Atkinson, 1997, 2004, Dorothy Atkinson, Mark Jackson and Jan Walmsley, 1997, Tim Booth and Wendy Booth, 1994a, Dan Goodley, 1996, Maureen Gillman, John Swain and Bob Heyman, 1997, Rannveig Traustadottir and Kelley Johnson, 2000, Sally French and John Swain, 2006). While this research is not oral or life history research, it does use story and art to reflect the everyday lives of Kay, Cindy, Evie, Lara and Shirley.

The lives of many people with an intellectual disability are known through official documents such as case histories, medical records, life plans, and risk management assessments that are completed, recorded and controlled by ‘professionals’. For the women in this research telling the stories of their lives gives them control over authorship, empowering them to define their lives within their own terms. For many people with an intellectual disability, reading and writing is difficult so it is important that their oral histories are recorded and documented.

Story telling is an ancient and universal way we communicate to others about our social world and lived reality: “life is a story put into practice” (Guy Widdershoven cited in Maureen Gillman, et al., 1997). If I think about life as a story, it becomes the vehicle for making sense of our lives and a way of passing on accumulated wisdom, beliefs, values and experiences. Stories can be found everywhere: in myths, parables, history, conversation, theatre, drama, tragedy,
comedy, mime, art, photographs, stained glass windows, films, books, diaries, and memoirs to name just a few.

This thesis is the story of my research journey. It is the re-telling of the women’s stories and the story of melding, separating and re-fashioning the data into a new story. Stories then become part of an interactive embodied performance as they are co-created. To make and then tell a story I draw from my own personal experience or the experience of someone else. When I tell that story to someone else, I pass that experience on and it then forms a part of the listener’s experiences. Telling stories and listening to other people’s stories is a part of our life rituals, and is shaped by our culture, race, gender, sex and age. As stories are discursive they have a political function and can be located within structures of power. Seeing stories as performative recognises that the subject position is culturally and historically produced and reproduced.

Hearing the personal narratives or stories of other people helps me to formulate, strengthen and challenge my own beliefs, as stories provide a link between the personal and wider social worlds. Keeping the women’s stories as intact as possible, rather than transcript fragments, enables us, as readers, to gain a sense of who they are. By presenting the individual stories of the women in this research I hope to challenge some of the dominant stereotypes about intellectual disability (Dan Goodley, 1996).

In this research, stories are a way of connecting life events or important facts. In a recent workshop by Catherine Kohler Reissman (Personal Communication 28th March 2009) there was a discussion about what constitutes a narrative. Something similar to the following three lines of text was used to illustrate the point:

24 The example used was taken from another person’s research. As I do not have permission to use their data, I have changed the text.
A narrative is defined as a speaker asking a listener to hear, connect and take away knowledge. The above three lines are not a narrative because the three events are not connected, they don’t follow a logical sequence and the reader is unable to construct the speaker’s meaning (Catherine Kohler Riessman, 2008, Peter Clough, 2002). In order to turn these three sentences into a story, as readers, we tend to fill in the blanks to make connections that are not there. In Catherine Kohler Reissman’s workshop story, the interviewer asked the same question repeatedly over weeks and the participant gave the same three line answer each time, highlighting for that researcher that not all people make legitimate research participants. Coming to this conclusion from these three lines raised two different concerns for me.

First and foremost, it raises the questions: Why didn’t the interviewer ask a different question? If the same question kept eliciting the same answer then the problem lies with the interviewer and the method of data collection rather than with the participant. Narrative is not just the spoken word it also includes written text and visual material. As a researcher, it is up to me to find creative ways for people to tell their story, to draw out information so that the threads of the narrative can be connected and not just dismiss them because they don’t make sense to me. Secondly, adopting a position that not all people can be research participants effectively excludes certain people from taking part in research, such as those with limited speech or cognitive abilities. If we adopt this position then what constitutes legitimate knowledge is constructed and controlled by the articulate only. The irony of saying this isn’t lost on me and it raises questions about the validity of authorship in this thesis.

Adopting a feminist ethics of care within a post-modern stance is not without its difficulties, particularly around authorship. Incorporating an ethics of care calls me to confront my own position of power in the research and recognise that I am the primary beneficiary of this research. In completing this research I benefit from publishing and in writing this thesis I hope to gain professional advancement. At the same time this thesis strives to reflect my belief that all life experiences and stories are valid and important. My story is just one of many
stories and to reflect this aim I have found creative ways to present different voices textually. I also need to acknowledge the place and position of power I speak from. I chose the stories, quotes, lines of argument, structure and presentation of each chapter. In writing this thesis I acknowledge that every idea has an owner and that the owner's identity matters. To this end, I have referenced extensively and have gone back to an original text wherever possible to gain an understanding of the author’s original intention.

In the process, verbal and visual methods were used to ask the participants to “recall, recount and review” (Dorothy Atkinson, 2004 pp. 692), their lives and then share a story or memory that the process of creating art sparked. Rather than building a life history that re-constructs whole lives, agreed themes were used as a focal point for story telling. Telling a story about our lives asks us to remember the past and pull that memory through to the present. Re-shaping the story in the present has the potential to change the future. Asking the participants why that memory/story was important gives the participant a historical context or anchor point to reflect on their lives and acknowledges their expertise in their own lives.

In re-telling some of the women’s stories as a reader, you have the opportunity to understand the world from the point of view of someone who has an intellectual disability. A point of view not often heard and that you may or may not share. The collective sharing and listening to other people’s stories provides us with different contexts, experiences and points of view to broaden our understanding of the world and our place in it.

Producing knowledge as a community is an important part of a post-modern feminist epistemology. It recognises that knowledge is not produced in isolation (Lynn Hankinson Nelson, 1993, Liz Stanley, 1994, Debbie Horsfall and Angie Titchen, 2007), but in a community. Rather than a single ‘knower’, knowledge is shaped, constructed, contested, accepted, negociated, dismissed and made meaning of in relationship to others.
A place for art
In this research project, art-making was used to access, convey and illuminate the stories of the women’s lives and as a part of my emotional reflection to tease out, unravel and focus my own thoughts. Rather than a window into our souls, art in this research is a created perspective that can have multiple meanings, depending on the perspective of the artist and the viewer. I have tried not to separate the women’s stories from the artworks, as they provide the context. Unlike art therapy or other visual arts or arts-based research methodologies, we did not analyse any of the artworks. Instead, the artworks were used to “build a bridge between the visual and the verbal” (Collier and Malcolm Collier cited in Patricia Leavy, 2009 pp. 217). The interpretation of each individual work was left up to its creator and is not part of my data analysis. This is an important distinction to make, as it stresses my intention for the women to analyse their own lives through the process of art making and expression.

Art has been used in research to “convey political ideas, concepts, beliefs and other information about the culture in which it was produced, including dominant views of race, class and gender” (Patricia Leavy, 2009 pp. 219). This was not my intention in this research. Rather, art was used as a way to disrupt and displace stereotypical ways of thinking. Thinking about my life, their life, your life, our lives. What does and doesn’t constitute art, research, academic writing, a thesis?

Art-making provided the women with different ways to express their identity and their personality creatively. Just as the women were unique, so were the personal images they produced. Apart from the spoken word, the women used a number of different media such as: clay, paint, water colour, charcoal, photographs, still life, ink, abstract and collage to explore their lives. Art has the potential to say things that words cannot. Using different art expression exercises was a way to tap into our subconscious or tacit knowledge and provided us with new ways to explore symbolic knowledge and meaning.

25 Other form of arts-based inquiry or research were outlined in Chapter 4
26 It needs to be made very clear that the art expression works were never intended by myself or Moi to be works of art but rather a way of collecting data.
Expressing ourselves through art was a non-discursive way to connect with, embody, and give meaning to our inner experiences (Susanne Langer, 1953).

Some of the art expression exercises were designed to accentuate the idea of art as an embodied process. To do this we used different sized and coloured paper, paint brushes and angles. For example, in one of the exercises we taped two large A2 size pieces of paper to the wall and using a 4cm wide paint brush we stretched our arms to make large exaggerated brush strokes. In another activity we blew ink through a straw or used sponges to apply paint. We also painted with our eyes closed.

Some of these activities challenged the women’s ideas about what art is, and art-making as a passive process. For example, blowing ink through a straw prompted a forgotten memory about visiting Nanna’s house and as a special treat being allowed to drink very milky sweet tea in a good china cup and saucer. This reflection prompted other childhood stories about our relationship with our grandparents. As a child, Lara’s family moved to Australia and her memories of her grandparents were tinged with sadness as she never got to see them again. For Lara, missing out on having a relationship with her grandparents has meant that she makes an effort to have a good relationship with her two grandchildren and see the boys regularly even though they live some distance from her.

Sharing stories within a community provided us the opportunity to think about our lives differently. While the rest of us weren’t grandparents, Lara’s story prompted us to think about her experience in relation to our own life experiences. In doing this we are able to make connections and this prompted a discussion about the pleasure we give and receive and the value we place on having a relationship with other people’s children, such as our nieces or/and nephews.

For some of the women, being asked to think about their lives and identity differently proved challenging. One reason was that they were often only asked
to speak about their lives in binary terms such as 'good/bad', 'happy/unhappy', 'angry/sad'. In addition, being asked to express themselves through art was a new experience. Having an artist and an art teacher facilitate the workshops gave the women the opportunity to learn new skills and ask questions about different aspects of art creation, technique, design, colour, medium and aesthetic appreciation. Gaining artistic confidence helped the women to push their personal boundaries and open up new ways of thinking about themselves and their abilities.

As we learnt about art and each other I also learnt the skills required for doing qualitative research, such as observation, attention to detail, and how to uncover implicit relationships between the women's lives and the world in which we live. The art expression exercises in the workshops were one form of art production within this research. Another form of art production within this research is textual.

As a feminist, embodiment was an important consideration within this research, and I wanted to weave the embodied experience of researching through the writing and into the reading. This called for a non-traditional academic style of writing that takes post-modern concerns about authorship into consideration and so I became interested in framing research differently (H. Lloyd Goodall, 2000). I wanted the experience for you, the reader, to be more than sitting, holding and turning the pages. To do this I have used a number of different techniques to produce a physical and/or emotional response as you read, such as textured paper, colour and different writing styles. Using sensation as a writing technique opens the possibility for you as 'the reader' to construct your own experiences from the sensation this reading provokes.

The movement between traditional and non-traditional writing displaces the boundaries of academic text and the distinction between the 'personal' and 'academic' become less clear (Laurel Richardson, 2000). Although the contents may be written differently, this text has the components of a traditional thesis: introduction, theoretical positioning, methodology, findings, data analysis,
discussion and conclusions. This thesis is influenced by the theoretical
concepts of feminist post-modernism — reflexivity, emotional reflection, ethics
of care, authorship, subjectivity, power, language, and representation. It is
experimental in method and the textual form includes poetry, story, emotion and
autobiography. I am concerned about research that represents 'the other' and I
have written about the women’s lives adopting the same ethics of care I have
taken in my own reflective writing. This thesis can only be a partial construction
of my research journey, the women’s lives and the world as I see it. It
represents five years of my life, twelve weeks of the participants’ lives, some
hours of your life and minutes of someone else’s life if you decide to share what
you read here. It also represents some of the lived experiences of six women,
the bric-a-brac of how we see and make sense of our world in the sea of
experiences that make up our lives.
Another Day

Every day she takes a morning bath, she wets her hair. Wraps a towel around her as she’s heading for the bedroom chair. It’s just another day.

Slipping into stockings, slipping into shoes. Dipping in the pocket of her raincoat. It’s just another day.

At the office where the papers grow she takes a break. another coffee and she finds it hard to stay awake It’s just another day.

6. ANOTHER DAY — WORKING LIVES

Prelude

The previous chapter set out the research method of this thesis. This Chapter presents some of the research findings and analysis. The findings that are presented here are taken from interviews, workshops and field notes and the focus is on the day-to-day work experiences of three women: Evie, Shirley and Kay. I decided to juxtapose the stories of these women for a number of reasons. Firstly, the three women work in two different areas of employment. From meeting the women in chapter three, 'I'm coming out', you will be aware that Evie and Shirley work in business services while Kay is employed in open employment. Although they all work in the non-government sector or not-for-profit organisations they work in three very different workplaces. Finally, as individuals, each women chose to voice their story in different ways.

Evie, Shirley and Kay stories are re-told using their own words. Their stories can be read individually or collectively by reading down or across the page. The gaps on each page are used for continuity, to link commonalities and the time of day between the three different stories. For people who have difficulties with reconstructing time, a technique used is to anchor time to a familiar activity, for example a television program or particular meal. Evie used this method of anchoring time into segments by telling the story of a typical working day through a series of storyboards that she created and designed herself in the fourth workshop. Some of her artwork along with a description of her day is presented on the left hand side of the page. Although Shirley began working on a storyboard, she decided not to finish it, instead telling her story over a cup of tea. Kay was not present at the storyboard workshop. Kay’s story is reconstructed from an interview that was conducted during her lunch hour at work.
Getting Ready for work

The alarm goes off at 6 o’clock every morning. I get up and have my shower, clean my teeth and brush my hair.

After that I make my lunch and have breakfast. I normally have toast, cereal and a cup of tea. Then I get ready to go to work.

Travelling to work

A taxi comes to my home and takes me to work and back home again.

At my last job I used to catch the train that’s when I lived at home with mum. My boss Jack was leaving to come and work here and he asked me if I would like come too. It’s the same sort of work, you know, putting things into packets.
I get up at 7 am. Have my breakfast: usually cereal and a cup of tea. I pack my lunch: a cheese or ham or vegemite sandwich. Then I have my shower and get dressed.

We don’t wear a uniform. I just wear old clothes: pants and a shirt. Sometimes I wear makeup but not all the time, usually just a bit of lipstick.

I catch the bus to the station, then a train and I just walk down the hill to work.

When I get to work I bundle on with a card and I finish at about 3 o’clock. I start at 8.30. I put my card in the clock and it went bung. It put the time on the card red or black if I was late. I put my handbag in the locker with my lunch and morning tea so no one will steal it.

I had morning tea at my table about 10am. Sometimes I have fruit: an orange, some prunes or apricots. We can only have a cup of tea just at the breaks. We could have some water any time from the bubbly. At lunch we sat around and chatted in the lunchroom.

I have my morning tea about 10-30 and my lunch about 12-30. I go back to work about 1 and then I finish at 3 o’clock. At 3 o’clock it’s time to go home and I bundle off. I catch the train from the station and catch the bus home. I usually have afternoon tea when I get home and a cup of tea.

I used to live a long way away. It was hard to get here and I sometimes came late. That’s not good. I spoke with the Department of Housing and they found me a unit just near here. Now I walk to work. It only takes about 10 minutes.

Monday, Wednesday and Friday are the days I go to work. TAFE on Tuesday and the Young Women’s Project on Thursday.

I work as the Admin Assistant of the office. I pick up the phone and I go to get the mail. I just help the staff. What they need like the info pads or help the members or what they need to have ready and yes just do office work. I fold pamphlets into packets of 100 or 50 or 300 or whatever. They come in a big piece and we need to fold it into little pieces.

We organise the functions like big staff meetings, consumer forums, working lunches. Sometimes we do all or part of the catering and sometimes we get it in.

27 A water fountain where you drink directly from the flow.

28 The Young Women’s Project is run by a Community Centre in a Sydney local municipality area to provide both educational and recreational activities for young women living in that area.
Evie’s Story

What we do at work

I put my handbag away and get ready to start work. We all sit in the same place every day around a large worktable.

There are two things we usually do. One is folding men's handkerchiefs and putting them into a plastic packet. You put five handkerchiefs in a bag. I've seen them in the shop at Big W. The other thing is putting coloured pencils into a box. It's really boring. Yes it does make me feel proud and a bit funny when I see my work selling in a shop.

I don't have a favourite thing about work.

The worst thing is the shouting. Someone is always being shouted at by the supervisors to “Shhh be quiet” or “Stop talking”. You’re only allowed to talk in the breaks... It doesn’t matter if they’re not supposed to do it, they just do... Complain to who? Even the big boss shouts at us. What can you do? We’re always in trouble for something, either going too slow or talking. I don’t like where I work but I have some good friends there.

29 A large national retail store chain.
Shirley’s Story

After I put my things in the locker I sit down at the table and wait until someone comes to give me the work.

I have a special spot to sit in every day and it is beside Mary or Kelly. Kelly is my best friend. Her mother just passed away.

My favourite job is A. L. We put A in a bag and we put screws in the bag. I put two screws. Yes the same size into a plastic bag. I don’t seal the bag I just put them in the bag. The bag is left open and I put them in a box or on the tray. Someone else would seal them up. Yes each person has a job. I put the screws in the plastic bag and then someone sealed the bag and they put them in one big box. That was the thing I liked to do the best.

I like to do lots of different jobs.

Um the job I hate doing is probably putting labels on crayons. It’s hard. It’s hard to put labels on crayons. You have to make sure it is nice and tight and not too loose. You have to put it on straight. If it was crooked I get in serious trouble……. Big trouble!

I can’t remember now what happened when we did a good job.

Kay’s Story

Every morning I check my computer diary. I use to write my diary but now I just go to the computer and write it in there. If I don’t finish some work I write it in the diary and I know what to do or to continue. I don’t have to worry I have forgotten my diary or search my bag. You click and it’s there for you.

I try to learn some skills like fax, e-mail, and excel. I like it best when I understand since I understand I know what I am doing if I don’t understand then I will be just sitting there and I don’t know what to do. I need to understand what I do first. Yes the best thing is when I learn new skills. Otherwise I feel bored. Oh I shouldn’t have said that.

The worst thing is when I don’t know...when communication breaks down. One thing I really really hate is being told to do something five minutes before it has to be done.

This doesn’t work. We already bring it up at the staff meeting last time. That is the one thing I really hate.

It makes it difficult that they tell you only five minutes ago they don’t tell you even last week or even on Monday you can tell me to do it. Unless two days before-hand you know or a week before even better I have lots of time to do it but they don’t. They just tell you this morning I got so many things to do maybe I got many tasks to deal with you know. So many tasks. That is the only thing I hate.

30 A computer spreadsheet program.
Evie’s Story

Friendship, Career Aspirations and Training

My friends Allan and Katie sit next to me and Cindy sits on the other side of the table from me.

A supervisor comes and gives us the work to do for the day.

Last week I wore my new sandals to work and I got sent straight home. I didn’t think I’d get into trouble because there’s no work and we’re just sitting around watching TV or reading.

I take a book to read when there is nothing to do... The books I like the best are romance. Barbara Cartland’s books are my favourites.

On your birthday you get a cake with candles and everyone sings happy birthday at morning tea time. I suppose that’s a good thing.

I told my supervisor a long time ago that I wanted to leave. The work is really boring. My dream job is to work with children.

If I want to change jobs I have to tell my supervisor and then they will find me another job. I have to be patient and wait until they sort something out.

The best thing about work is the money. Why else would you go to work?
Shirley’s Story

I made some friends there: Kelly, Mary and Lucy. Kelly is my best friend.

I learnt new things. We put perfume, powder or something else in the trays and then into a box. It smelled good. During the day the radio was on. We were able to sing along a little bit, not a lot. If anyone talked too much they were told to be quiet. The supervisors were a bit tough but not much. If I got worries or problems I tell Wendy. She’s my supervisor. Sometimes the boys would call me names. I would go and tell Wendy and she would talk to the boy and tell him not to do that. If they didn’t stop they would be in a lot of trouble. Sometimes not all the time we were yelled at. If someone yelled at me I could complain to a supervisor.

There were times when there was no work31. We sat and did nothing all day. We watched TV or videos. Usually they just turned the television on “Friends”32. I helped wash up the cups in the lunchroom for something to do. Just to keep busy.

The best thing about work’s having lots of different jobs to do and the money. I like to spend it on music and clothes.

On my birthday they would buy me a nice cake and sing happy birthday. I think they did it for everyone but I am not quite sure.

Kay’s Story

I have my plan for next year already. Every year I have a review with M and we decide what I need to do. Next year I will be learning to do my timesheet on Excel. At TAFE this year I learned how to use Excel in “Database On Spreadsheet”.

We decide that I have homework about spreadsheets in Excel so it can help me for my timesheets. I hope that next year I can cope with it because since I first come here I can’t do it.

Now I print the template from Monday to Friday for two weeks every fortnight because we get paid every fortnight and then I just do by hand. So I hope next year to learn how to do it on the computer in Excel.

I am learning petty-cash too. You know when I spoke with you before I told you how I am not good at math. It’s very hard for me. You have to add up all the dockets, write them in the book and make sure it balances.

I’m always busy. There’s lots to do. We have no time just to sit. If I have everything done I just ask. There is always something to do.

The money! That’s the best thing about working. I like to buy clothes and shoes.

I used to work in business services before I came here. It was terrible. I know some people have to work there but I would never want to go back there again.

31 When going through the transcripts Shirley’s mother commented that the latest period without work had been around three months. 32 American sitcom about six friends.
orking in paid employment outside of the home can be important in enhancing women’s autonomy and well-being. Employment can provide companionship, alleviate feelings of isolation, build self esteem and is a way to lessen dependence on partners for financial and/or emotional support (Lesley Doyal, 1990). Apart from economic, social and personal gains, working is a way of participating in and contributing to the wider community (Patricia Reid and Anne Bray, 1998):

Paid work provides not only the money to live on and raise a family, but also improves self esteem and provides a connection to the community (Centrelink, 2006c pp. 2).

Employment therefore is seen as central to a productive and fulfilling life.

Despite the government’s stance on the need for job creation, unemployment among people with a disability remains unacceptably high. In the 2003 Australian Survey of Disability, Ageing and Carers it was reported that 53% of people with a disability are in the labour force as compared to 81% of people without a disability. The extent to which a person is able to participate in the labour force may be influenced by nature and severity of their disability and this may be one reason for the disparity between people with and without disabilities. Of the 53% of disabled people employed, however, it is more likely that they will work part-time with their main source of income coming from government pensions and allowances (ABS, 2004). Women with a disability are less likely to be in the workforce than men with a disability. While the unemployment rate for women without a disability has decreased over the past five years, the unemployment rate for women with a disability has increased (Sharan Burrow, 2008). Women with a disability who work are more likely to be employed in general clerical work and the service sector, earning considerably less than their non-disabled equivalents (Marjorie Baldwin, 1999). This final
point is consistent with the women who took part in this study. All the women work in the disability services sector: Kay is an administration assistant; Cindy, Shirley and Evie’s work revolves around packaging components into boxes or bags in business service organisations; and Lara’s main area of work is as an advocate for people who have an intellectual disability.

**INCOME**

All of the five women were long term employees who had been employed by their current employer between four and twenty-five years. They worked part time with their primary source of income being the Disability Support Pension (DSP) plus Federal Government Allowances. Based upon April 2009 calculations from Centrelink (2009), this places the three women who work in business services, estimated level of income either under or marginally above the minimum wage (see tables 5 and 6 for a breakdown of estimated earnings). The women’s income had to be estimated as Lara was the only woman who knew how much she earned. The Senate Inquiry into Poverty and Financial Hardship has argued that “poverty is disability’s close companion” (Community Affairs References Committee, 2003 pp. 363). Shamefully, the income level of Australians with a disability is one of the lowest in Organisation for Economic Co-operation and Development (OECD) countries (Human Rights and Equal Opportunity Commission, 2005). In 2003, Australia was ranked 13 out of 19 countries on the employment rate of people with a disability (Sharan Burrow, 2008). Within the Asia Pacific region, women with disabilities are “on the whole desperately poor” (Foo Gaik Sim, 1999 pp. 3), due to a number of factors that include low incomes, a greater likelihood of unemployment, limited employment opportunities and additional costs due to their disability.

**Pro-rata wage system**

The Australian Government commissioned the Ronalds Report – *National Employment Initiatives for People With A Disability* in 1990. Chris Ronalds (1991) examined a range of employment issues for people with a disability. Her report identified the major barriers preventing people with a disability from entering the open labour market. These included: type of position and job design; training and on-going support; and income support. The report
recommended that in order to facilitate the creation of job opportunities for people with a disability in the open labour market, a pro-rata wage system that provided for the payment of fair and equitable wages based on the skills and productive capacities of a person should be developed, monitored and regulated.

This report led to the development of a Supported Wage System (SWR) in 1994. The SWR model includes a set of guidelines for a transparent and reliable process to determine the percentage of an award rate that should be paid to workers who have a disability who work in the open employment market. It was not until 2004, however, that a pro-rata wage system, the Business Services Wage Assessment Tool or BSWAT, was introduced. This system was phased in over the next four years by the then Howard Government for people with a disability employed in the business services sector. At the same time, the Federal government funding model changed from block grant funding to case-based funding (Health Outcomes International Pty Ltd, 2001b).

While many business service organisations did have wage assessment processes in place prior to BSWAT, many operated without a formal process. The processes often did not comply with the new policy initiatives or provide a fair wage outcome for employees who had a disability. In some instances, wage assessment processes were used to lower wages in order to maintain an organisation’s financial viability (Health Outcomes International Pty Ltd, 2001b).

Business service organisations are unique in that they operate using a combination of government funding and commercial income (Australian Chamber of Commerce and Industry, 2006). Traditionally, business services were run as an incorporated charitable, not-for-profit organisation that operated outside of the formal industrial relations system. Being seen more as a community service than a business enterprise, however, enabled many of these organisations to pay their employees with a disability substantially below award wages and conditions (Health Outcomes International Pty Ltd, 2001b). This highlights a clash of two very different set of ideals that many business service
organisations now have to manage. Firstly, a ‘profitable business enterprise’ due to a government emphasis on economic rationalist and competitive principles. Secondly, a ‘disability service organisation’ centred on an institutional framework that is historically grounded in notions of welfare and providing for the needy and disadvantaged.

Arguments used against a pro-rata system included the “financial fragility of many business services, the vulnerability of the employees and the significant social role that business services play in the lives of people with a disability, their parents and carers” (DEEWR, 2006 pp. 351). In 2006, it was estimated that around 17,500 people with a disability were employed by 224 business service organisations operating from approximately 380 locations across Australia (DEEWR, 2006). Prior to linking a condition of funding to meeting quality assurance standards in 2004, Shirley, Cindy and Evie only had to be paid $62.00 per week for working 28 hours. This amount of money was equal to the income threshold a person with a disability could earn before their disability pension began to be reduced at a rate of $0.40 in the dollar for every dollar they earned above the threshold. By December 2008, all Disability Employment Services were required to be certified as meeting the revised Disability Service Standards as per the Disability Services Act (1986). This revised set of standards was introduced in part by the government to regulate the way people with a disability working in business services were renumerated. ‘Standard 9’ relates to employment conditions and requires the payment of wages to employees with disabilities be based on an award, order or industrial agreement.

How the pro-rata wage system works
People with a disability who are unable to work at a “full productive capacity” because of their disability, have their rate of pay calculated according to a wage assessment tool (FACS, 2004a pp. 1). Every employee working in the business services sector is independently assessed using a wage assessment tool to measure their productivity and competency. For example, Cindy would have her productivity measured against an established benchmark for each task she performs, such as folding handkerchiefs and putting them into a packet. A person performing the same task who does not have a disability usually sets a
productivity benchmark. Cindy’s competency would also be measured against a set criteria such as knowledge, understanding and skills. Her pro-rata rate of pay is then based on the outcome of her productivity and competency assessments.

At June 2007, the vast majority of people working in supported employment services were earning $100 or less per week. For people with an intellectual disability the median gross weekly earning was $71.00 (FaHCSIA, 2007). This works out to approximately $2.60 per hour or 20% of the minimum hourly wage of $13.74 as set by the Australian Fair Pay Commission (2007) for people with a disability working in business services. It may appear that there is little difference between paying people the disability pension income threshold of $64.00 and the pro-rata wage of $71.00; however, being paid under an industrial award ensures that people working in business services have the same wage conditions as the general workforce (Jenny Pearson & Associates Pty Ltd, 2007). For Shirley and Evie, who have worked in their current employment for over 10 years, working under award conditions now entitles them to long service leave.

There are two major criticisms of the pro-rata wage system. The first is that unlike the situation in open employment where there is one wage assessment tool, SWR, the business service sector has no single assessment tool that must be used. This has created inconsistencies across the sector so that people doing similar tasks in different organisations can be paid different wages depending on the assessment tool used (Health Outcomes International Pty Ltd, 2001b).

The other criticism relates to the payment of superannuation. In Australia, employers are required to pay a 9% superannuation guarantee levy for all employees who earn above $450.00 per month, unless otherwise stated in an industrial award (ATO, 2007). Based on the median gross earning of $71.00 per week, people with an intellectual disability have a gross monthly income of $308.00. This amount falls below the superannuation minimum income levy
threshold. Upon retirement, unlike intellectually-abled workers, a large majority of people with an intellectual disability will have to rely solely on the aged pension to fund their retirement.

Advocacy groups have argued that based on the limited earning capacity for most people with an intellectual disability, the $450.00 minimum monthly threshold for superannuation should be waived. Although medical advancements have increased the lifespan of many people with an intellectual disability, for some particular disabilities, such as Down’s Syndrome where a person ages more rapidly, access to superannuation should be upon retirement, rather than the general age of 65. Current assessment tools have also been criticised for being embedded within Anglo-English concepts and values (National Ethnic Disability Alliance, 2001), and for not taking into consideration a person’s ethnicity, culture and ability to speak and understand English.

The participants’ estimated income
It is not until you start to break down each woman’s level of income that you realise how little the women in this study actually earn. For Shirley, who lives at home, her income is under the poverty line at approximately $281.04 per week (see table 5). Currently the poverty line in Australia is $400.68 per week for a single person with no dependants working 28 hours per week (Melbourne Institute of Applied Economic and Social Research, 2008). Of all the women, however, Shirley has the most disposable income, as she lives at home with her parents.

Although Cindy and Evie also work in business services and perform similar manual labour tasks to Shirley, their incomes are higher. This is because they receive additional government allowances as they live in supported accommodation and travel to and from work by taxi. In addition to the basic pension they receive a mobility and rental allowance that increases their weekly income to around $362.28 per week (see Table 7). Out of their income they have to pay all their day-to-day living costs.
Table 6 - Estimated Income Calculations 2009 – Shirley

<table>
<thead>
<tr>
<th></th>
<th>Shirley Living at Home &amp; Business Services</th>
<th>Fortnight</th>
<th>Quarter</th>
<th>Week</th>
<th>Annual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability Support Pension</td>
<td>$569.80</td>
<td>$284.90</td>
<td>$14,814.80</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telephone - 3 person household</td>
<td>$7.67</td>
<td>$0.59</td>
<td>$30.67</td>
<td>$14,845.47</td>
<td></td>
</tr>
<tr>
<td>Wages Earned</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wage Payments $14.31p/hr 28hrs</td>
<td>$400.68</td>
<td>$20,835.36</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less Pro-rata wage assessment 80%</td>
<td>-$320.54</td>
<td>-$16,668.29</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gross Wage Earned per week</td>
<td>$80.14</td>
<td>$4,167.07</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income Tax</td>
<td>-$0.00</td>
<td>-$0.00</td>
<td>-$0.00</td>
<td>-$0.00</td>
<td></td>
</tr>
<tr>
<td>Net Wage Earned per week</td>
<td>$187.34</td>
<td>$4,167.07</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less Pension Reduction</td>
<td>-$4.45</td>
<td>-$231.63</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Estimated Net Income per week</td>
<td></td>
<td>$281.04</td>
<td>$18,267.27</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Cindy and Evie live in supported accommodation that is run by a not-for-profit disability service that is funded through the Department of Aging, Disability and Home Care (DADHC). Their actual cost of accommodation is unknown however for people living in DADHC supported accommodation the “basic residency fee charged is 75% of the full Commonwealth Disability Support Pension and Rent Assistance less the Pharmaceutical Allowance” (DADHC, 2005c pp. 6). This fee is a contribution to the cost of board and lodgings. Other costs include the use of DADHC transport and the use of DADHC aids or appliances that enhance independence and improve functioning. Because of the strict nature of regulation, policy and funding guidelines, it can be assumed that the costs would be similar to the 75% fee charged by DADHC. Based on the figures outlined in Table 7 this would leave Cindy and Evie around $147.59 per week, or $21.00 per day, to purchase any personal items they require such as clothes, social events or gifts.

33 This income was estimated through government payment publications available on the internet and in conjunction with consultation with customer service officers from Centrelink and the NSW Department of Housing.
The women in open employment, Kay and Lara, have a greater capacity to earn a better income than the women in business services. While Kay rented a unit through the Department of Housing, Lara rented a house in the private rental market. According to Australian Property Monitors, the average house rental in Sydney as at the March 2007 quarter was approximately $380.00 per week (Bridget Carter, 2007). In checking with local Real Estate Agents in the suburb where Lara lived, the rent for a three bedroom, single garage and one bathroom home was anywhere between $360 and $420 per week in rent. Taking the median rate of $390, and assuming that Lara and her partner split the rental payment, this leaves Lara around $340.00 per week, or $48.00 per day for all her day to day living costs (see Table 8 next page).

Because all these women are on a DSP, they are eligible for public housing in NSW. As of June 2006 there were 186,934 applicants Australia-wide on the waiting list, 58,172 or around 1/3 of whom were from NSW. (AIHW, 2006b). Unless there is an urgent requirement, a person with a disability is not automatically eligible for priority housing, and has to wait his/her turn on the list.

Table 7 - Estimated Income Calculations 2009 – Evie and Cindy

<table>
<thead>
<tr>
<th>Cindy &amp; Evie</th>
<th>Fortnight</th>
<th>Quarter</th>
<th>Week</th>
<th>Annual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living Supported Accommodation &amp; Business Services</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disability Support Pension</td>
<td>$569.80</td>
<td>$284.90</td>
<td>$14,814.80</td>
<td></td>
</tr>
<tr>
<td>Rental Assistance Single Share</td>
<td>$74.13</td>
<td>$37.07</td>
<td>$1,927.38</td>
<td></td>
</tr>
<tr>
<td>Mobility Allowance:-Taxi to work</td>
<td>$79.30</td>
<td>$39.65</td>
<td>$2,061.80</td>
<td></td>
</tr>
<tr>
<td>Telephone – 2 person household</td>
<td>$11.50</td>
<td>$0.66</td>
<td>$34.50</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>$362.28</strong></td>
<td><strong>$18,838.48</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Wages Earned**

<table>
<thead>
<tr>
<th></th>
<th>Fortnight</th>
<th>Quarter</th>
<th>Week</th>
<th>Annual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wage Payments</td>
<td>$14.31p/hr 28hrs</td>
<td>$400.68</td>
<td>$20,835.36</td>
<td></td>
</tr>
<tr>
<td>Less Pro-rata wage Assessment 80%</td>
<td>-$320.54</td>
<td>-$16,668.29</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gross Wage Earned per week</td>
<td>$80.14</td>
<td>$4,167.07</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income Tax</td>
<td>-$0.00</td>
<td>-$0.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Net Wage Earned per week</td>
<td>$80.14</td>
<td>$4,167.07</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Less Pension Reduction**

<table>
<thead>
<tr>
<th>Reduction of Pension by $0.40 above $69 threshold</th>
<th>Fortnight</th>
<th>Quarter</th>
<th>Week</th>
<th>Annual</th>
</tr>
</thead>
<tbody>
<tr>
<td>-$4.45</td>
<td>-$231.67</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Estimated Net Income per week**

<table>
<thead>
<tr>
<th></th>
<th>Fortnight</th>
<th>Quarter</th>
<th>Week</th>
<th>Annual</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>$437.96</strong></td>
<td><strong>$22,773.92</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The wait at present is longer than twelve months\(^{34}\) depending on a person’s assessment. If a person meets certain requirements and relies on a DSP as his/her main source of income, the NSW Department of Housing may provide him/her with a ‘Special Assistance Subsidy – Disability’ (SAS-D), while he/she are on the housing list. This subsidy entitles a person to access private rental accommodation and pay the “same amount of rent as they would if living in a home owned by the Department” (NSW Department of Housing, 2006). The tenant pays their portion of rent to the Department of Housing, who in turn pays the full rental to the landlord.

| Table 8 - Estimated Income Calculations 2009 – Lara |
|-----------------|-------|-------|-------|-------|
| Independent Living & Open Employment               | Fortnight | Quarter | Week | Annual |
| Disability Support Pension                          | $569.80  | $284.90 | $14,814.80 |
| Pensioner Education Supplement                      | $62.40   | $31.20  | $1,622.40 |
| Rental Assistance Single no dependents              | $74.13   | $37.07  | $1,927.38 |
| Telephone                                            | $23.00   | $1.77   | $92.00 |
| Reduction in pension $0.40 per $ over $69p/wk       |          |         |       | $92.60  | $4,815.41 |
| Wage Payments $14.31p/hr 21hrs                      |          |         |       | $300.51 | $15,626.52 |
| Income Tax                                           |          |         |       | -$28.00 | -$1,456.00 |
| **Estimated wages earned**                          |          |         |       | $534.84 | $27,811.69 |

As at October 2008, people on a DSP are required to contribute 25% of their gross income towards payment of rent plus the full Commonwealth Government rental assistance (Housing NSW, 2008a). Renting a home through the Department of Housing would provide a significant saving for Lara, providing that she was able to find a landlord or real estate agent who was willing to have a person on a DSP rent their accommodation. Even though a DSP is a stable income, research in Tasmania has found that landlords have expressed concerns that people with disabilities will be unable to pay the rent or maintain

\(^{34}\) How long a person has to wait is not documented. The Staff at the NSW Department of Housing call centre were not able to advise me as to how long the wait would be, just that unless it was urgent it would be more than twelve months. Some estimates have been reported as long as 5 years.
the property (Teresa Hinton, 2006). It has become evident that there are very few options available for many people with a disability who live on a low income. In Sydney, there is a lack of low-cost rental accommodation that is close to the public transport, amenities and essential services that an individual may need to live independently. Having to relocate to suburbs where the rent is lower may also mean moving away from their family, friends and social networks that can lead to isolation.

*Shirley* is the only woman to have an income below the Henderson Poverty Line of $415.06 per week (Melbourne Institute of Applied Economic and Social Research, 2008). All the women earn below the minimum wage of $543.78 as set by the Fair Pay Commission in October 2008 (AFPC, 2008). This makes them among Australia’s working poor, and rather than promoting feminist ideals of women’s financial independence, the consequence is that having to rely on a DSP as their main source of income these women have little chance of becoming financially independent.

The ‘dependency trap’ is one of the greatest obstacles Vashti Gosling and Lesley Cotterill (2000) found, in the UK, for adults with an intellectual disability to move to full time employment. In Canada, a group of people with an intellectual disability who moved to a co-operative corporation rather than staying in business services had a similar experience. Even though the move was seen as successful as “all workers doubled to tripled their previous productivity rates”, none of the workers earned enough money to move off government welfare benefits (A. McWhoter, 1998 pp. 11).

The flow-on effect is that the daily lives of people with a disability become more regulated through a myriad of federal and state laws (Lisa Schur, Todd Shields and Kay Schriner, 2003). For example, any changes in a person’s income or living arrangements has to be provided to the New South Wales State Government in relation to rental assistance, health concession cards and public housing, and to the Federal Government for assessing a DSP fortnightly payment. Failure to notify may result in large fines, commencement of legal
proceedings for fraud, debt recovery for any overpayment and suspension of payments.

Table 9 - Estimated Income Calculations 2009 – Kay

<table>
<thead>
<tr>
<th></th>
<th>Fortnight</th>
<th>Quarter</th>
<th>Week</th>
<th>Annual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independent Living &amp; Open Employment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disability Support Pension</td>
<td>$569.80</td>
<td></td>
<td>$284.90</td>
<td>$14,814.80</td>
</tr>
<tr>
<td>Pensioner Education Supplement</td>
<td>$62.40</td>
<td></td>
<td>$31.20</td>
<td>$1,622.40</td>
</tr>
<tr>
<td>Rental Assistance Single no dependents</td>
<td>$74.13</td>
<td></td>
<td>$37.07</td>
<td>$1,927.38</td>
</tr>
<tr>
<td>Telephone</td>
<td>$23.00</td>
<td></td>
<td>$1.77</td>
<td>$92.00</td>
</tr>
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<td></td>
<td></td>
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</tr>
<tr>
<td>Reduction in pension $0.40 per $ over $69p/wk</td>
<td></td>
<td></td>
<td>-$92.60</td>
<td>-$4,815.41</td>
</tr>
<tr>
<td>Wage Payments $14.31p/hr 21hrs</td>
<td></td>
<td></td>
<td>$300.51</td>
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<tr>
<td>Income Tax</td>
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<tr>
<td><strong>Estimated wages earned</strong></td>
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<td></td>
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<tr>
<td><strong>$534.84</strong></td>
<td></td>
<td></td>
<td>$27,811.69</td>
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</tr>
</tbody>
</table>

Working in open employment places Kay in a much better position to increase her income, make choices and be more involved in community life. It should be noted that even though Kay works in open employment, she is a recipient of the DSP. After discussions with Customer Service Officers at Centrelink (Personal Communication, May 15, 2007) and the NSW Department of Housing (Personal Communication, May 15, 2007), I estimated Kay’s gross income and pension payments as of December 2008 would be around $535.00 per week. As per the detailed breakdown in the table 9.

The Federal Government has set an Income Test that allows for a single pensioner to earn $138.00 per fortnight before their pension is then reduced by 40 cents for every dollar earned (Centrelink, 2006d). For every dollar Kay earns above $69.00 per week, her DSP is reduced by $0.40. When the Income Test of $69.00 per week is deducted from Kay’s gross weekly wage of $300.51, the balance is $231.51. This amount is then multiplied by 40 cents for every dollar earned, meaning that $92.60 or about 32% of her pension is deducted from her DSP. When personal income tax is also deducted two questions are raised: why stay on a pension? And why work?
WHY STAY ON A DISABILITY SUPPORT PENSION?

The primary reason for the women being caught in the welfare bind is two-fold. A very real fear is that if they stop receiving the DSP they will not be able to get the DSP reinstated if their circumstances change. There is a safety net provision in that if the women were to be employed over 30 hours per week their DSP could be held in suspension for up to two years and be immediately reinstated without review if their hours were reduced below 30 per week in the first two years of employment (see Section 96 (1) of the Social Security (Administration) Act (1999)). Even though all the women were long-term employees none of them had worked or been offered full-time positions so what appears to be a generous policy provision, is in reality unlikely to be taken up. In Australia, if you have a disability you are more likely to be employed part-time, making this provision redundant (ABS, 2003).

During the fieldwork, Lara’s DSP came up for a medical review. Like all the women in this study, her DSP is reviewed every five years, as her disability is unlikely to improve (see Section 6.2.5.10 DSP of the Social Security Act (1991)). Lara, who is normally self-assured, became quite fearful and very apprehensive that her DSP would not be renewed. She was living some distance from the doctor who had initially diagnosed her as having an intellectual disability, and being in good health, she had not seen any doctor on a regular basis for a number of years. This made Lara concerned that a new doctor who did not know her and performed her medical review may not consider her to have an intellectual disability.

Even though Lara was highly skilled in the disability sector as an advocate, Disability Standard auditor, and trainer she was unsure she would be able to find full-time employment that would provide her with the higher level of income she needed to live on without the allowances that are provided with a DSP. Working a full 38 hour week and earning $14.31 per hour, Kay and Lara’s gross wages would be $543.78. This is $8.94 more than they currently earn for working 21 hours per week and receiving a DSP. This is a no-win situation for people like Kay and Lara, as it leaves them open to exploitation by employers.
who are able to offer DSP recipients low-paid, part-time work. For the people themselves, their capacity to earn is restricted, as they are unable to find full-time work where they can earn an independent income sufficient for them to live. In short, they become locked into relying on a DSP as their primary source of income, because of the benefits that come with the pension. For Kay and Lara working full-time in open employment would mean that they would not be entitled to a Disability Support Pension.

In addition to a public housing subsidy, Kay relies on DSP allowances such as the education, health care and travel concessions that support her to live independently:

*Everywhere I go I have to take public transport. I would have to pay so much more without the pass. Kay*

If Kay was working full-time she would no longer be eligible for a travel concession card. This card allows Kay to travel anywhere in Sydney for $2.50 a day. In a typical week, Kay would travel by train to attend the Young Woman’s Project, to visit her mother on the weekend, to study at the local TAFE College. The total full fare cost of these trips is $21.60 per week. Having a travel concession card saves Kay $14.10 per week (CityRail, 2009). This is a substantial saving per week. The women in this study relied on some form of public transport to go to work, study and/or visit family and friends. Without a travel concession card they would experience greater restrictions on their lives.

The loss of a Health Care Concession Card would place further financial burden on Kay and Lara if they worked full-time. The income threshold for a single person with no dependents is $450.00 per week. Moving to full-time employment and no longer being a recipient of a DSP, Kay and Lara would earn above this threshold. Any pharmaceutical prescriptions they require would now cost $32.90 rather than the $5.30 they currently pay (Medicare Australia, 2009).

The Human Rights and Equal Opportunity Commission (2005) *WORKability II* report highlighted that the “simultaneous loss of income support, health concessions
and transport concessions can have a devastating impact on people with disability who enter the workplace. This financial impact can be a strong disincentive to people with disability to seek employment” (pp. 58-60). This statement should have also included public housing and rent subsidies. Although one of the report’s recommendations to decrease the barriers for people with a disability to work was to maintain Health Care Cards and increase mobility allowances, the Australian Government has failed to take up the initiative.

**Why Work?**

Kay, Shirley, Cindy, Evie and Lara had very clear opinions on the reasons why they worked and its benefits. Research has found that people with an intellectual disability have reasons for seeking and valuing work and wages similar to most people in the community (Vashti Gosling and Lesley Cotterill, 2000; Anne Bray, 2003). For most of the women, the primary benefit to working was earning money to cover their day-to-day living costs (Michele Di Terlizzi, 1997):

> You work to get money. If you don’t have any how can you live?  
> Kay

While most of the women did not have direct access to their income, they had clear ideas on how they liked to spend it. Mainly they talked about using their savings to buy personal items such as music, clothes, shoes, lipstick, getting their hair cut and coloured or going out. They also enjoyed shopping, and selecting and buying gifts for relatives and friends:

> My thing is clothes. I love to go clothes shopping. Evie

Some saved or used lay-by for purchasing large items such as jewellery, holidays, Christmas presents or household items:

> I like to buy jewellery. At the moment I have a green emerald and diamond ring on lay-by. I pay a small amount off each payday.  
> Lara
Other reasons they worked were to provide a routine and rhythm in their lives, and to meet some of their social needs. Work also had an impact on their identity and their self esteem. Meeting people and interacting with co-workers was another important reason for going to work (David Robinson and Tricia Fitzgerald, 2001).

**Career Aspirations**

Light manual work, such as the packing of products into boxes or plastic bags in Shirley and Evie’s stories, has been the historical basis of employment for many people with intellectual disabilities (Brenda Smith, 1996). In Australia, sheltered workshops were traditionally set up by parents in the 1950s to provide employment, social contact and care for their children who had a disability. When Evie and Shirley started working in the 1970s there would have been little or no choice other than to work in Sheltered Workshops. The introduction of the Disability Services Act (1986) provided a framework for funding and support services, so that people with a disability achieved equal opportunities and conditions for employment and training. To realise this goal, people with a disability would be required to move out of the segregated environment of a sheltered workshop and/or institution and into the community.

After 1986, those sheltered workshops that remained open moved to a business services model to become competitive in the market place (Health Outcomes International Pty Ltd, 2001a) and provide employment support for people with medium to high levels of disability. Support is provided through training, career planning and counselling. Although one of the charters for this sector is to improve the quality of life for people with disabilities, “the majority of its senior staff are able-bodied people” (Roland Hurst cited in Colin Barnes, 1991 pp. 67). This finding would appear to be reflected in this study as none of the women could ever remember an immediate supervisor or manager having a physical or intellectual disability. Although Lara had become a state delegate for the Miscellaneous Workers Union while working in business services, she was never given the opportunity for advancement from the workshop floor to become a supervisor:
I would really like to be a supervisor. I think I would be good at it…
It is really important for people with an intellectual disability to have role models. Lara

Overall the women liked the people they worked with and were happy, even though Shirley and Evie found the work boring. Under-employment for people with disabilities is a serious issue (Colin Barnes, 1992). Work often lacks stimulation and fails to reflect an employee’s aptitude or interests with little interface between work and personal fulfilment (Lisa Schur, et al., 2003). As with Cindy, Shirley and Evie, many people with a disability are placed in employment rather than being offered work options (Michele Di Terlizzi, 1997):

When I moved here… this is the job that they gave me to do.
Cindy

Cindy enjoys speaking with people and so is often in trouble where she works:

I’m always in trouble for talking but it’s the only time I get to see my friends. Cindy

Talking is discouraged, unless it is about work, and having a gregarious personality, Cindy is genuinely interested in people. She has a flair for colour and style and “a passion for fashion”. This raises questions as to why she isn’t working in an area that reflects or compliments her interests and personality. With supported training there is no reason that Cindy could not be working, for example, in a Boutique or Department Store. Cindy would be able to perform many of the necessary skills such as speaking with customers, sorting, folding clothes, stocking racks and with support and training there is no reason that she would not be able to use a cash register.

Evie’s dream to work with children has remained unrealised for some time. While Evie’s disability may prevent her from working in a school as a teacher’s aid, there are other alternatives that may fulfil this dream such as joining a voluntary organisation like the Girl Guides. Evie is able to read and write, so it
raises the question as to why she has not been given the option of going to TAFE to gain training to fulfil her career aspirations.

One of the functions of business services is to support their employees to learn skills that will help them move into the open employment market, although this does not appear to be monitored in Australia. Concerns have been raised since the 1970s that working in business services hardly ever leads to work in open employment (Anne Bray, 2003). A 2001 US survey of sheltered workshops found that nearly 60% of the people with an intellectual disability working in sheltered workshops could have been working in open employment (Marjorie Olney and Joe Kennedy, 2001). The push to become commercially viable has resulted in managers and supervisors often being “reluctant to lose their ‘best’ workers” (Mark Hyde, 1998 pp. 209), resulting in many people with a disability being discouraged from moving elsewhere (Colin Barnes, 1991). The lack of work opportunities further ensures that many people with a disability who could, with support, be employed in open employment are locked into working in business services.

Although not expressed by the women in this research, other studies have found that some people in business services have no desire to move into open employment. In these studies, participants voiced concerns about the possibility of experiencing discrimination, and appreciated the relative job security and low stress levels that comes with working in business services and supported employment (Mark Hyde 1998; David Robinson and Tricia Fitzgerald 2001; Anne Bray 2003).

Lara and Kay both heard of their current position in open employment through word of mouth. It should be acknowledged that they both work for disability advocacy agencies, and so in terms of this research, the findings many not be reflective of other people working in open employment. Being actively involved in the community outside of their workplace helped these two women move from business services to open employment and find more satisfying work. Kay
was involved with the advocacy agency that she now works for, as a volunteer in a program that spoke to people in the community about having a disability:

*We went to different places to talk to people about our community work. We use the voice; it is the main thing, the voices. It is the voice. I tell them about our organisation. My part of intellectual disability, you know, how I feel. They find someone with a disability and go up and talk. They go to training … for community voices. They tell me how to talk that’s how I started and then I go to different organisations and talk. I’ve been to schools, uni and different associations like the Chinese Association. Kay*

It was through doing community speaking and being involved with the advocacy organisation as a volunteer that Kay heard about the position of an Administration Assistant, for which she applied and was successful. Just after Kay started at her new position, she used the services of another self-advocacy office to support her in constructing a plan so she could move closer to her work, study at TAFE and live independently:

*I had to leave that place. It was horrible. So boring, just putting things in bags every day. I would go mad if I had to stay there. It was hard, I was a good worker so they didn’t want me to go. Kay*

Kay’s manager expects that Kay is able to fulfil a number of specified tasks to meet the requirements of her current job description. These include petty cash, answering the telephone, filling in her time sheets and sometimes getting the lunches. Part of Kay’s disability impacts upon her capacity to process numbers. Apart from general maths skills, Kay has difficulties in remembering telephone numbers and street addresses. To overcome some of the difficulties that Kay experiences with learning new tasks, particularly those with a maths component, Kay is supported by her manager and together they work on an action plan:

*If you told me to do this say something new. I ask to have a meeting with the trainer... and we break the tasks down into steps and write down the steps. When you told me to do something I have it step by step. Not just say ‘oh here you go’. I can’t so I need to have steps that tell me how to do it”. Kay*
Kay plays an active role in the development of her career and at the time of the interview had just completed her annual review. This review included career planning, training, performance based on her job description, strengths and weaknesses, and any issues and concerns that Kay had. Together, Kay and her supervisor went through the previous year’s review and discussed what she had achieved, areas she was currently working on and any items that had not been addressed. Together they discussed and set new challenges for the next twelve months. The conversation was documented and Kay was given a copy for her records. It was this plan that Kay was referring to in the story she told about her work.

Kay keeps a folder in her desk of all the task instructions and when she is required to do a certain job, if necessary, Kay can look back over her notes. This builds Kay’s confidence and autonomy and allows her to work independently.

**Self-determination**

There is a marked difference between the women who worked in business services and those in open employment in their level of self-determination, empowerment and career aspirations. This may have something to do with the level of expectation of the different sectors the women work in. Kay manages her working day and makes decisions about what jobs need to begin or be completed that day. These tasks range from picking up the mail to organising the catering and equipment for board meetings or functions. Kay uses a computer diary as a tool to list, prioritise and forward plan any tasks that she is required to complete, and therefore the intervention from Kay’s superior on a daily basis is minimal. It would appear from discussion with Kay that she is actively involved in staff meetings and is treated as part of a team. If Kay is unable to get through her workload and has any difficulties in prioritising work, she speaks with her supervisor.

Feminists have argued that this style of management is empowering as it fosters ‘power with’ relationships in the workplace through promoting problem-
solving, and personal power. This type of relationship is egalitarian and is characterised by respect for and valuing of others. Kay felt she was a valued member of staff and was proud of the new skills she had learnt and the challenges the job presented her with.

Kay’s working environment reinforces many of the goals of self-determination, as it supports Kay to evaluate her skills, recognise her limits, set and attain goals, accept responsibility, communicate her preferences and needs and monitor and evaluate her progress (Mark Kilsby and Stephen Beyer, 2002). This has a flow-on effect into other areas of her life where Kay has to make choices and decisions such as what elective subjects to take at TAFE.

Both Shirley and Evie’s stories about their working days highlight a power structure where they have little control, input or decision-making opportunities. This type of structure cultivates an environment of dependency, and learned helplessness, and promotes a lack of autonomy (Mark Kilsby and Stephen Beyer, 2002). Relationships of this style “form a social power base in domination and are characterized by hierarchy and inequality in relationships” (Jeanne Neath and Kay Schriner, 1998 pp. 221). Shirley and Evie’s days begin with them sitting down at a work table waiting to be given work, and is rigidly structured from then on. In the confines of working in a production line, there is little room for autonomy.

Cindy and Evie’s workplaces appear to have strict monitored controls. Some of the inflexible controls relate to occupational health and safety, while others relate to productivity, such as not being allowed to speak.

Apart from her dream of working with children, Evie had expressed a desire to people in her workplace and her accommodation provider to change jobs:

I told my supervisor I wanted to leave. That was a while ago. Evie

Evie’s lack of autonomy is one reason that she has stayed locked into working in business services. There are a number of self-advocacy support groups that would be able to help Evie realise her dreams. Evie has very little control over
many parts of her life. The accommodation agency is aware of her desire to change jobs and there have been no steps taken to support her in changing her career.

**Training**

In relation to workplace training, it would appear from discussions with all the women who have previously, or are currently working in business services, that opportunities for updating or enhancing their working skills are limited:

> I don’t remember talking to anyone about what I wanted to do… If a new job came in the supervisor would show us what to do. Shirley

> The supervisor shows us what to do, like how to fold a hanky the right way. Cindy

Both *Evie* and *Shirley* had experienced long periods of time where there was no work. Over the twelve week period of the field work, there had been no work at the company where *Evie* was employed. This would appear to be a common occurrence, as both *Lara* and *Kay* had also experienced periods of no work when they were employed in business services. Rather than using these long periods of down time as an opportunity to teach new skills to enable the women to progress into open employment, the time was spent either reading books or watching daytime television.

People with an intellectual disability, with support, are able to learn new skills. Research has found that people with "severe intellectual disabilities are able to learn quite complex tasks" (Anne Bray, 2003 pp. 1). The training that *Shirley* could remember was provided by Centacare in the form of home cooking and money counting skills. A number of these life skills courses had been organised through *Shirley*'s parents, and not her employer. These courses were important to *Shirley* in building her esteem and independence. *Shirley* has a love of food, and sharing a meal with friends and family is important to her. She appreciates the time and effort it takes to prepare a meal, and being able to cook for other people gives her great pleasure.
Shirley’s self-confidence in preparing meals, making shopping lists and caring for herself has enabled her parents to go away for short periods of time, leaving Shirley at home by herself. Without these skills, it would be difficult for her parents to go away without a great deal of organisation, as only one of Shirley’s siblings lives in Sydney and finding short-term care is difficult. The result of Shirley’s increased independence and confidence has a positive flow-on effect for her parents and siblings, as Shirley is not totally dependent upon anyone for her day-to-day needs. This gives her parents time out to live their own lives and reduces their responsibility in being Shirley’s primary carers.

Another course provided through Centacare’s Access Community Team is ‘Money Skills’ (Personal Communication, May 15, 2007). This course is one-to-one training, with someone coming to Shirley’s home to help her learn how to manage her money. The course included budgeting, how to use an automatic teller machine, as well as money skills. The program is taught in a number of stages based upon a person’s individual needs. They run for a long period of time and the exercises are designed to be repeatedly practiced to reinforce the skill and then transfer that to a number of different situations. At present, Shirley is working on identifying different money denominations, counting coins and notes and making change:

It’s important to know about money. How to count so you know how much to give and your change. I can buy my own cup of tea and dinner when I go out. Shirley

The life skills courses that are run by Centacare are fully funded by the New South Wales State Government’s Department of Aging, Disability and Home Care, and are provided to people with an intellectual disability at no cost. For Shirley, these courses enabled greater autonomy and control over her life, as well as improving her self-esteem. She is confident about being able to go shopping and have coffee with her friends.

Kay had previously finished a Fine Arts Diploma and was currently studying towards her Business Administration - Certificate IV at TAFE. Kay had to complete the same course requirements as people without a disability. The only
consideration that she was given a longer time to complete the course.

Similarly, Lara had completed her Training and Assessment — Certificate IV. Instead of the usual six month completion time, Lara was able to do the same course over twelve months. In addition to the lecturer at TAFE Lara and Kay both had a disability support person to discuss any issues they had, such as selecting elective subjects:

*Carmel is the special tutor, you know the consultant in TAFE. She chooses the best course for me because I have no time you see. I have to come here three days to work so I say I am worried about homework and she says this course you do the homework at TAFE.* — Kay

**Conclusion**

The women in this study have the same reasons many of us have for going to work. They have career aspirations and can clearly articulate them. They like to spend their money on people and things that are important to them: Christmas, birthday presents, music, movies, clothes, makeup, pets and holidays. These are things that create a common bond as women and as members of the community. Yet their capacity to earn a level of income that allows them to partake in that same community is limited. They live on an extremely limited income so that many of the things that I take for granted, such as meeting friends for coffee, having takeaway, buying lunch and going to the movies, have to be budgeted and planned for.

Living on an income of between $281 and $534 per week or between $40 and $76 per day in Sydney is difficult. Current state and federal government rhetoric states that people with disabilities should be integrated into the community. Yet the system that is designed to ‘empower’ people simultaneously works against them. The very nature of being locked into part-time work effectively keeps these women financially poor. If they move to full-time employment, they lose their DSP and benefits and if they earn above the gross income threshold of $515.00 per week, they may not be eligible for public housing. If they decide to work full-time and are then retrenched, leave or are dismissed after a period of two years they do not automatically go back onto the DSP but onto Newstart which has a lower level of payment and benefits.
The women employed in business services, *Shirley, Evie* and *Cindy*, work for wages of around $2.86 per hour. They work in a closed environment that allows them to be subjected to bullying from staff and/or co-workers, and where there is little chance of advancement beyond the assembly line. This may be because Australia business services is a place of transition for those people with mild to moderate disabilities. There is an expectation, however, that while working in business services people with disabilities will be provided with training and preparation for working in open employment. There is little evidence that this is happening, even through the long periods of down time.

These women want to work, and they understand the value of work. One of the fundamental principles of work is to lessen the financial dependency on partners. Conceivable however, the true partner in the lives of these women is not a man or woman, but rather the State, and working does not lessen their dependency but in many ways reinforces and strengthens it. Having to rely on a DSP keeps these women financially poor and indirectly excludes them from participating in the wider community. In no way am I advocating that there should not be a social security system however, because of employer discrimination, low community expectations and the undervaluing of the contribution these women make to society, they remain part of the working poor. Low-paid, part-time employment leaves them with little alternative other than to rely on a DSP as their major source of income.

To be 52 years old and holding onto the dream of working with children demonstrates *Evie’s* tenacity for not letting go when many of us would have given up the dream years ago. It also highlights a system that instead of empowering, has disempowered, dismissed and ignored the career aspirations of an individual it was designed to support. Most concerning is that it can still be argued that women with intellectual disabilities continue to face double disadvantage through few employment opportunities, a low level of income and high rates of poverty.
You Don't Own Me

...I don't tell you what to say
I don't tell you what to do
So, just let me be myself
That's all I ask of you

...You may have given me the breaks
Amended all my life's mistakes...
You don't own me

You may be more than just a friend
On whose assistance I depend...
You don't own me

...Well don't forget for all your power
Even in my darkest hour
You don't own me

You may be fully in control of
Every dream I'll ever hold...
You don't own me

7. YOU DON’T OWN ME — SUPPORTED ACCOMMODATION

The previous Chapter, Another Day, recounted the stories of Shirley, Evie and Kay’s daily work routines. These three stories were followed with a discussion on the women’s earning potential, why they choose to work, their career aspirations, autonomy, and training opportunities within their workplace. All the women relied on a Disability Support Pension not only as their main source of income, but also for the benefits and services that being on pension provides them, such as the Pension Concession Card. This card entitles the holder to a range of concessions such as transport, pharmaceutical benefits and telephone allowance. These concessions were crucial to the women being able to live on their limited income.

One of the most insightful findings in this study was that the women knew their rights and were able to clearly articulate them. They were aware of the right to make decisions for themselves, to work, choose where to live and to be treated with respect — not abused, shouted at, punished or hit. As the weeks went on, it became clear that while the women knew their rights some of them were seldom able to exercise their rights.

This chapter builds on the last as it moves from workplace experiences to an examination of Cindy and Evie’s experiences living in supported accommodation. The chapter also includes my observation of their daily lives. Based on my observations and the women’s stories, this research found that

35 Taken from journal notes of the conversations at the second art workshop.
there is a significant difference between the principles in the Australian Government Disability Policy and the embodied experience of Cindy and Evie. The further the women interacted with the welfare sector, the less personal freedom and life choices they had.

Document analysis
When I began to conceptualise and write this chapter I set out to look at the power dynamics within the relationship between two clients and their support workers, because they appeared to have direct control over the women’s lives. Part of this analysis included an examination of regulation including: the Commonwealth Disability Services Act (1986), NSW Disability Services Act (1993), Health Records and Information Privacy Act (2002), Guardianship Act (1987) and the Disability Discrimination Act (1992). Policy, procedures and guidelines (see Ageing and Disability Department, 1998b, 1998a, 1998d, 1998c, DADHC, 2003b, 2003a, 2004, 2005c, 2005b, 2006c, 2006b, 2006a, 2007c, 2007a, 2007b, 2008b, 2008c, 2008a, FaHCSIA, 1993, 2003, 2008a, 2008b, NSW Health, 2005) that relate to people who reside in and providers of government-owned and government-funded supported accommodation services were also examined. It was during analysing the discourse in the policy and guideline documentation that the issue of power was revealed to be far more complex than just asking: Who has control of Cindy and Evie’s lives?

Rather than just focussing on their support workers, a broader perspective had to be adopted that focussed on the discourses that shape disability legislation and supported accommodation policy and guidelines. A discourse analysis was used to analyse these documents. Rather than word order or sentence construction, I was interested in the structures of the meaning within the documents. Attention was given to the structure and social strategies embedded within the documents, and to the way discourse or its meaning were overtly or covertly positioned (Ruth Wodak and Michael Meyer, 2001, Katrina Scior, 2003).
WHEN IS A HOUSE A HOME

This is your home
But I cannot see you
Depersonalised Sanitised
   Clean, neat and tidy
No dust. Floors are shiny.
Barren walls painted white.
Television blaring late at night
Neighbours don’t speak
They look away
   you say hello every day
   Air conditioning on
   Doors & windows open
Nothing there to personalise the space
Lounge room’s such a sterile place
   Signs of living
   Is what is missing
   This turns a house into home
No picture, no photograph
Nothing personal
Black vinyl lounge
Wooden coffee table
   One person’s work place
Another person’s home
Wall charts, routine, organisation
Tv’s on while you’re waitin
   Is it a home if it means
   The place is spotlessly
   Sparkling clean?
J Welsby 2007
As I read each document, I noted down the intention of the policy, how the policy position was justified, the use of strong language to identify the policy objectives and whose interests the policy served. I also considered who the 'ideal subject' and/or 'audience' of the policy were, what was omitted or unspecified and how people with an intellectual disability were characterised. I also documented anything that occurred to me as I read through and what wording the documentation had in common.

The analysis revealed three main discourses: human rights; managerialism; and risk management. Foucaultian (1972, 1983) understanding of the multiplicity and competitive nature of discourse requires a further examination of how the power dynamic between these three dominant discourses shape the meaning of intellectual disability. This in turn highlighted how the government exercises power and control over government-funded supported accommodation providers, their employees and people who live in supported accommodation through standards, requirements, evaluation and assessment.

The reality for most people with an intellectual disability who live in government-funded supported accommodation is that opportunities to make real, meaningful choice and be autonomous are eroded. Resonating with previous research, this chapter affirms that people with an intellectual disability have less choice than people without a disability, and the level of choice more often relates to daily living decisions such as what to wear, what to watch on television, and do with their leisure time (Dawn Apgar, Sharon Cook and Paul Lerman, 1998, Roger Stancliffe, Brian Abery and John Smith, 2000, Louise Young and Adrian Ashman, 2004a, Kathy Sheppard-Jones, H. Thompson Prout and Harold Kleinert, 2005).

The first part of this chapter discusses the findings of the discourse analyses and purposely adopts the language of the policy, regulation and guideline documents. I have used the word 'client' rather than a 'person who lives in supported accommodation' or any of the participants' names to reflect the
distance between written policy and personal lives and also to reflect the impersonal, gender neutral language within the documents.

Dispersed within the first section of the chapter are three stories that focus on the lives of Cindy and Evie. These narratives are taken from their reflections on what they considered to be important to them in their lives. Layered over their stories is my own narrative drawn from my relationship with Cindy and Evie during the field work. This layering of stories is used to examine the lack of opportunity for real and meaningful choice and autonomy. These stories highlight the struggle many people with an intellectual have in obtaining “what the rest of us in the community would consider to be an ordinary life” (National People with Disabilities and Carer Council, 2009 pp. iv).

The final section of this chapter draws together the analysis and stories into a discussion of the implications of living between policy and practice. At no time am I arguing that people with an intellectual disability should not be given the support they require to live the life they choose. My purpose is to highlight the disjunction between disability policy and practices and the everyday lives of real people.

**Community Care and Independent Living**

In NSW, state-funded accommodation options for people with an intellectual disability range from large residential care centres, cluster facilities, group homes, and supported accommodation. Most people with a disability in Australia, however, do not live in specialised disability accommodation. The majority of people with a disability live with their family or in their own home (ABS, 2004). In 2006-2007, there were 37,473 users of Australian accommodation support services; of these, 30,728 or 82% had an intellectual disability (AIHW, 2008). The fact that most clients of supported accommodation are people with an intellectual disability, is thought to be partly due to historical patterns of accommodation provisions. People with an intellectual disability lived in institutions segregated from the community throughout the 20th century, while people with a physical disability, acquired brain injury or mental illness have
traditionally been cared for at home or independently with the aid of an attendant (Roger Stancliffe, 2006). The deinstitutionalisation of large-scale institutions saw the movement of people with intellectual disabilities into community accommodation, with group homes being the most common form of community living. This move into community care or rather, care by the community, had more to do with economics than egalitarian ideals (Mike Clear, 2000, Jenny Morris, 1993).

**Disability accommodation legislation in Australia**

In Australia, unlike the UK, the management of mental health institutions or asylums has always been the responsibility of the government (Cyril Cummins, 2003). In the mid 1980s, after an extensive review of services provided to people with a disability the *Commonwealth Disability Services Act (1986)* was passed in Australia (Ian Dempsey, 2006). In 1992, there was an agreement that legislation, policy-making and funding in Australia in the area of Disability would be shared between the State/Territory and Commonwealth Governments. This was a landmark event in the disability sector, as it nationalised the provision of specialist disability services across Australia, to ensure an integrated service tailored to meet individual needs. The Commonwealth, State and Territory Disability Agreement (CSTDA) 2009 is to be reviewed every five years. Under the agreement, the Commonwealth Government is responsible for the planning, policy-making and management of employment services for people with a disability. Planning, policy-making and management of accommodation support, community support, community access and respite care is the responsibility of the State and Territory Governments. Both levels of government are responsible for advocacy and print disability services\(^6\) (FaHCSIA, 2008b).

A requirement of the Disability Agreement is that all disability services should meet a minimum standard as outlined in the *Disability Services Act (1993)* and the National Standards for Disability Services (FaHCSIA, 1993). These standards, along with other monitoring systems, are meant to assure a client

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\(^6\) Print disability services produce alternative formats of printed material for people who are unable to read, hold or manipulate printed materials in standard form because of their disability. For example, Braille, large print and computer disc are produced by Print Disability Services.
that they can expect a minimum level of service when they access any disability service across Australia. All disability service providers (Government, Non-Government Organisation (NGO) and private companies) are expected to comply. Funding is conditional upon this, and failure to comply can result in sanctions or withdrawal of funding (Ian Dempsey, 2006).

Policy in relation to supported accommodation is legislated in the state of NSW under the *Disability Services Act, (1993).* The responsibility for the administration of the state disability services is the Department of Ageing, Disability and Home Care (DADHC). Founded on a clear set of principles and values, Australian disability policy and legislation is derived from international human rights declarations such as the *1975 United Nations Declarations of Rights of Disabled Persons,* and Australian Anti-Discrimination legislation. Central to the ideology underpinning the legislation is the recognition of individual capabilities, respect, dignity, choice, inclusion and participation for people with a disability and the provision of support and services to obtain a quality of life equal to that of other members of Australian society.

Within disability policy a tension exists due to the infusion of two opposing disability models: the medical model and the social model. With Australian legislation and policy reflecting elements of both models of disability, the difficulties of turning policy into practical implementation has created significant gaps (Christine Bigby, 2006) and raises three prime issues of concern.

The first issue is lack of government-funded accommodation places for people with an intellectual disability. In NSW, DADHC does not publically release data on waiting lists for accommodation services. A recent report from the Australian Institute of Health and Welfare (2007), however, estimated that there were

37 An accommodation support service, under section 7 of the *Commonwealth Disability Services Act, (1986)* provides a service to assist people with a disability to live independently in the community. This also extends to providing “personal administration, transport, mobility, transfers, personal hygiene, bathing, grooming, dressing, eating and drinking, and similar personal activities” (*Disability Services Act 1986*).
23,800 people with unmet need for accommodation and respite services in 2005. Approximately one-third of these people were living in NSW.

Secondly, as a result of under-funding, cuts have been made to vocational training and life skilling programs for clients, such as the money skills training Shirley attends each week. These life skills programs are imperative for many clients achieving and maintaining independence:

One class we did was learning to read and write for shopping. We would catch the train and walk down to the shops... Sometimes we would read a menu and order something or have a cup of tea or coffee. Other times we would write a list and go shopping but I don’t go there any more. It is finished now. Shirley

This vocational life skills training supported Shirley to learn and gain confidence in the skills necessary to shop independently, to read a menu and order a drink or meal from a café. Shirley uses these life skills when she goes out and with the ongoing addition of her money skills classes, Shirley is able to pay for and check her change these are skills that are important to her in leading an independent life.

The third issue impacts on the payment of wages offered to support workers within non-government organisations. Due to the competitive tendering process, NGOs are often only able to offer low-paid casual or part-time positions requiring little or no experience or skills compared with similar positions within government agencies (Peri O’Shea, 2009). My own one-month review of Sydney employment advertisements, from 14th January to the 14th February 2009, for accommodation support staff and social educators in the Sydney Morning Herald and on ‘Seek’, an internet employment site, confirmed the finding of Peri O’Shea’s (2009) larger study of the NGO sector. The same positions advertised within DADHC offered wages ranging from $7,500 to $12,500 higher per annum.

The difficulty in attracting staff into support positions is reflected in the lack of importance placed on trained and experienced staff in the advertised positions.
Of the twenty-seven advertisements reviewed, the two main requirements were a positive attitude toward people with an intellectual disability and a current driver licence (81%). The next criteria were good written and oral skills (58%); a first aid certificate (44%); and the ability to work in a team (41%). Less than 20% of organisations included both experience and a Certificate III in Disability, as a necessary requirement of employment, although 52% did state that an applicant had to be willing to undertake study.

Part-time and casual low-paid positions lead to high staff turnover rates. As a result, employee continuity is a problem within supported accommodation. In a report just released in Victoria, staff turnover is seen as detrimental to the quality of life for residents and clients with high support needs. The impact includes: disruption of long-term planning for clients; unmet support needs; and a lack of appropriate training of new staff members (Tim Clements and Christine Bigby, 2008b).

In addition, research suggests that staff attitudes and beliefs about disability also directly affect the emotional and physical well-being of residents (Pamela Wolfe, 1997, Marjorie Aunos and Maurice Feldman, 2002, Monica Cuskelly and Rachel Bryde, 2004, Tim Clements and Christine Bigby, 2008b). This will be discussed later in this chapter. The impact of the attitudes of direct care staff on the lives of people with a disability should not be underestimated. While there has been research in the area of staff attitudes towards the sexual expression

38 In NSW the disability sector is slowly introducing qualifications for award-based workers. The industry standard appears to be a Certificate III in Disability or Welfare from TAFE.
39 Victoria is state of Australia.
40 Australia has historically used the American Association on Mental Retardation’s (AAMR) definition to define intellectual disability. Up until 1992, based on an IQ score level, the AAMR categorised intellectual disabilities into borderline, mild, moderate, severe and profound mental retardation (Australian Institute of Health and Welfare, 2004). Influenced by the disability rights and people first movements, definitions of intellectual disability have now moved towards a person-centred approach that focuses on support needs rather than IQ. Although this language is reflected in most Australian disability regulations and policy (Tim Clements and Christine Bigby, 2008b), the deficit level classification system still remains embedded within the community, disability sector, academic writing and some government reports and policies. For example, the Australian Bureau of Statistic uses mild, moderate, severe and profound core activity limitations to define disability in its statistical analysis (ABS, 2003, 2004, 2006). A client with high support needs would be seen in the old class system as a person with severe to profound disability.
and the sexuality of people with a disability (see the list in the Introduction – Real Stories), little attention has been paid to the direct impact carers’ beliefs have on other areas of disabled people’s lives.

**Funding modules**

In Australia, like other Western countries, there has been a move by the state to transfer part of the control of the economy to the private sector:

> The theoretical assumption of neoliberalism is that the free functioning of the market forces leads to a better utilization and allocation of resources, guarantees a better satisfaction of the requirements of consumption and bigger balance of the foreign trade, and altogether produces higher economic growth and therefore development. (Linda Strum, 1998)

DADHC sees itself as the purchaser of services from non-government accommodation support providers. This places the government in a position of power, from which it is able to dictate, control and regulate the type of service provider and provision being the only purchaser of services. All accommodation providers have to pre-qualify to be part of a limited tendering process where services are invited to tender for a single contract. Pre-selection requires DADHC to assess an organisation’s financial management, governance and capability to deliver a level of service that is competitive and meets the Disability Service Agreement. The preferred tender is a consortium rather than one single provider and although small community organisations are encouraged to apply, 80% of tenders are awarded to consortiums (DADHC, 2008b).

Successful tenders are funded for an initial one-year period. During this time the organisation is again assessed, and if successful, receives funding for a further three years. Part of the funding agreement is that organisations have to report annually and conditions of funding are highly prescriptive, regulatory and subject to change in line with new legislation, regulation, policies and guidelines from the commonwealth and/or state governments (DADHC, 2006c). In a recent study by Peri O’Shea (2009) that looked at community management in the
quasi-market\textsuperscript{41}, organisations expressed concerns about the complexity of contracting systems and reported that increased bureaucratisation took time and resources away from service provision.

It has been reported that there is a direct link between the lack of choice offered to people with an intellectual disability living in small community homes, and the high degree of external regulations, requirements and policies that organisations have to adhere to in order to obtain licensing, or funding (James Conroy, 1998, Roger Stancliffe, et al., 2000). These funding conditions create a situation that enables organisations and staff to become more involved and proscriptive in the lifestyle choices and household decision-making of clients.

**Discourses at Play**

The discourses in supported accommodation policy, regulations and guidelines are historical moments in time that reflect the current attitudes and approaches to disability. As discussed in Chapter 2, discourse links power, knowledge, the modern state and the control of populations – in this instance, providers of supported accommodation and their clients. As each discourse competes for a dominant position of power, people with an intellectual are portrayed in different, sometimes opposing, ways: as people with equal rights; as clients requiring support; as vulnerable people in potential danger; as people who pose a potential danger; and as consumers with choice. The examination of federal and state government supported accommodation documentation identified three main discourses that shape and construct supported accommodation policy, regulations, guidelines and procedures. These are: human rights: managerialism; and risk.

**Rights discourse**

With the rise of the Disability Rights Movement, and since the United Nations Year of the Disabled in 1981, there has been a shift from viewing people with a disability as an *object* of charity requiring social protection, to *subjects* with

\textsuperscript{41} A quasi-market is a public sector institutional structure that is designed to reap the supposed efficiency gains of free markets, without losing the equity benefits of traditional systems of public administration and financing.
This shift in language is reflected in current state and commonwealth disability documentation. All the policies, regulations, procedures and guidelines relating to NSW government-funded supported accommodation make reference to the rights of people with a disability (see Ageing and Disability Department, 1998d, DADHC, 2005b, 2008c). Disability rights are based on the ‘moral’ right that every human has the potential to become rational and autonomous. Human potential is achieved by individuals making and developing themselves through personal interests, choices and life projects (Julie Rooke, 2003). In line with the theory of normalisation, the premise underlying the rights discourse, as the examples below demonstrate, is to integrate people with an intellectual disability into socially valued positions within mainstream everyday life (Wolf Wolfensberger, 1972):

Individual Plans enhance the client’s life through greater community participation and integration in a way that accommodates the least restrictive approach and demonstrates that the client is socially valued (DADHC, 2005b pp. 4).

Each person with a disability has the opportunity to develop and maintain skills and to participate in activities that enable him or her to achieve valued roles in the community (Disability Service Standards Working Party, 2006 pp. 8).

A rights discourse is based on the premise that it is only through formal legal rights that people with a disability will find equality, and overcome discrimination and exclusion, to take their rightful place in society. This perspective is based on a deficit focus, as it constructs all people with a disability as dependent and powerless, rather than already being a valued and contributing member of society. This discourse conveys people with a disability as requiring the aid of an advocate (usually a person who is not disabled) to realise their status (Ruth Quibell, 2004). The wording within disability policy reflects this unrealised or dependent status and rather than adopting an inclusive stance, it reinforces and sustains the belief that people who have disability are not valued members of society.

All the supported accommodation documentation reviewed had either a section or a list of rights and a reference to the Disability Services Act (1993). This Act
relates to the provision of disability services in NSW. The policy and guideline documents clearly articulate that people with a disability have rights, and usually refer to the following documents as a point of reference:

The Disability Discrimination Act (1992)
Commonwealth Disability Services Act (1986)
Universal Declaration of Human Right (1948)
National Standard for Disability Services (FaHCSIA, 1993)

The rights discourses within these documents also position people with an intellectual disability as having equal rights and requiring support to realise their full potential:

- Adults with a disability have the right to the same standards of health and medical care as other members of the community (DADHC, 2007c pp. 2).
- Each person with a disability is supported and encouraged to participate and be involved in the life of the community (Disability Service Standards Working Party, 2006 pp. 8).
- Enable people with a disability to achieve their maximum potential as members of the community (NSW Disability Services Act 1993).

The rhetoric of policy, regulation, procedures and guidelines reflects a commitment to "social justice, the eradication of social exclusion and the role of the active citizen" (Peter Handley, 2001 pp. 516). They infer that the government's political duty is to ensure its citizens with a disability are not disadvantaged by limited access to education, health, employment, accommodation and other government services (Disability Discrimination Act 1992). Adopting a social model approach, disablement is not a personal consequence, but rather a societal failure to accommodate the needs created by individual impairment. Yet disability discourse in supported accommodation documentation is a function of discrimination and distributive injustice (Carolyn Baylies, 2002) through the segregation of services and current funding models.

In Australia, without a 'bill of rights', the level of rights to which a person with a disability is supported, and protected relies on the level of fiscal benevolence
the commonwealth and each individual state government is prepared to commit to services out of its budget. The National Standards for Disability Services, which sets out the benchmarks for acceptable standards of care across Australia, suggests that these standards can be lowered in time of fiscal restraints:

It is recognised that agencies must operate within the resources available to them. It is also recognised that services are subject to external factors, for example, the current economic climate which may impact on their ability to achieve the results for consumers envisaged in the National Standards. These factors will be taken into account when monitoring the implementation of these standards (FaHCSIA, 1993 pp. 5).

Further, while a rights discourse underpins government disability policy there is a fine balance for disability support workers between respecting the rights of clients who use their services and fulfilling the responsibility of duty of care to protect people who may be seen as vulnerable. For disability service providers, the same balancing act occurs between rights discourse and complying with funding obligations that regulate and control how a service is managed and funded. Rather than inclusion and integration, there has primarily been a focus on ‘service quality’ based on economic feasibility and leading to a "compromise between what is needed and what is available" (Peter DiRita, Trevor Parmenter and Roger Stancliffe, 2008 pp. 620). It is at this point that rights discourses become subordinate to the discourse of managerialism and risk management.
Ring, Ring

I like Evie and, although she didn’t say much, she didn’t miss a trick. She was the matriarch of the group and in the art workshops she would sit, listen and watch. Occasionally I would catch her raising an eyebrow or smiling to herself at some of the conversations. Evie spoke when she felt she had something important to say. Otherwise she sat quietly listening and taking in the conversation. This was one of Evie’s many survival strategies. At times it worked against her — like being locked into a job that she hated. At other times remaining quiet meant that she was underestimated or not noticed. Being invisible and underestimated was a great survival strategy. Evie, being so quiet and unassuming, circumnavigates the system.

It is a bit chaotic at the workshop. I don’t know about Moi but I am frazzled. When Kay, Cindy, Evie, Lara and Shirley are all here together it’s hectic. But now sitting around the work table having our last afternoon tea together, a gentle, comforting quietness descends on the group, as we reflect back over the workshops. “This is the best thing that has ever happened to me!” declares Cindy.

“It’s been a lot of fun and I’ve met new friends” Shirley states as she looks around the table every one is smiling and nodding in agreement.

“Should we exchange our phone numbers so we can all keep in touch then?” Lara asks.

“Oh we can’t do that” Cindy quickly answers.

“Why?” asks Lara.

“Our carers don’t know who you are” explains Cindy.

With a somewhat confused look on her face, Kay quietly asks “Why should that matter?” Lara, Shirley, Moi and I nod in agreement. “Yes but we know you” I continued. In an effort to try to and make us understand, Cindy puts out her hands, palms up and shakes them saying “You could be anyone!”

“But we are your friends” Shirley replies as we all try to grasp why giving out a telephone number to each other is so difficult.

Cindy looks to Evie for support: “Evie?”

Evie places her mug carefully on the table “Well” she says, clasping her hands together, “our carers don’t know who you are, and unless you are family or they know who you are, we aren’t allowed to give out our phone number or address to anyone. It’s for our safety”.

“It’s a rule” Cindy asserted in a voice that left us in no doubt that there were consequences if broken.
“Well if you can’t give out your phone numbers then we won’t do it” says Lara.

When I think about it, Shirley, Evie and Cindy are the only three adults I know who don’t have a mobile phone. Using the telephone is something I take for granted. When I telephoned Evie and Cindy to arrange transport or interviews, their individual support worker would shout out or physically yank the telephone away from either Evie and Cindy and ask me who I was and why I was calling, before giving the telephone back. In addition to the rule of not being allowed to give out their telephone numbers, Evie and Cindy’s personal telephone calls were monitored and screened.

It was at my first meeting with Cindy that I came face-to-face with one of the paradoxes of having an intellectual disability. I was sitting in the lounge room of Cindy’s home with Cindy and her carer, Judy, going through the consent form. We had just been going through each point and explaining the concept or process to Cindy. Then to make sure Cindy understood, Judy would ask her to explain it back to us in Cindy’s own words. The process was long and slow, but is an important part of gaining informed consent and ensuring that the participants understand what they are agreeing to.

Reading a paragraph of the consent form, Judy stops and thinks for a few seconds, “Ok Cindy”, she says, “You can stop being a part of this research at any time. It’s voluntary. That means you don’t have to do it”.

“Ok” Cindy replies, listening intently to the conversation.

“So you can say ‘no’ to anything or say you don’t want to talk about something I might ask you. That’s Ok. Nothing will happen to you” I add.

“I can say no” Cindy nods her head indicating she understands.

“Yes. You know about how no-one can make you do anything you don’t want to do” continues Judy.

“Yes. My rights” Cindy replies.

“Yes that right. You have the right to make choices and do what you want to do in your life. So if Janette asks you to do something you don’t want to do?” asks Judy. “I don’t have to...I can say no” Cindy replies.

We had spent I suppose around 15 minutes talking about what being a voluntary participant meant. Judy had really stressed the point about rights: the
right to make your own decisions; the right to say no; no-one had the right to tell you what to do or force you to act against your will.

_Cindy_ had walked into the kitchen and had just finished popping a Sheppard's Pie into the oven. I was packing up and talking to Judy about the art workshop arrangements when _Cindy_ came back into the lounge room.

“Judy, can I call Lottie please?” _Cindy_ asks.

“No, I have to leave early tonight and if you get on the telephone you will start talking and there'll be no stopping you. It's your turn to cook dinner. So no you can't make a phone call”.

_Cindy_ said nothing as she turned and walked back into the kitchen.

The reply had been so abrupt and rude that I was really taken back. It was such a complete change to just a few minutes before when Judy had taken so much time and care in going through the consent form and explaining it in terms of _Cindy’s_ rights.
Managerialism discourses

The global shift to neoliberal doctrines views the market as the prime regulatory instrument in the public domain. Neoliberalism is comprised of two notions – 'neo' meaning new, and 'liberal' meaning free from government intervention (Sue McGregor, 2001). The privatisation and deregulation of government services such as social services, welfare, energy and transport, combined with competition, is believed to “eliminate bureaucratic red tape, increase efficiency and productivity, improve quality and reduce costs” (David Harvey, 2005 pp. 65) for its citizens, through lower taxation and cheaper commodities.

Neoliberal ideals

In Australia managerialism arose in the 1980s out of neoliberal ideals that private industry models of accountability, “efficiency, effectiveness and value for money” (Denis Saint-Martin, 2000 pp. 1) were seen as ways to improve the capital performance of the government. Rather than political, managerialism is seen as practical, rational and focused not on inputs but on measurable outcomes. Its main feature is the separation of public bureaucracies into agencies that operate on a user-pay basis, and the outsourcing of service delivery from the public sector, to the private and community sector through a competitive tendering process with specific standards and measures of performance and an emphasis on outcomes and results (Jim Chalmers and Glyn Davis, 2001, Sue McGregor, 2001).

Efficiency is constantly improved through controlling costs, measuring performance, financial transparency and accountability, controlling quality through output indicators and the reduction of staff (Christopher Pollitt and Geert Bouckaert, 2004). Managerialism discourse therefore places an emphasis on the strict management of the disability services sector to ensure better service delivery. The implementation of disability service standards reflects managerialism discourse, as specific outcomes that measure service quality are integral to securing future funding for service providers (Peter DiRita, et al., 2008), and ensuring consumer protection through industry wide-benchmarking.
Client as consumer

Having consumers purchase the services they require within the market is seen as more efficient and effective than making them dependent upon the administration of social and welfare services through bureaucratic state agencies (Hans Reinders, 2008). With a focus on a 'customer-centred' approach, citizens are portrayed as being active, knowledgeable 'clients' or 'consumers', rather than passive recipients of welfare services (Ross Fergusson and Gordon Hughes, 2000). This change in discourse is reflected in the language of the documents reviewed, and can be seen in the examples below:

Where 'consumer' is used, this refers to a person with a disability (or his/her family or carer) who receives a service from an agency funded under the Commonwealth Disability Services Act or State/Territory services funded within the scope of the Commonwealth State Disability Agreement (Disability Service Standards Working Party, 2006 pp. 2).

All clients with a disability have the right to services which optimise their health without compromising their quality of life (DADHC, 2007c pp. 2).

Free from the old bureaucratic regimes, this discourse portrays 'clients' as abled and empowered to make informed choices to meet their individual needs. Rather than the previous 'one size fits all' approach to services and policy-making, power is transferred from the bureaucracy into the community:

Each person with a disability receives a service which is designed to meet, in the least restrictive way, his or her individual needs and personal goals (Disability Service Standards Working Party, 2006 pp. 8).

Individual responsibility and obligations of citizenship under neoliberalism and managerialism are based on the belief that a person is an autonomous, independent individual (David Harvey, 2005). This has raised concerns by academics and activists as to the extent people with an intellectual disability can be adequately served through the market, because of the level of independence and social skills that neoliberalism presupposes consumers possess (Hans Reinders, 2008, Tom Shakespeare, 2006). The capacity of some clients who have an intellectual disability to make a full and free choice may be limited by their cognitive abilities and/or social experiences.
Access to information also poses problems for some clients. This research found that Cindy and Evie were neither autonomous nor independent. These two women were not allowed to catch public transport, make telephone calls either at work or at home without permission and do not have computer skills or access to a computer to search the internet. Without access to points of communication or information, how do they research the market to make independent informed choices? Another issue is that complete information is often omitted in an effort to make it easier for many clients to understand. Assuming all clients are only “capable of limited thinking and knowledge acquisition” (Simone Aspis, 1999 pp. 174) creates barriers to a client’s ability to make informed choices.

Clients are, however, more likely to be limited through little or no choice in services provided, particularly in regional or remote areas. Disability services in Australia are thought to be “chronically under-funded and under-resourced, crisis driven, struggling against a vast tide of unmet need” and “characterised as unavailable or unaffordable or of such poor quality as to be of little benefit” (National People with Disabilities and Carer Council, 2009 pp. 19) to many clients, their carers and family members. Finding and accessing support services is seen as a constant battle, with programs being built around organisation and system needs rather than the needs of individual clients.

Managerialism practices

In neoliberalism, the focus on organisational needs is reflected in the rise of a new welfare manager as an expert replacing the bureaucrat. The expertise of these managers resides chiefly in their capacity to make social welfare organisations more ‘business like’ and more “customer centred’ with the manager striving to put together and control packages of care for service users” (Ross Fergusson and Gordon Hughes, 2000 pp. 142-142). With an emphasis on constant improvement, terms such as quality service, monitoring, evaluation, maximise opportunities and best practices are commonly seen within this discourse:

These outcomes will be monitored and reported against Key Performance Indicators (DADHC, 2006a pp. 2).
This poem is taken from field notes hastily scribbled down after Evie told me the story of her soul mate after an interview. The memory is still very vivid. Evie had just stepped out of the car, she turned and told me about her loss, closed the car door and walked up the driveway and into the house. The wave of grief she felt washed over me and I just had to sit for a couple of minutes to take in what she had just told me. It was one of the most profound moments in this research and when I got home I wrote down what Evie had said and how I felt about being privy to such an intimate detail of a person’s life. Both Evie and Shirley’s depth of grief made me think about my relationship with my partner, and what my life would be like if I spoke with him one afternoon and the next morning he was dead.
He was my soul mate
and now he’s dead.

Some times things get so bad
I just have to get out
go for a walk.
I still can’t walk past his
house
or see his parents.
It’s too much.

I miss him.
Our eyes met across the room
and I just knew
he was the one.
He was the best dancer.

I go out with someone now
but it’s not the same.
He’s company.
Makes me laugh.
Helps me forget for a while.

No one can ever replace him
He was my soul mate.
(Evie 2005)
A plan developed by a manager that describes strategies to identify and assess risks, and the process employed to eliminate or manage risk (DADHC, 2007a pp. 4).

This discourse assumes that management strategies can be applied to all current problems. Any future problems and failures are juxtaposed against the control and certainty of efficient management strategies of identifying and managing known risks (Ruth Quibell, 2004). As government departments providing welfare and social services have decreased the need to check frontline agencies through close monitoring and contractual obligations has increased. Targets and key performance mechanisms are audited to determine their efficiency, effectiveness and value for money.

The need for constant monitoring is also reflected in the extensive number of guidelines and policies that relate to the micro-management of care of clients who live in supported accommodation. For example, the two-page Menstruation Chart (see Figure 48) is used to monitor and code the days a client menstruates, along with any physical, behavioural or psychological symptoms, such as abdominal pain, mood swings, or an altered interest in sex (DADHC, 2007b). The management of clients’ finances clearly outlines what constitutes personal expenditure, and includes a guideline for the number of times a client should eat fast food per week:

Eating out or bringing in ‘fast food’ is a private expense and must not be excessive (as a general guideline, this should not occur more than twice a week) (DADHC, 2005c pp. 8).

It has been stated that in managerialism, there is a need to control the environment through rules and procedures embedded in the structures of an organisation. In this way, potential or foreseeable problems can be identified, solved and managed. Risk assessment then becomes paramount in order to avoid financial loss, breaches of policy or legislation, legal liability and an organisation’s reputation. Vulnerabilities or risks are required to be identified and quantified in terms of likelihood and possible consequences. Although risk management at an organisational level is linked to managerialism, it is the
construction of risk and vulnerability of clients that has the greatest impact on their lives.

Figure 48 - DADHC Client Menstruation Chart highlights the gender neutral position of government policy and guidelines.
**Dancing Queen**

*Cindy* has two great passions in her life: food and music. She loves to dance, and although she doesn’t particularly like line dancing, she loves to be that social butterfly and catch up with her friends.

Going to a line dancing class is *Cindy’s* weekly activity that would come under social and recreational activities in her Individual Plan. A bus comes and picks *Cindy* up from her home and takes her to the offices of her accommodation service provider where the class is held. *Evie* loves to dance, that’s what first attracted her to *Alex*. Apart from being a great dancer, *Alex* is a bit of a lad and flirts with all the girls but he always has the last dance with *Evie*. “That’s the slow dance and you only dance a slow dance with someone you really like” *Evie* told me.

*Evie* prefers to go to craft classes on a Monday night. Friends are really important to *Evie* — most of her artwork included people: her nephew, her friends and her workmates. Like *Cindy*, most of her friends are her workmates or people who use the same supported accommodation provider. Neither *Cindy* nor *Evie* see their family very often, so the opportunities for social outings are confined to those operated by business service organisation where they work, or their accommodation support provider.

*Evie* loves to shop. Clothes are her passion. In order to go clothes shopping, *Evie* has to wait for a suitable time for her carer to take her, and not having access to her own money, she needs to ask her carer for the money to go shopping. Although *Evie* loves to go shopping, instead of going to the large regional shopping centres that are near to where *Evie* lives, she is taken to a small local shopping centre where her choice for purchasing presents, clothes, shoes is limited to Big W. Big W is an Australia-wide department store chain that sells a limited range of low cost goods. When asked, *Evie* said it was easier for her carer because she could take *Evie* into Big W after they did their grocery shopping.
Risk discourses
The risk management of people with an intellectual disability is Australia not new. Prior to 1811, people with intellectual disabilities were loosely supervised with minimum restraints placed upon their lives. As the NSW colony grew, so did the call for greater security of people with disabilities and mental illnesses and the first lunatic asylum in NSW opened in Castle Hill in 1811. It was not until 1872 that the first asylum for imbeciles was established in the old military barracks in Newcastle42 (Cyril Cummins, 2003). Now known as the James Fletcher Hospital, the site remains a mental health facility today. The most well-known, Sydney asylum — Callan Park Asylum — was established in 1878 and remained open until April 2008 when the last remaining patients were transferred to Concord Hospital.

In 1883, Francis Galton coined the term ‘eugenics’ to describe strategies for improving the health or racial purity of the Anglo-Saxon or Nordic races (Patrick McDonagh, 2001, Anna Stubblefield, 2007). The purpose was to eliminate the traits considered unhealthy and degenerate, and people with intellectual disabilities became defined as the major eugenic threat, as they were considered biologically inferior and unfit to breed (David Mitchell and Sharon Snyder, 2003). This was based on the idea that ‘feeble mindedness’ was hereditary. In Australia in the 1930s, as in the UK, Canada and the US, prominent doctors and academics such as professor Harvey Sutton, a leading eugenicist from the School of Public Health and Tropical Medicine at Sydney University warned about the “increase in feeble-mindedness and the possibility of its control by eugenic methods” (Jeff Goldhar, 1991 pp. 170). Although debate raged in the community, newspapers and parliament, neither the federal nor state governments passed legislation to support the proposal of enforced sterilisation, as occurred in the US and UK. Instead, the risk was controlled through ‘environmental eugenics’ which moved people with intellectual disabilities into large-scale institutions, where they lived and worked segregated from the rest of

42 Newcastle is a large regional city and 127km or a two-hour drive from Sydney.
the community. Eugenics continues to influence negative community attitudes towards people with an intellectual disability marrying and/or having children.

Risk management continues to play an important role in shaping policy and services for people with an intellectual disability. The move from institutions towards community living and care, apart from fiscal reasons, were based on the belief that people with an intellectual disability had the right to lead an ordinary life and to take associated risks. Since the early 1990s, the importance of risk management has been steadily increasing within service provision for people with a disability (Andy Alaszewski and Helen Alaszewski, 2002). This has created additional barriers for clients in taking part in everyday community life.

The discourse of risk within supported accommodation documentation is implicitly entwined and links back to managerialism through the micro-management of clients’ lives. Discourses that construct risk take divergent positions. On one side, this discourse takes its truth from a belief that people with an intellectual disability are vulnerable, thus positioning clients as perpetually at risk. Conversely, the community and supported accommodation staff are positioned as being at risk from clients. This creates a situation in which clients are constructed as being both a potential risk to and from other clients, the community and staff.

*Clients ‘at risk’*

People with a disability have historically been seen as vulnerable and dependent. Vulnerability is often assumed to be a risk-creating characteristic, particularly for people with an intellectual disability. While clients have the right to self-determination, and to the risks associated with everyday life, they are perceived as not fully appreciating the implication of these rights (Peter McGill and Eric Emerson, 1992). ‘Clients at risk’ are constructed from the belief that

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43 I have chosen not to define what an ‘ordinary life’ or ‘normal life’ or being a ‘part of the community’ is in this section of the chapter. I have done this to replicate how not providing a definition of a fundamental key principle of disability within policy documentation leaves it up to individual or a service provider’s own interpretation, based on their moral creed.
people with an intellectual disability are “vulnerable through their reduced capacity to deal with complex social and cognitive demands” (James Harris, 2005 pp. 143). This makes them unable to make social judgements or fully comprehend their situation. Nor are they able to read the motives of others who may abuse or exploit them. For example, this calls for the extensive monitoring of Cindy and Evie's telephone calls. In this way, adults with an intellectual disability are often constructed as underdeveloped or not discerning.

Attainment of adult status is said to be characterised by self-sufficiency and an individual’s participation in social, political and family life (Mark Priestley, 2003). Adults who do not fit this criterion, such as elderly and disabled people, are defined by their perceived dependence upon non-disabled adults. This is reflected in document language that uses words such as ‘requires support’ ‘assistance’, ‘guidance’, ‘under the care’ or ‘intervention’.

With a perceived limited capacity to make choices or know what is best for themselves, clients are then required to be supported to make correct and good decisions, from healthy food choices (DADHC, 2003a) to how they spend their savings (DADHC, 2005c) and their leisure time (DADHC, 2005b):

People with a disability have a spectrum of nutritional support needs that include: Assistance in making wise food choices (DADHC, 2003a pp. 3).

Any person with a disability should have access to an advocate to assist them if necessary(Disability Service Standards Working Party, 2006 pp. 3).

The attitudes and moral beliefs of staff have a large impact of the lives of their clients. Staff are able to override any incorrect decision or choice a client may make if the staff member perceives the action to be unwise or unsafe:

Balance the ideals of individual choice and self determination with duty of care (DADHC, 2003a pp. 4).

Alternatively, clients in other situations can be placed directly under the protection of staff:
Staff are to ensure that, to the best of their ability, clients are protected against financial exploitation or abuse (DADHC, 2005c pp. 4).

The managerialism approach to reducing the potential risk to clients is through constant assessment, monitoring and planning. To ensure compliance by an accommodation provider, client risk management assessment and profiles are a condition of government funding. The need for an accommodation provider to mitigate against any unforeseeable harm to a client often means that clients' lives become controlled and subject to inflexible rules that are based on the lowest base level of skill rather than at a client's individual skill level.

A real life example of this is Cindy and Evie not being allowed to use public transport. As a result their contact and interaction with the wider community is limited. Paradoxically, this management system — aimed at keeping clients safe — can be counter-productive when the outcome places clients at a greater potential risk (William Gaventa, 2008). For Cindy and Evie, being over-protected may mean that they are not actively able to access or use public transport systems a skill often recognised in children as a right of passage and part of learning how to be independent.

The move from institutions to community care to improve the lives of people with an intellectual disability has fallen short of the positive service outcomes and status that were envisaged under the principles of normalisation (Anne Louise Chappell, 1997, Lindsey Williams and Melanie Nind, 1999, Jill Bradshaw and Steven Carnaby, 2002, Andrew Culham and Melanie Nind, 2003). Advocates of normalisation have argued that community accommodation has resulted in providing better care and living conditions (Kent Ericsson and Jim Mansell, 1996 pp. 2). The reality in the lives of people with an intellectual disability, however, is that living in the community does not necessarily equate with "social connectedness and inclusion" (Christine Bigby, 2006 pp. 179).

The reduction in the size of living arrangements has not automatically resulted in a greater opportunity for self-determination for people with an intellectual disability. As a client’s support needs increase, the opportunity to make even
simple choices become significantly lower (Rosanne Burton Smith, Michaela Morgan and John Davidson, 2005). While research raises concerns about the failure of normalisation to provide the opportunity for real and meaningful choice, the power dynamics in which managers hold onto key decision-making, has gone largely unchallenged.

Clients ‘as risk’
Each service a client requires comes with its own set of rules, conditions and regulations designed to control particular behaviours. For clients who live in supported accommodation funded through DADHC, many controls that limit their autonomy and determination can be linked backed to service providers’ obligations under duty of care.

Occupational health and safety
Duty of care is often associated with occupational health and safety (OH&S), and also applies to a range of situations and requires that everything reasonable and practicable is done to protect the health, safety and wellbeing of others. If it can be established that a person acted without care, attention, caution, and prudence, their actions may be considered negligent. For example, if an employee gives oral or written advice to a client they have to take steps to ensure that that person has understood the information. This can mean taking into account a person’s English language and literacy skills.

Duty of care in NSW for all workplaces is regulated through the Occupational Health and Safety Act (2000). This act places an obligation on an employer to cover the health, safety and welfare for both employees while they are at work, and for any other person such as visitors, contractors or clients who come into the workplace. It is the obligation of an employer to plan and implement reasonable measures to organise their workplace and their work systems to control all possible risk and harm from workplace accidents, injuries and illnesses. As part of mutual obligation, it is expected that employees are also responsible for taking care of themselves and others while at work.
In fulfilling organisational, legal and regulatory obligations of not putting people in harm’s way, risk assessments have to be undertaken and analysed, and strategies implemented, to minimise harm. For accommodation support providers, part of this risk analysis is to manage any perceived risk their clients may present to their employees, contractors, visitors, or other service users, and to the individual client themselves. As such, part of duty of care for a service provider also extends to protecting a client from themselves.

Client risk policy
Sylvia Bercovici’s (1983) study of accommodation for people with an intellectual disability in the US in the late 1970s found that there was a general conservatism among accommodation providers and staff regarding community experience and interaction for their residents, which was based on perceptions of capabilities and a fear of risk. The possibility of a resident getting taken advantage of, lost, assaulted, robbed, or getting into social or legal trouble was enough for many caregivers to justify to themselves their custodial position, even when the potential risk involved in a particular activity might be the same faced by any person in the community. This remains true today, and is reflected in the DADHC (2008a) Client Risk Policy that all supported accommodation providers have to adhere to in order to be funded.

In today’s world of litigation and OH&S regulation, risk analysis covers a wider spectrum. Clients in supported accommodation are required to have a ‘Risk Profile’ and be accessed not only for risks to their own lifestyle, health, safety and well-being, but also the risk they may pose to staff and other people they may come in contact with (DADHC, 2008a). All potential risks are assessed and graded from low to high by a professional in consultation with the client using the service.

Closely related to OH&S concerns, and adopting a managerialism discourse, a risk management approach requires the constant identification, control and monitoring of risks, so that any perceived risks can be prevented, minimised or eliminated before they arise. This is achieved through a Client Risk
Management Plan (DADHC, 2008a), drawn up from the initial risk profile assessment and any additional risks behaviours or problems observed by staff.

In reality, a tension exists between adhering to the rights of clients and the department’s/accommodation provider’s duty of care towards its employees, clients in their care, the avoidance of possible litigation and loss of profits. Although the second paragraph of the Client Risk Policy makes reference to the dignity of risk — that “people with a disability have a right to make their own decisions and are entitled to take reasonable risks in their everyday life” (DADHC, 2008a pp. 4). What constitutes a ‘reasonable risk’ is not defined, leaving it open to interpretation. In addition, the proceeding twenty-three pages undermine this right as the policy clearly indicates that “line managers should consider whether new or different risks are likely to be present in other locations or situations, and ensure that risk assessments are undertaken for those identified” (DADHC, 2008a). Many activities a client undertakes have to be assessed by a support worker, including everyday activities such as meeting a friend for coffee. As risk assessment comes under OH&S, a client, their family or advocate has little or no input into the assessment.

The risk assessment process is complicated and takes time to complete, and the result can impose a total sanction or limitations being placed on the activity (Marie Knox, 2007). When the possibility of risk has to be assessed before a client begins any activity, it leaves little room for spontaneity or taking any ‘reasonable risk’, particularly when another person defines what is ‘reasonable’, based on their set of moral judgements. This again demonstrates how a disability rights discourse gives way to the discourse of managerialism and risk.

The comprehensive checklist that covers the accommodation providers against possible litigation is extremely invasive for the client. Documented risky behaviours range from living skills such as door slamming, traffic awareness and stranger danger, to personal habits such as smoking, having unsafe sex and drinking alcohol, to dangerous behaviours of self harm, physical assault and abuse. It also includes medical conditions and diseases, specific day-to-day
care requirements such as help with grooming, as well as anything that may trigger a perceived risky behaviour.

The policy also discusses privacy and confidentiality in relation to the *Privacy and Personal Information Protection Act, (1998)*, and *Health Records and Information Privacy Act, (2002)*. In Australia, an employer or any employee under the privacy laws cannot pass on any private information about a client unless they have permission to do so. Personal information within this document, however, is accessed by any person involved in providing the client with support. In addition to this the *Client Risk Management Plan* is signed off by a number of people in positions of power — the “line manager, the family, person responsible, appointed guardian, and any person who has been involved in providing advice in relation to culturally significant matters” (DADHC, 2008a pp. 6). Interestingly, although not surprising in terms of risk analysis, the ‘client’, the person whom the report is about, does not sign or sight the report.

In the management of risk, personal and private information about a ‘client’ becomes public. This can leave clients in a vulnerable position and open to abuses of power by people who manage their care. It also means that the lives of clients living in supported accommodation are micro-managed, with every possibility of risk documented and managed.

The workings of this risk minimisation policy can be clearly located within the medical model of disability, and can be seen within the language of the document. Hierarchical language is used to highlight positions of power with ‘key worker’, ‘line manager’, ‘carer’, and ‘expert’ holding the dominant positions, while the person living in supported accommodation is placed in the subordinate position and is only referred to as the ‘client’. Even in gender-specific documentation such as the Menstruation Chart, women are referred to as gender-neutral clients (see Figure 48). The low status of clients is further reflected in them not signing or sighting the *Risk Profile* or the *Client Risk Management Plan*. Managerialism discourses can also be clearly seen within the same plan.
Knowledge about perceived risk is constructed and controlled by a key manager, as each risk is ranked and its trigger is documented along with a plan to eliminate or minimise the threat. Adopting a paternalistic position, clients are continuously placed under protective surveillance “where their best interests are determined by more competent others” (Jayne Clapton, 2008 pp. 576). This risk profile and plan is constructed from a position of deficit. Through the ranking system of low, medium or high, the extensive list of behaviours and conditions ensures that clients are always positioned as being at risk. For example, if the client is not a smoker, rather than being ‘not at risk’ in the ranking structure, the person’s level of risk is rated as low. Clients are therefore never free from the possibility they may take up smoking in the future. In this way, a client is always a threat to themselves, staff and others, and there is a need for service providers to constantly evaluate, monitor and control the situation.

The need to manage an organisation’s OH&S requirements is at odds with one of the guiding principles in NSW disability policy — to promote and increase the independence of clients (DADHC, 2005b). The Client Risk: Policy and Procedures document clearly states that people with a disability have the “right to make their own decisions and take reasonable risks in their everyday life” (DADHC, 2008a pp. 4). At the same time, the policy requires that risks are “identified, assessed, controlled and monitored to minimise risks to clients and staff as part of a risk management approach” and that “Client Risk Profiles and Client Risk Management Plans are incorporated into Individual Plans and are subject to regular review” (DADHC, 2008a pp. 5). This leaves little room for clients to be truly independent.

Individual planning policy
All clients who live in accommodation support services funded or operated by DADHC must have an individual plan. The purpose of the policy is to identify, discuss and plan the resources/services a client will receive over the next twelve months, as it is linked back to the funding obligations of the NSW state government under the commonwealth, state and territory disability agreement (FaHCSIA, 2003).
Based on a client’s strengths and needs, an individual plan is a formally written agreement that is reviewed every six months. Taking a team approach, a client, his/her family, advocate, financial manager, staff members and significant others develop and then agree on the plan. There has been a significant shift in policy and practice since the introduction of the principles of normalisation in service delivery for people with an intellectual disability. With a managerialism focus on the client as an ‘informed consumer’, clear guidelines relating to client consultation and input in the individual plan process are outlined within the policy guidelines.

An integral part of the plan is that clients and their families are communicated to in ways that enable participation and understanding of the process. This includes:

- What an individual plan is and why it is done
- The purpose of the meeting and what will happen
- Who will be there and whether they would like a support person
- What they would or would not feel comfortable about discussing in front of the group
- What assessment will be done and why.

The assessments include:

- Health Care plan, including medication
- Epilepsy and/or Asthma Management plans
- Nutrition and Swallowing checklist and plan
- Review of Behaviour Support plan
- Lifestyle Environment review.

While the policy is clear, research into individual planning has found that although clients may be present at the planning meeting, they have little input into the process (Centre for Developmental Disability Studies, 2004, NSW Ombudsman, 2009). Being locked out of the planning process has also been the experience of some clients’ families (Roger Stancliffe, 2001).

Although the individual planning process appears at first to be in consultation with the client, there are a number of additional reviews that are completed that are not included in the above list, and do not involve any client input. These additional reviews include:
It is of interest to note that a client can exercise his/her rights and refuse to participate in the process. An individual plan is still developed by the other team members, however, and is based on a client’s needs assessment (DADHC, 2005b). This highlights the dominance of the managerialism discourse where a client’s rights only extend up to the point where they can opt out of being part of process, but not stop it. This practice supports Sylvia Bercovici’s (1983 pp. 15-16) argument that referring to people with a disability as clients portrays an “individual in narrow, economic terms, and conveys an impression that is frequently a considerable distortion of the actual nature of the situation”, as in reality, they have little or no consumer power, choice or control.

Part of the negative impact of managerialism and risk management approaches to policy and guidelines as demonstrated here, is the abject lack of privacy. In trying to reduce the power of a professional over the lives of clients a ‘person-centred’ consultative team management approach to life planning now requires input from a number of different ‘expert’ people: the key worker; a client’s family; guardian; advocate; financial manager; support workers and other professionals. Although a ‘person-centred’ plan is based on a shared understanding about what is important to a client now and in the future, it nevertheless is primarily constructed by ‘expert’ others.

Generating ideas from different perspectives can provide a range of different and creative options. However, any options have to be balanced against and negotiated from available funds and resources (John O’Brien, 2002). While this approach may provide clients with a variety of life options criticisms of ‘person centred’ planning, particularly within managerialism discourse have been that
organisations have to “focus on budgets as a primary function with outcomes secondary” (Tony Osgood, 2005 pp. 58).

Client finances
A part of the individual plan process involves setting an annual budget to aid in managing a client’s finances and assets. The policy sets out the minimum requirements for managing clients’ finances in residences operated and funded by DADHC. One of the main aims of the policy is to safeguard clients from financial exploitation or abuse from staff, family members, and other individuals within the community, through a strict code of ethics, guidelines, procedures and documentation.

Although the policy recognises that “clients have varying levels of ability in relation to handling finances” (DADHC, 2005c pp. 4), clients do not have direct access or control over their finances or assets even if they have the potential to or already possess the skills. Rather, clients’ finances are managed in one of three ways: a formal financial manager as appointed by the Guardianship Board; a banker arrangement; or an informal financial arrangement such as the appointment of a family member (DADHC, 2005c).

Evie’s support worker monitors and controls her day-to-day finances to ensure that as a client, Evie lives within her financial means and does not spend her daily living allowance on just one item. Part of this monitoring is to seek prior approval for any one-off expenditure items not included in the annual budget from the client’s “family/advocate/guardian/financial manager” (DADHC, 2005c pp. 8), such as the purchase of a concert ticket.

Once again, this policy highlights the three competing discourses: risk; managerialism; and rights. Firstly, the risk discourse is embedded within the policy aims of fiscal administration of a client’s assets and protecting a client from financial abuse. In terms of control, there exists a dichotomy where the discourse of risk within disability policy clearly allows for the strict control and lack of direct access of a client to his/her income and savings. This form of financial control of a person’s finances within the general community and as
outlined in a recent report from the NSW Bureau of Crime Statistics and Research is commonly acknowledged as abuse or domestic violence (Julie People, 2005). The focus of the discourse within domestic violence literature is not defined by a person’s perceived intellectual ability but rather as a form of control. Yet within the discourse that surrounds intellectual disability, in terms of risk, the focus on controlling a client’s finances is seen as a justifiable and cost-effective way of mitigating against all possible risk, and indirectly serves to keep clients dependent and under control. This highlights the gap between the lived experience, and the human rights principles that underpin disability policy.

The policy of managing a client’s finances also reflects the discourse of managerialism through ensuring that clients receive all the financial allowances and benefits they are entitled to, due to their disability. Providers of accommodation services are placed in a position which they are required to ensure a good lifestyle for their clients, despite their clients having extremely low incomes and the providers’ limited funding.

These difficulties are compounded when government funding is lost or reduced or when current funding arrangements do not keep up with increasing costs. It then becomes imperative for the accommodation service provider that clients receive all their entitlements. Performing this task ensures that the provider is able to charge for any additional services over and above food and accommodation. Services attracting an extra charge would include the use of an organisation’s motor vehicle and/or any support aids a client may need.

As outlined in the last chapter, DADHC is able to charge their clients 75% of the Disability Support Pension, plus any additional services they provide. In reality, supported accommodation providers are landlords who in many instances have direct access to their client’s bank accounts. This can create a conflict of interest, particularly when rules are made for the benefit of the service provider and not the residents/clients. People who live in supported accommodation are not protected under the same tenancy laws or rights that apply to people renting in the open market or in public housing.
In contrast, Kay, who rents her home through the NSW Department of Housing, pays considerably lower rent. Public housing charges 25% of her total income plus the full rental assistance allowance. Also, Kay’s rights as a tenant are protected by law. Based on Evie and Cindy’s earning capacity, as outlined in the last chapter (see Table 7, page 206), the current cost of living in supported accommodation is more than twice the amount they would pay if they lived in public housing. Although the accommodation service provider has government funding, a proportion of the amount Cindy and Evie are charged would contribute to the overheads of the supported accommodation provider.

In the Australian Capital Territory accommodation for people with an intellectual disability is separate from support services. This provides clients with public housing and residential tenancy agreements protected by law. They pay their own accommodation and living costs, the same as other people in the state. Clients are then able to access and purchase services that enable them to live within the community. This provides more flexibility as clients access a range of services that best suit their individual needs, and reduces the high level of control that accommodation service providers currently have over their lives. As with the rest of the community, they have the opportunity to choose where they would like to live, who they would like to live with, the décor and furnishing of their home.

The discourse of risk gains its authority through managerialism discourses within neoliberal supported accommodation policy. Managerialism promotes the evaluation of services through: sound financial management; service activities; outcomes and performance indicators. Rights discourses that advocate quality of life outcomes are subjugated, leaving clients disempowered and hidden behind balance sheets and organisational audits (Alan Tyne, 1992).
Money Money Money

It is a cream 1970's brick home in a quiet street in a leafy suburb of Sydney. If you were to drive by the house, there would be no indication that this was a group home. It is community living at its best. The garden is weeded, the lawns are mowed and edged, and the house is well maintained. It is a house the same as the other houses in the street. I drive up, park and check my watch. It's 1.55pm. Evie is waiting on the front veranda, ready for her interview. She looks lovely.

I glance down, suddenly conscious that I am only wearing jeans and a cotton shirt. At the workshops, Evie had worn her hair tied back in a ponytail, t-shirt and track suit pants that were a number of sizes too big for her; so much so that every time she stood up she had to hold onto the waist band in order to stop them sliding down. Now she stood smiling, holding a white handbag, her long auburn hair drawn up into a tight bun that sat on the left side of the top of her head, wearing make-up, her new black sandals that she was sent home from work for wearing, a light blue floral A-line skirt and a plain white blouse. She was dressed as if she is going out on a special occasion rather than to an interview at the local coffee shop.

“Hi Evie, you look lovely”, I say. “Thanks”, she replies holding her skirt out to show me. Evie takes a step backwards, turns her head to call back into the house “see you later Helen, Janette's here!” We both turn. As we begin to walk back down the drive, the door opens and a young woman aged around 23-25 years old steps out, saying, “Hi Janette, I'm Helen”. “Hello”, I reply, smiling. Helen continues: “Evie, do you need money? I can get some out of your money tin if you need to buy a drink or something?” Helen turns to me “does she need any money?” “Not unless she wants to buy something at the shops. We agreed that I'd pay for what we have at the coffee shop because it's part of the research”, I answer. Evie says nothing. Helen nods and goes back inside.

Evie and I arrive at the coffee shop a little after 2pm. “I haven't had my lunch” declares Evie. “Well I suppose you should order something to eat then. Do you need a hand with the menu?” I ask smiling at Evie. “No”, Evie replies, and orders quiche, salad, iced chocolate and a slice of cake. I order a flat-white coffee and a cheese and tomato toasted sandwich. We find a quiet place to sit, eat and chat before starting the interview. At around 3.30pm, we arrive back at Evie's house to
find Paul, one of the men she shares the house with, pacing up and down the veranda. “Do you think something has happened?” I ask Evie. “I don’t know”, she replies looking a little concerned. Then as soon as Paul realises it is Evie in the car, he runs inside shouting “she’s here! she’s here!”.

I usually dropped Evie off out the front of her home without going inside but something in the way Paul had reacted made me think something may have been wrong. Evie hurried ahead. As I walked through the front door, Helen was taking out of a cupboard three bank books in plastic covers with red withdrawal slips sticking out the top. “It’s a long time since I’ve seen a bank book. Key cards must have replaced them about 20 years ago”, I think to myself.

“James, Evie, Paul, I have filled in the withdrawal forms — you just need to sign them” Helen says. “We’ve been waiting to go Christmas shopping” James tells me. “I am sorry, I didn’t realise”, I reply to them all still standing just inside the front door. “We have to get to the bank”, Helen says in a firm voice that is more a request for me to leave than a statement. “Yes. Of course. Bye Evie” I mumble, stepping back outside.

The front door slams. Paul, James, Evie and Helen rush past me and quickly get into Helen’s car. The car backs down the driveway onto the street and drives away. I’m left walking to the car feeling quite shell-socked. I had, I suppose, thought it was a bit strange but didn’t really think much of the initial conversation with Helen about Evie needing money for the interview. It wasn’t until I dropped Evie home and witnessed Helen calling each person by name, them stepping forward, and Helen handing them their bank books, like a teacher handing back assignments, that the reality of the situation hit me. The handing out of a bank book, holding money locked in a tin, not having access to an auto teller machine. Evie’s only access to her own money is through Helen.
Living Between Policy And Practice

Although disability policy and regulation in Australia, are strong on values and principles that promote independence and equality for all people with a disability, the daily experience for many people with a disability is vastly different (Tim Clements and Christine Bigby, 2008b, National People with Disabilities and Carer Council, 2009). In relation to living in supported accommodation, the ‘norms’ imposed on Evie and Cindy affect their lives on three different levels. Firstly, at a government level through legislation, policy and guidelines; then at the service provider level through the interpretation of policy into procedures; and finally at the level of individual support staff through the implementation of procedures and ‘caring’ practices.

This ensures that Evie and Cindy’s lives are largely dominated and controlled by others — professionals, family members and carers. This section of the chapter is interested in how risk is monitored and controlled by support workers, and the impact these strategies have on the day-to-day lives of Cindy and Evie.

The power relations between Cindy and Evie, and their respective support workers can be seen as embodied, as Cindy and Evie’s bodies become a site of regulation, abuse and tension as well as resistance and transgression of imposed ‘norms’ (Deborah Phillips, 2005).

An ordinary life

A ‘normal’, ‘ordinary’, ‘community’ life and ‘valued social roles’ are not defined within the policy, leaving it open to interpretation. What recent research has revealed, and my research supports, is that these terms are often defined and interpreted by direct support workers (Marie Knox, 2007, Tim Clements and Christine Bigby, 2008b, National People with Disabilities and Carer Council, 2009). Yet these terms are fundamental principles that Australian disability policy is based upon. One purpose of keeping the terms very general and vague ensures some flexibility in the interpretation. This is particularly important for people with intellectual disabilities who have different and often complex needs. Having prescriptive definitions promotes rigid thinking and can lock people into taking a literal interpretation, rather than finding creative solutions. I
believe, however, that there is a need to define these key terms to ensure that accommodation service organisations, staff and the community have a clear understanding of the government’s expectation and goals.

In terms of this research, an ‘ordinary’ or ‘normal’ life is a life that reflects the personal desire and goals of people with an intellectual disability to access the everyday things that people who are intellectually-abled take for granted. This includes: to choose where they would like to live; and whom they would like to live with; to give and receive love, and have lasting, meaningful personal relationships; to have employment prospects that will increase their earning capacity and give job satisfaction; to have their values respected; to have the opportunity to grow, learn and develop throughout their life span; and to be valued for who they are (National People with Disabilities and Carer Council, 2009).

Carer or support worker?
What is clear in this research is that Cindy and Evie do not live a ‘normal’ life; rather, their day-to-day lives are controlled by their respective support workers. What I particularly found interesting was that both Cindy and Evie refer to their supported accommodation support worker as their ‘carer’. ‘Carer’ was not a term used within the policy documents or guidelines to define employees of accommodation providers. In my conversations with the managers of supported accommodation organisations when approaching them about this research, they referred to these key workers as ‘social educators’ or ‘residential support workers’, and not ‘carers’.

The name ‘carer’ and ‘support worker’ have two very different meanings in terms of the power structure within the relationship. A ‘social educator’ or ‘residential support worker’ is expected to provide support and/or teach the skills necessary so that a person with a disability is able to lead an independent life. The title indicates a more collaborative relationship between the support worker and the client in regards to levels of support and/or skills training, in
which people with a disability are supported to take ownership and/or control of the decisions that most affect their lives (Marie Knox, 2007).

The term ‘carer’, however, can be linked back to institutional care, and the medical model of disability and the personal tragedy discourse (as discussed in Chapter Two) in which people with an intellectual disability require care or cure. Within the feminist literature and the community in general, ‘carer’ implies that a person is responsible for the physical and emotional well-being of another person — usually a dependent who is unable to do this for themselves. The power structure within the relationship Evie and Cindy described as having with their support workers, and which I observed, can best be interpreted as one of subordination. Through conversations with Cindy and Evie, it was clear that rather than support, they saw themselves as under the protection and charge of their support workers. Failure to comply for Cindy often resulted in threats, punitive restrictions and/or attending behaviour management classes.

**Risk-based approach to support**
The need to control people with intellectual disabilities remains a dominant feature in their lives due to the strong focus on risk management and OH&S within supported accommodation policy and guidelines. Rather than a strengths-based approach to support and life skilling, risk-based or deficit-based practices are used. Strengths-based approaches are based on the understanding that people are capable of positive change. That change is “incremental and builds on existing strengths and resources” thus “capitalising on the capabilities and abilities” (Margaret Spencer and Gwynnyth Llewellyn, 2007 pp. 176), of clients, their family, and formal and informal support networks. Providing support while a resident develops his/her skills allows the person receiving support to feel in control. A risk-based approach concentrates on people’s weakness and inabilities, and looks for what is going wrong rather that what is going right. It is hardly surprising then that support workers trained to look for risks or problems are able to find them in their clients. This approach denies people the opportunity to overcome problems on their own. It
undermines their self confidence and provides little motivation for them to make changes in their lives (Tim Booth and Wendy Booth, 1998a, 1994a).

Rather than social inclusion, as advocated within supported accommodation policy, a risk-based approach to support and case management creates multiple barriers to meaningful participation in community life, as the real life experiences of Cindy and Evie clearly demonstrated. The impact of segregation, exclusion and marginalisation on the health and wellbeing of people who live in supported accommodation, such as Cindy and Evie, also poses a great risk.

The dignity of risk
The need to protect against risk is argued to be a symptom of modern life (Anthony Giddens, 1991, Ulrich Beck, 1992). In colonising the future we attempt to reduce insecurity and fear. Risk, in this sense, becomes a “moral attitude to hazard which every culture needs to negotiate” (Bob Heyman and Sarah Huckle, 1993 pp. 1558). We construct our knowledge of perceived risk based upon our direct and indirect experiences and observations. These perceptions are also influenced by our culture, race, age, gender and social status. As society and ideas change, the production of risk knowledge becomes contested and constructed. As with the discourses about power, risk discourses are not fixed; rather, they are historical and local (John Tulloch and Deborah Lupton, 2003).

Risk is also used to control certain classes of people who are likely to be “victims of hazard” (Deborah Lupton, 1999 pp. 49). For people with an intellectual disability, there is a heightened sense of fear about the dangers and hazards associated with them taking risks by the community, parents, support workers and carers (Robert Perske, 1972, Sylvia Bercovici, 1983). Perceived risks can be both in the home — such as knives or hot water — and out in the community — such as getting lost or run over. When others are primarily responsible for a person, the tendency for tighter restrictions is heightened (Mary Douglas, 1985). In the case of accommodation providers, the need to mitigate against social or legal ramifications is often enough for people within the organisation to justify
their custodial position even, when the risk involved for a particular activity might be the same faced by anybody (Sylvia Bercovici, 1983).

Taking risks is a necessary part of “normal human growth and development” (Robert Perske, 1972 pp. 2). We live in a world that is not always safe, secure and predictable. Developing human resourcefulness is a skill most of us learn over a lifetime. The total avoidance of risk in the lives of people with an intellectual disability limits their spheres of behaviour and interaction in the community, employment, recreation and relationships. Although having mainstream life rhythms for people with intellectual disabilities was a fundamental part of Bengt Nirje’s (1970) Principles of Normalisation, it is clear that in Australia we still struggle to achieve this.

The practical difficulties in striking a balance between people with an intellectual disability engaging in everyday life activities that include taking risks, and a service provider’s duty of care not to leave their clients open to unacceptable risk, is not easy. The severity of a person’s intellectual disability also impacts on the extent to which they are able to interact with the community. Duty of care is, however, often used as an excuse for placing restrictions on the lives of supported accommodation users.

From the perspective of the accommodation provider, it is important to have staff that are capable but not costly. As previously mentioned, given these requirements, employees are often hard to find and not easy to keep. One of underlying rationales for the high levels of governance that are akin to institution-oriented management practices, is labour saving concerns (Sylvia Bercovici, 1983). The ideal client then is someone who is cost effective, poses the least risk, is dependent and compliant; a client who can dress, bath and feed themselves, perform routine household tasks, has limited outside contact and no behavioural problems. For clients such as Cindy and Evie, this culminates in a ‘life managed’ rather than a ‘life lived’.
A managed life
Since the early 1990s, professional and support staff roles have increased (William Gaventa, 2008), and they play a significant part in their client’s lives. Apart from the responsibility of keeping the household running, support workers organise the shopping, daily activities, take the women to any appointment, manage their money and maintain contact with their families. They are also involved in their client’s ‘case management. This often includes: organising and conducting the annual individual plan; monitoring the implementation and evaluation of the goals set in the plan; and ensuring medical and health needs are met. They have the ultimate responsibility for the clients they support (Marie Knox, 2007).

Figure 49 - Carer/Support workers as gate keepers.
It is these key workers who make the day-to-day decisions in supporting and encouraging their clients to develop and maintain the skills necessary to live independently within the community (FaHCSIA, 1993). More importantly, they are also responsible for facilitating opportunities for their clients to engage with the wider community.

What this means in real terms is that for Cindy and Evie access to life necessities is restricted as they are tightly controlled by their support worker (see Figure 49 on the previous page). Whether Cindy and Evie have the life skills or not makes no difference. Controlling life necessities reduces the possibility of risk and ensures that they are unable to live independently as they are forced to be reliant upon their support worker. The strict control of incoming and outgoing telephone calls, lack of direct access to their savings and day-to-day spending money, and not being allowed to use public transport, ensures that most social contact or social activity can be scrutinised.

A number of leisure activities were home-based, such as drawing, reading and watching television. A lack of leisure activities has also been found by other researchers (Louise Young and Adrian Ashman, 2004b). Most social activities Cindy and Evie attended were organised by their supported accommodation provider or their employer, so there were always staff on hand facilitating the activity. Being confined to these two organisations for their social life places severe restrictions their ability to meet new people or continue old friendships. Like many women, Evie had met her current boyfriend at work however they were rarely able to see one another alone. The opportunity to nurture their relationship, go out alone on a date or have any privacy was fraught with difficulties.

44 Evie on a rare occasion made arrangements to meet her boyfriend in secret. Late at night when everyone else in the house was asleep Evie, who was 52 years old, climbed out her bedroom window and walked some distance to meet him. Evie knew the risk she took walking by herself late at night; however, they were in love and they wanted time to be together alone – just the two of them. Due to the sensitive nature of this information it will only be included in the examiners’ copies of this thesis.
In addition to limited social networks, Cindy seldom had any contact with her family. One of the highlights of her birthday was receiving a telephone call from her sister. During that conversation, her sister had mentioned that her mother was also going to call but by the time the fieldwork ended some three weeks later, Cindy was still waiting for her mother to telephone. These two women's ability to sustain any relationships was further hampered through their lack of contact with the wider community. Of all the women, Shirley was the only person whose neighbours spoke to her. Cindy and Evie's neighbours never spoke to them not even to wave or say hello. This is probably not unusual, as many Australians do not know their neighbours other than to say “hello”; however, the street where they live is a possible way to increase their networks and personal relationships (Tim Clements and Christine Bigby, 2008a).

The only regular interaction they had with the general public was when they went grocery shopping, an activity that calls for limited communication and community engagement. This situation left them with little opportunity to make friends outside of their closed environment of work and home. With telephone restrictions and little outside contact with friends or the community, Evie and Cindy live an isolated life. Unfortunately, it would appear that Cindy and Evie’s lives are not the exception. Whether people with intellectual disabilities live in supported accommodation, in family homes or in the community, they often live very isolated lives (Sylvia Bercovici, 1983, Dorothy Atkinson and Fiona Williams, 1990, Tim Booth and Wendy Booth, 1994a, Tim Clements and Christine Bigby, 2008b).

Part of the individual planning process is to provide the opportunity for residents to have choices in major life and social activities, yet research has found that there is little evidence of “attempts to develop residents' choice-making skills” (Josephine Jenkinson, 1993 pp. 362). Despite clear guidelines that people with intellectual disabilities should be involved in decisions that affect their lives, research has raised concern that staff make decisions without consultation (Tim Clements and Christine Bigby, 2008b). At times, this was due to staff anticipating or predicting the choice a resident may make (Josephine
Jenkinson, 1993). Other research has found that in some cases, residents appeared to be happy to have support workers make their decision for them. When given a choice, some residents chose to do what they thought would please the staff (Roger Stancliffe, 1991).

**A managed identity**

Research has also found that where inappropriate choices were made, staff restricted or overruled the choice a person living in supported accommodation made (Roger Stancliffe, 1991, Josephine Jenkinson, 1993, Louise Young and Adrian Ashman, 2004a, 2004b). The DADHC policy is very clear that support workers should intervene when they believe the decision made by a client is not wise or has duty of care implications (DADHC, 2003a, 2003b). It then becomes the responsibility of a support worker to decide what is acceptable behaviour — the ‘right’ way of being, acting and how this is achieved, based on their beliefs. Cindy, for example, wanted to express her individuality by dying her hair purple; however, her support worker refused to allow her to do so:

*I want to dye my hair purple but my carer says I will look stupid so I can’t do it. Cindy*

In this example Cindy’s body became a contested site of power and identity, where Cindy’s body was placed in a position in which her support worker was able to override Cindy’s personal style to create and impose an identity that she perceived as best for Cindy. This reveals the extent of governance Cindy experiences and her inability to make simple choices about her personal style that most of us take for granted as being part of an ‘ordinary life’.

Organisations also have to take some responsibility for the level of control exerted by direct support staff. A recent Australian study found that often support staff conceptualise their role in narrow terms of “‘caring’ or ‘looking after’”, and did not envisage their support role as being “educative and facilitative” or

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45 This research did not extend to interviewing Cindy’s support worker. As I have no way to ascertain the reasons why Cindy was not allowed to dye her hair, I have used the idea of the body as a site of regulation.
building community engagement (Tim Clements and Christine Bigby, 2008b pp. 41-42).

Group homes are often scattered through the community, isolated from the accommodation service provider’s offices. This often means that clients have little contact with other staff members as it is left up to the support worker to organise the client’s day. If there are no clear guidelines activities can revolve around the worker’s needs and ideas, rather than the client’s. A good illustration of this is how the support worker’s needs have taken away Evie’s right to do her personal shopping in more than one store. Failure to comply often results in getting a bad reputation (Marie Knox, 2007).

**Having a reputation**

One of the first conversations I had with Cindy’s support worker about Cindy was in regards to ‘behavioural problems’. Cindy had a reputation for non-compliance. Her failure to legitimise the demands made by her support worker often brought their relationship into conflict. With Cindy holding the subordinate position of power, the support worker was able to legitimise his/her superordinate position by forcing Cindy to submit. In the example of dyeing Cindy’s hair, having no access to her own money the support worker held the financial means for Cindy to act independently. Power was also exerted through other mechanisms such as threat, coercion and punishment (Michael Kelly, 2001).

On the first morning of the workshops, Cindy’s support worker had forbidden her to leave the house until she had tidied her room and made her bed. As an act of defiance, Cindy left the house without following her support worker’s instructions, and although Cindy knew that she could not be made to stay in the house, she nevertheless spent most of the day in tears and expressing her fears about what would await her when she got home:

> I know my rights. She can’t lock me in the house. I don’t know what’s going to happen to me when I get home. I shouldn’t have
By the time Cindy got home that afternoon her support worker had left. We made sure Cindy was safe and made arrangements to call her that evening. I had to make a time so she would know who was calling, otherwise she was not supposed to answer the telephone. Her punishment for her disobedience was the withdrawal of some minor privileges. Although Cindy was 28 years old, this example highlights how she was treated as a child.

Cindy’s stories often reflected a sense of powerlessness. One of her acts of resistance or transgression (depending on your point of view) was to lose her temper and begin shouting. This response usually resulted in Cindy being sent to behaviour modification classes, having ‘time out’ in her room, or as the above example highlights, punitive sanctions. DADHC’s Behaviour Intervention Policy (DADHC, 2003b pp. 2) recommends “exclusionary time out” as a part of positive behavioural training; however, the policy makes no mention of punitive sanctions. Another effective technique used on Cindy by her support worker to control her behaviour was to threaten Cindy that if she did not comply, she would not be able to stay where she currently lives. For Cindy, this meant being sent back to parents who abused her if she “didn’t toe the line”. Cindy clearly articulated her feelings of powerlessness and fear of being sent home:

> If I lose my temper or don’t do as I’m told one too many times, they’ll tell me to go. What can I do? I know I have rights but I have nowhere to go and I can’t go home. I can’t go back there. I have to be careful and do what I’m told whether I like it or not. I have no choice. Cindy

Although the accommodation service provider has a duty of care not to send Cindy back into a dangerous situation, she nevertheless lives in fear. Whether this threat was true, imagined or implied is immaterial. What is real is Cindy’s genuine fear of her situation and of her carer. For Cindy, it is clear from her conversations that she felt contained, organised and policed. On one hand, she was treated as a child, and on the other she was expected to come to terms
with complex life situations (Dan Goodley, 1998) such as the physical and emotional abuse she experienced from her parents. Cindy was seeing a psychologist, so she was not expected to deal with the complex issues that surround abuse by herself. A condition her support worker placed on Cindy’s participation in the research, however, was that she was not allowed to talk about her abuse. If she raised the topic I was to tell her that she could not talk to me about this. The reason given was that my name was similar to the psychologist’s and Cindy might get us muddled.

We live in a society where personal choice and freedom is paramount to citizenship (Sue McGregor, 2001, David Harvey, 2005, Hans Reinders, 2008). For people living in supported accommodation, like Cindy and Evie, choice is something that is conditional. Allowing choice can conflict with support staff health and safety obligations, keeping within budgets or organisational targets, or may not be possible within their allocated time on shift. Choice then can become narrow, routine and confined to within the domestic sphere. Cindy and Evie did not appear to be involved in deciding where to live or work, although, as mentioned in Chapter Five, Evie had made the decision to follow her boss from one business service enterprise to another — the realisation of her dream to work with children remained just that: a dream. She had little or no power to make it a reality other than to keep mentioning it to her supervisors at work and supported accommodation provider.

In discussing Evie’s desire to work with children at one of the workshops, Lara asked Evie if she had included it in her individual plan. Even though Lara explained in detail what an individual plan was and how it worked, neither Lara nor Cindy could remember having one or ever being involved in putting one together. Because they cannot recall having an individual plan does not mean that Cindy or Evie do not have one or were not consulted, as these plans are a condition of government funding. Although the system is based on the ideals, values and language of customer service, rather than the market being driven by the consumers of accommodation services, it is public funding sources that shape the services through regulation and policy.
Relying on public transport

I am there yesterday at the expo and I bring my artwork there. One people they buy one of my pots. I don’t know what people will do with it (laughing)! We are there, we have different art. There are lots of different things.

I brought my work there. I wasn’t even thinking about it. I was just thinking I had better bring it home. Then I find out one of my pots is sold…

Yes it felt very good! Kay

Where I did my ceramics is moved to Campbelltown because they got a bigger place. You know Macarthur TAFE? They got a bigger space that is why they moved. You know you need a big place to build a kiln. You can’t do it at home.

The only place to do ceramics is at Campbelltown. Other places like Meadowbank do art, but they haven’t got ceramics. If I could do it close to where Mum lives or close to where I live like before then it is better.

Too far for me to travel to Campbelltown, it takes so much time. It’s too far at night on the train. It’s not safe you know to travel at night by yourself on the train. I don’t go out late at night. Kay
Kay was very proud of selling one of her pieces in the art exhibition. In the art workshops Kay was able to continue her passion for art and was able to pass her experience and expertise as an artist onto the other members of the group.

In Sydney most people travel by private transport. Shirley, Kay and Lara usually caught buses and trains to travel to work, college, shopping or social outings. When the ceramics department at Kay’s local TAFE relocated to an outer suburb of Sydney, she was no longer able to continue attending ceramics classes. Travelling to the campus by public transport took a number of hours and this made attending classes difficult particularly when her classes finished late.

When this happened Kay would have to travel and walk home late at night by herself. Travelling on trains at night in Sydney is considered dangerous as there are often few commuters and guards do not regularly patrol the carriages. The risk and fear of sexual assault, physical attack, and harassment have a significant influence on the travel habits of many women.

Women are more likely than men to use public transport and they are more likely to be a victim of sexual assault, harassment or indecent exposure than men (Anastasia Loukaitou-Sideris and Camille Fink, 2009). For many women personal safety is often a consideration in planning activities outside of the home and Kay was no different. In this case it was not Kay’s disability that excluded her from attending ceramics classes but her gender and the social environment in which she lived. Janette

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46 Seeing people with intellectual disabilities as ‘artists’ is not an identity that is widely acknowledged in the community nor is it an area that is well researched. If I were to replicate this study I would meet once a week for around two hours over twelve months. This would provide the participants the opportunity to develop their artistic skills and an exhibit their work.
The counter-argument, and one that is used as a justification for the restrictions placed upon Evie and Cindy’s communication, money and movements, is that of safety from potential danger. These restrictions highlight how the management of risk has become a restrictive barrier to live what is generally perceived to be a ‘normal’ life. Paradoxically, these types of everyday practices can heighten risk, as they do not provide the necessary tools for people to learn the skills of character judgement, how to make and maintain friendships, manage money or use public transport (Sylvia Bercovici, 1983). What is most disconcerting is that many of the restrictive and exclusionary practices are seen by Evie and Cindy as for their own protection. It should be stated that overall, the women were happy with their lives. Like most of us, there were things that they would have like to changed, but generally they “wouldn’t change much”.

Evie

Material needs
The women lived in ordinary homes within the community. The gardens were regularly maintained and landscaped. The houses were also well-maintained and proved a good material environment for the women to live in. The living areas were air-conditioned and the walls were painted in a neutral colour. Both homes had similar furnishings and décor. Cindy and Evie had their own bedrooms and they shared the household duties with their housemates.

There was a strong emphasis on keeping the houses very clean and tidy. Inside their homes, there was no clutter and few personal items on display. The lack of personal items, photographs, knick-knacks, magazines and paintings on the walls made the living rooms feel very bare and clinical rather than homey and comfortable. Personal items appeared to be confined to their bedrooms (Tim Clements and Christine Bigby, 2008b). The poem When is a house a home on was written from my reflections about the starkness of Evie’s home.

Although Cindy had difficulties with her support worker, she appreciated where she lived now, and both of the women felt safe where they lived. Both Cindy and Evie thought that that there was a level of genuine care their support
workers felt towards them. As Cindy was not able to return home for Christmas, arrangements had been made for her to spend the holidays with close friends and their family, so she wasn’t alone. Cindy told us how she was looking forward to spending time with her friends and was “glad I don’t have to be by myself on Christmas day. I wouldn’t like that”.

**Conclusions**

The pursuit of quality, efficiency and compliance within managerialism and neoliberal regimes requires the tight control and monitoring of finances and the management of organisations who provide supported accommodation. Even though they are consumers of services, people with intellectual disabilities have little input or influence over policies, regulation and guidelines that directly affect their lives. This has contributed to preconceived ideas about intellectual disability resulting in academics, other professionals, and policy makers reluctant to consult with this section of the population (Kirsten Stalker, 1998). Whether this will slowly change with the rise of the self-advocacy movement is yet to be seen.

Although disability policy in Australia has good intentions and has shifted from institutional-based services, the move has had more to do with funding rather than ensuring support is provided in a way that is not institutional. At present supported accommodation tends to focus on narrow assessment and planning processes that largely revolve around risk management. This results in: governance; conservative planning; keeping things the same; and promotes community presence rather than active community membership for people with intellectual disabilities. In human services enough support brings freedom, and too much ‘service’ brings segregation and restriction allowing lives to be managed rather than lived (Sue Swenson, 2008).

DADHC (2004, 2005a, 2006b) policy states it has a commitment in valuing, and supporting their clients to independently participate in community life. A truly independent person is someone who can: make telephone calls; leave the house on their own; use public transport; go to eat-in restaurants; have friends
and acquaintances visit their home; and have partners who stay overnight. This picture is vastly different from the lives lead by Cindy and Evie.

They live a managed life where they live and work in isolation, and social exclusion, under constant surveillance and control. Often the only people who do not have an intellectual disability they come in contact with hold positions of power. Such an ever “shrinking social world” (Isabel Dyck cited in Edward Hall, 2004 pp. 302), often leaves people with an intellectual disability vulnerable and desperately lonely, leaving them open to a greater risk not only to their well-being but also to exploitation and abuse.
... I get knocked down
But I get up again
You’re never going to keep me down.

...He sings the songs that remind him
Of the good times
He sings the songs that remind him
Of the better times:
“Don’t cry for me
Next door neighbour...”

I get knocked down
But I get up again
You’re never going to keep me down.

We’ll be singing
When we’re winning
We’ll be singing.

8. TUBTHUMPER — LIFE ACCORDING TO LARA

You don’t own me used a discourse analysis to explore the dominant themes in NSW state and federal government policies and regulation that relate to supported accommodation for people with a disability. The analysis revealed that the policies’ philosophical stance promoted a rights discourse in which people with intellectual disabilities have a right to self-determination and to take an active role in the community. Competing with a rights discourse were the discourses of managerialism and risk.

Managerialism discourses came to prominence through neoliberal ideas of unrestricted market forces free from government intervention. This discourse advocates the deregulation of government services into the private sector, as they are seen as cost-efficient, productive and able to improve the quality of services. While the government appears to be at arm’s length, it remains in control through funding agreements that have strict guidelines, and high levels of monitoring and reporting.

Part of the guidelines and policy in relation to supported accommodation pays close attention to the risk management of clients/residents through duty of care. Residents are positioned as ‘at risk’ from themselves, other residents, staff and the community. Accommodation service providers also have a duty of care towards their employees, contractors and other people who come in contact with their organisation under OH&S legislation. This calls for a risk assessment; however, in this assessment clients pose the greatest ‘risk to’ others. The process of keeping ‘clients safe from others’ and ‘others safe from clients’ has
tended to result in high levels of governance in the every day lives of residents. The need to keep residents safe is often the responsibility of support staff, as a result their personal attitudes, beliefs and approach to ‘support’ practices affects the day-to-day lives of people under their direct control.

As this research has demonstrated, the women who took part are tenacious and resilient; hence the title of this Chapter, *Tubthumper — Life According To Lara*. This Chapter focuses on *Lara’s* stories and how she negotiates what she sees as two very distinct worlds — the ‘normal world’ and the ‘world of intellectual disability’. Her stories about intellectual disability reflect these dual worlds. Disability theory and in particular the social model of disability tends to see all people with a disability as one unified group. Yet the women who took part in this research are very different. As *Lara* navigates her dual worlds, we see that her identity is not fixed to the label of intellectual disability; it is much more fluid. *Lara’s* story makes an interesting platform to begin a discussion on self-identity and friendships.
Chapter Eight

Being Lara

Lara: There’s the “normal world” and “our world”. You have to decide whether or not to say if you have an intellectual disability, as most people’s attitudes change when you tell them - government departments are the worst. People start talking in a loud voice and speaking really ... really... slowly. If I am with a client then I usually can’t say anything because they can get quite nasty. Depending on how I’m feeling I’ll say “there’s no need to shout. I’m not deaf! I just have an intellectual disability”. You’re not allowed to get angry or be rude but they can speak to you like you’re stupid. Most of the time you just have to take it but it makes you really cranky.

Janette: As the researcher in this study I was a witness to the stories that the women told me about their lives. I believe that I have a responsibility to honour those stories and to present them in a way that honours their lives. I have tried not to drown out the women’s voices by presenting their stories differently.

The design of this chapter is influenced by Patti Lather and Chris Smithies' (1997) book Troubling the Angels: Women Living With HIV/AIDS. In particular I like the juxtaposition and the layering of stories. I have experimented with something similar in this chapter.

Splitting the page and having Lara’s story at the top recognises her as an authority in her own life and her extensive knowledge of the disability sector. I have tried to keep any changes to Lara’s story to a minimum. Any changes have mainly been contextual so that the stories about a particular event, time or theme have been placed together. To protect confidentiality, parts have been omitted or changed. In wanting you to know Lara as she revealed herself to me, I haven’t ‘sanitised’ her words.

Positioning my writing below Lara’s story is another way of layering stories. It physically reminds me that as an academic text, my own life history and world view influences, colours and lies beneath the text. Writing this way also presents different historical moments in time. Lara’s stories are a reflection of a position she took three years ago. It is unknown whether her ideas have changed or not.

As I write this now in my present, my ideas and understanding of the complexities that surround ‘intellectual disability’ have significantly changed and developed since I spoke with Lara. In this moment, I write with the image of you reading this thesis in the future, knowing that for you, this moment will be in your past.
Gaining confidence

Lara: There was this lady that used to live across the road from me. One day we were talking and I told her I was having trouble trying to find a job. Anyway she said “Why don’t you come and work where I work?” I thought “Oh well here goes!”. So anyway I rung up and made an appointment. I wasn’t aware that it was what we used to call a sheltered workshop. So anyway, I go along for the interview and I ask the person “Do you have to have a disability to work here?” They said “It depends on what you call a disability. What you’ve got is a disability”.

I never thought of myself as having a disability before. I always had a very bad nerve problem. If I’m upset or anything or I’m asked to write in front of people I shake. I’ve had tests and everything they just call it common nerves as I am getting older it is getting worse. Sometimes I can’t control it. I have to just let it go. From 1987 it’s been known as an intellectual disability. That’s what they put it down as. So I went to work.

At first I thought “Oh poor me. How come I’ve ended up here? This isn’t a place to work, it’s awful”. I was like that for the first three days. I found that I was doing more work than this guy next to me. I was doing my own work as well as half of his. I thought “Oh I’m not doing this. I’m not going to do his work. I’m going to have to get out of here”.

Then I stopped... I looked around me and I thought... Wake up! These people need you. There’s a lot you can do here. Stop feeling sorry for yourself. Just look around... That’s when I started getting more confident but I needed help first myself.

Janette: Like Patti Lather and Chris Smithies (1997) this chapter moves between autobiography and academic text, mirroring Lara’s movement between worlds. I wanted to include these chapters on Lara as she challenges many of the stereotypical ideas of how a woman with an intellectual disability is perceived. Lara is a mother who cared for and brought up her son and she is a grandmother who is actively involved in her grandchildren’s lives. She has been in a long-term relationship with her current partner, lives independently and is actively involved in her local community. As an advocate, business service workplace auditor and qualified trainer, Lara sees herself as holding a unique position and considers herself a role model who has the potential to influence and change the lives of other women, in particular women with an intellectual disability, for the better. This is reflected in the way she lives her life, in how she dresses and grooms herself, her high level of professionalism and her general concern for the other participants in the study. This concern was also extended to me as a person with little experience of intellectual disability. She felt at times it was necessary to warn me about some of the
Lara: I became the chairperson on our work committee. I had to have meetings with the bosses and I was never scared of them. I will always be grateful to the workplace I worked in. They never ever stopped me from doing the work I wanted to do.

I used to go down to the welfare officer and say “I shouldn’t be here. I should be in an open employment job. I am taking the job of someone who really needs this job”. She would say “You’re happy here aren’t you? If you’re happy here you can stay”. But I felt inside that I was doing someone out of a job.

Oh there is something else what we did. Our supervisor played a trick on one of the guys. This guy used to talk and talk and talk about all his problems. This time he was worried about his pension so the supervisor rang up, asked to speak with the guy and said he was the Premier and wanted to speak to him about his pension. I happened to answer the phone and so I knew what was going on and I handed the phone over.

Although this text reflects Lara’s experience it has been useful to distinguish story from voice to highlight the different discourses that Lara manages and contests in constructing her story. For example, Lara’s concern that I believed everything the women told me lead her to disclose that in her experience people with an intellectual disability could not be trusted to tell the truth. At this moment in time Lara adopted a cultural stereotype that people with an intellectual disability are untrustworthy. This is a negative trait that she does not associate with her identity.

Within the disability movement, and in particular the social model of disability, there is an assumption that all people with a disability identify as one universal group (Mark Deal, 2006). As an oppressed group, having a collective

47 When Lara refers to the “normal world” she uses two fingers on each hand to imply inverted commas.
Lara: The next day we come into work and we can’t see our supervisor. The company had sacked him. So we refused to go to work until they explained what was going on. Anyway we all sat there in our jobs and they said “Come on get to work!” and we said “No!” “Why won’t you work?” the bosses asked and we said “Because we want an explanation why our supervisor was sacked”. The boss called the committee members down and they told us what happened.

I said “Well why aren’t you sacking me?”
They said “Why?”
I said “Well I answered the phone. I knew what they were up to”.
“No, no, no, we refuse to believe that” said the manager.
“Well you should have because I was as much to blame as they were”
I said and my manager turned around and said at the time “No you are a person with a disability. You were coerced into doing it”.
I said “No I wasn’t. I volunteered to do it”, but he would not believe it.

identity is a necessity as it offers a way to share their oppression and draw strength from one another to bring about change (Rose Galvin, 2003). It is clear, however, within Lara’s story that her identity was not fixed. Nor were the other women’s identities who took part in this study. The fact that they all identified as being able-bodied clearly demonstrates that the identity of ‘disabled’ was not universal.

It has been argued by John Tringo (1970) that if discrimination and prejudice exists towards people with a disability, then a hierarchy of different disabilities will be present. This accounts for the finding in Mark Deal’s (2003, 2006) research that the participants who used wheelchairs saw themselves as being superior to people who have an intellectual disability. This does not, however, explain how Lara embraces the label of ‘intellectual disability’ while at the same time socially distances herself from other people with the same label in particular circumstances.

Patricia Linville (1998) suggests that this occurs because it is more difficult to see difference in other peoples’ ‘in-groups’. That is, they appear similar whereas in our own ‘in-group’ we are more able to distinguish sub-groups this goes some way to explain how Lara identifies with some characteristics of intellectual disability, such as how people often treat you differently after disclosing that you have an intellectual disability, and not other characteristics such as untrustworthiness.

Alternatively, Stuart Todd and Julia Shearn (1997 pp. 342) argue that because the label of intellectual disability has such negative consequences, people with the label are “invisible to themselves”. This can be attributed to overbearing or fearful parents or that adults with an intellectual disability have little understanding of their lives. This position
Lara: I answered the phone, I knew what was going on and I admitted that to them, but my manager refused to see it. They could have sacked me. I was in the wrong as well, I shouldn’t have handed the phone over. I didn’t know that the supervisor was going to get laid off. He was a real ‘A hole’ of a supervisor. He had us jumping when he said jump because we really like this guy and even after he was sacked he was having us around to his house telling us what to say to the bosses. He made us all these promises about getting us better jobs but it was all lies. We didn’t realise until much later.

Anyway, a few days later we all walked out about 1pm that afternoon. One of the bosses called me over and said to me you can’t go out on strike. I say “no but we can go home with stress” and so we did.

We headed straight for the local Community Legal Centre and told them that they sacked our boss and what they had done to us. In the end it turned out that they wouldn’t replace our boss so we started pushing for respect by the management because they would walk past us and not say anything. We were the workers; we were the ones keeping them in a job so we went for that. In the end we got what we wanted and we had to write a letter to the legal centre and say we don’t want them anymore that we are happy with the result we got.

We had the courage to go outside and things were different after that. You don’t do that you are there to work and that’s it.

has been challenged by Mark Rapley, Patrick Kiernan and Charles Antaki (1998).

This research supports their findings as Lara clearly demonstrates that she is acutely aware of her impairment and how other people perceive her. For example, Lara believed that she should have been sacked regardless of her disability for her part in the prank played on her co-worker, even though her boss could not accept that she had been a willing participant because of her disability.

Lara was not the only woman to speak about her experiences who specifically related to her intellectual disability. Kay was aware that her intellectual disability was caused through having meningitis as a baby. As a result she has difficulties with processing and remembering numbers. Cindy was able to recognise her own status by virtue of her treatment by others. As discussed in the previous chapter, seeing herself as having the right to live her life on her own terms often brought Cindy into conflict with her support worker. This is the very opposite of being ‘invisible to herself’.

Lara makes her identity as a person with an intellectual disability very clear and relevant. This can be seen when she speaks about her achievements and accomplishments and also when she has been the object of other people’s abuse or jokes. For example Lara’s sister had called her ‘stupid’ for many years and although
Lara: After that and with a lot of support from my boss I became the union delegate. It was great. I loved it. I had power! I could bounce my bosses. I wasn’t scare to do that because I knew what to say and I knew what I wanted to do. I was so proud about being able to help my fellow workers. One of the bosses would stand at the table and said “what are your people going to do now you can’t go on strike” and I’d say “no but we can go home” and we went home.

Then in the union I got up to being a state councillor. I was the first state councillor for the employees in supported employment. I was really proud of it. As I got higher in the union I kept seeing more and more political and the more political I saw the more I backed down. I did not want my workers to see how political it was. I then left the union as a delegate but they refused to take my resignation because they said “they need me” but I said “no”. At the time I was having a bad relationship and I just wanted to get out of it and they said “why are you leaving” and I said “personal problems and family reasons”. They rang me and said “your personal problems won’t last forever we’ll give you three months off”. After three months I went back and said “I don’t want to be a union rep”. Then they wouldn’t take my resignation and kept coming and asking me for advise and I said “I am not a delegate or in the union any more”. They said “we refuse to take your resignation”.

Lara didn’t like it, she never spoke out until her sister’s children started to refer to her as ‘Aunty Stupid’. Then she felt it was time to “set the record straight” Lara.

A further position argues that self-identity is both dynamic and fluid. Reality is constructed, negotiated and defined depending upon the situation and context of every conversation (Mark Rapley, et al., 1998). At the beginning of the research I had no understanding of the disability service sector, and at times during interviews and workshops, I used Lara’s extensive knowledge of the field to clarify different terms, procedures and disability plans. This created a shifting power structure within our relationship as we moved in and out of interviewer-interviewee and mentor-mentored roles.

The unique exchange involved constant renegotiation of our roles. Likewise, Lara’s position as an advocate had conflicting roles where she saw herself as traversing worlds in providing support and/or mentoring for her ‘customers’. Part of this work involved speaking with different Government departments, disability advisers at TAFE, and/or parents.

It could also be argued that Lara identifies her two worlds in terms of power, where the ‘normal’ world has authority over the world of intellectual disability. While Lara does acknowledge that people with an intellectual disability are actively discriminated against and oppressed, she certainly does not see them as powerless.
Lara: I worked so hard to get where I was in the union but I got tired of all the political. After I stopped being the union delegate there were no challenges left for me at work. I applied to be a supervisor but I didn’t get the job because they said I didn’t have the experience. When ... came along and asked if I would like to come and work for them. I had done all that I wanted to do at my last job and the people were happy so I felt it was time to leave.

That company is gone now. It closed down and all the people are working at ... I’m glad I’m not there. It used to be a top place but now it’s about quality and all the old bosses got sacked. They are all working for another place now and it’s a wonderful company.

I’m really proud of what I have done in my life. I only wish now that I had been diagnosed before I was 41 so I could have gone earlier to a sheltered workshop because that way I think I could have done a lot more.

Since I have been at ... I got my Certificate IV in Workplace Training and I have become a technical expert. That means I have a lot of knowledge and experience in the area of disability. Before I became a technical expert I was a peer tutor. That was going around doing self-assessment with a disability training consultant going to all different workplaces and interviewing people with an intellectual disability.

I teach self-advocacy. That’s about being independent and standing up for yourself. Or I can be an advocate. Then I speak on my client’s behalf. We do both where I work.

Through active support such as advocacy, disability rights services and teaching people self-advocacy, Lara had witnessed many people with an intellectual disability living, gaining control of their lives and doing the things that were important to them. Things such as moving out of home and living independently, studying at TAFE, going on a holiday, changing employment or using public transport.

As with the other women in this research, Lara’s personal story reflects a resilience, and a remarkable ability to resolve that if nothing can be done you have to make the best out of a ‘bad’ situation and get on with it. “That’s life! That’s the way the cookie crumbles” was an expression Shirley often used to explain situations that she didn’t like, but had no control over such as the death of her boyfriend.

This research takes the theoretical position that self-identity is constructed through discourse and experience. The assumption that people with intellectual disabilities are passive recipients of the social construction of their label is firmly rejected. While the women’s social world may have been narrow, they lived in the world. They went to work each day, listened to the radio and watched television, so they had clear and definite opinions and they were able to express them.
Standing up for yourself

Lara: Once people know you have an intellectual disability if you can’t stand up for yourself they tear you apart – push you over. But if you stand up for yourself and say “Hey this is me I want to…” they let you do it. If you are quiet you’re sort of “Oh well we will forget about them. They won’t wake up”. Maybe that’s why when I worked in the workshop… I was too vocal. So they let me do what I wanted to do. If they had of come I would have jumped because I found out all these agencies I could go to. I wouldn’t of hesitated going.

At the first workshop there had been a segment on a current affairs program the night before about a husband and wife who had been married for 19 years and had 17 children. We talked about how this size family was very unusual today and why someone would have that many children and still want more — Kay thought it was for the government-paid baby bonus, Lara said that the child endowment paid by the government would have been a large amount of money or that they were very religious. Shirley could not understand how anything in the house got done because the mother would have spent most of her time in the laundry just doing the washing and ironing let alone the cooking and cleaning. Her sister had two children and they were very time-consuming; therefore, anyone who had 17 children had to be crazy.

Drawing on her experience of being one of five children, Lara was able to explain that the older children look after the younger ones and everybody has chores to do. This way the responsibility was shared and everything gets done. The three women present in this conversation were clearly able to draw on their own and other people’s experiences and put that within a broader social context. Like other people with and without intellectual disabilities, the women asserted their own ideas and rejected others that did not conform to their view of the world. In this instance, the views they expressed were about the acceptable number of children a couple should have.

The women also had strategies that they used for changing the subject and confronting power relations (Mark Rapley, 2004). There was a different power structure in the interviews and the workshops. Evie’s yes/no answers when I strayed into areas that she was not prepared to discuss in the interviews is a clear example of avoiding the question. Within intellectual disability literature, the use of yes/no answers is more often seen as a form of acquiescence or being unsure of how to answer the question (Leena Matikka and Hannu Vesala, 1997). This discourse ensures their answers hold little validity and it fails to recognise the power differential within the relationship. As Mark Rapley (2004) so aptly reminds us, people in
Professionalism

Lara: It's important to look your best when you're training. People have to sit all day they don't want to look at someone who doesn't look their best.

When I tell them I have an intellectual disability, someone usually says “You don't look like you do” and I say “How are people with intellectual disabilities supposed to look?”

When you’re told “You can’t do that” all the time you stop trying. It’s important for people with intellectual disabilities to have role models. It makes them stop and think “If she can do it so can I!”

positions of power can influence the most intelligent people to be compliant.

Unlike assertions made by Robert Edgerton (1993) that people with intellectual disabilities pretend to be competent, the women in this study were competent and describe themselves as capable. For example, they saw themselves as a ‘good employee’ — they did what was asked of them, followed the correct procedure and were diligent. They disassociated themselves from people they considered ‘bad employees’ such as people who were always late or rude or inconsiderate.

Apart from being good sisters, friends and daughters, the women also saw themselves as competent in other areas of their lives and were able to talk about their talents: Kay was proud of her artistic skills and qualifications; Evie was good at handicrafts; Shirley loved cooking and like many women she had a few different favourite recipes she like to cook on special occasions; Cindy described herself as a good dancer; and for Lara, being able to listen to and speak with any person was important to her personally and also professionally.

Lara took great pride in her work and projecting a professional image. Like the label ‘intellectual disability’, what it means to be a ‘professional’ is formulated through social interaction and the positioning of certain discourses as truth. For Lara to behave in a professional manner included keeping confidences, having integrity, maintaining up-to-date qualifications, knowing what is happening in her field, and having a level of confidence and expertise that put her clients at ease and left no doubt in the minds of others that she knew what she was talking about. The latter was very important when negotiating and dealing with people in government departments.

Portraying a professional image that lets people believe in your personal power without having to say anything incorporates dressing in a particular way. Lara’s personal style at work was to wear navy pants, jackets, stockings and clean shoes. She styles her hair, manicures her nails, wears natural makeup and
Humour

Lara: Not long after I started at the workshop this lady came up to me and said “You should see my two little girls”.

I thought “Oh she’s got babies. Oh that’s lovely!”. That’s what I was thinking. I thought no more of it. All of a sudden these two ugly girls came in and they ran up to me and gave me a kiss. They were the ugliest kids I’d ever seen. As I’m thinking “Who the hell are they?”,

She came up to me saying “Did you see my little girls” and I went “oh.. ok..”. After that nothing surprised me!

Can I advise you on something because I am really worried for you?

Janette: Sure. What are you worried about?

Lara: I told you that story because you have to be careful. We’ve been caught before like people come in and we think “oh poor thing!” We enquire into it and they are only telling you half of what they know. So be careful. Please be very careful.

ACCESSORISES WITH JEWELLERY AND A HANDBAG THAT MATCHED HER SHOES. HER DRESS STYLE REFLECTED THE WESTERN STANDARD UNIFORM OF A PROFESSIONAL PERSON. LARA WASN’T ’PASSING’ AS A PROFESSIONAL, SHE WAS ONE.

The women who took part in this research were also aware of the negative images many people in the community have about people with intellectual disabilities. For example, when people totally ignored them and spoke with their partner or parent or support worker assuming that they could not understand what was happening or being said. All the women commented on how they found this annoying; however, Evie also felt that it worked to her benefit sometimes because “if you stay quiet they tend to forget you’re there and that’s when you hear what’s really going on”.

As this comment shows, the women had a great sense of irony and wit, and they incorporated this into their story telling. Humour within intellectual disability literature is more often sited in negative terms where people with disabilities are the brunt of other people’s jokes or disparaging remarks (Sylvia Bercovici, 1983).

Some research does make comment about the use of humour used by people with intellectual disabilities. Dorothy Atkinson (1997) found that speaking in a group and sharing memories about a specific subject, for example working in a sheltered workshop, stories of rebellion and humour are recounted where people with intellectual disabilities are the victors over people in positions of power. Lara’s story about how the ‘workers’ went to the community legal centre to get their supervisor reinstated and using stress as a way to stage a walkout rather than going on strike are two examples of this type of story-telling. This was not the only time, however, the women used humour. They also incorporated a sense
Partners

Lara: I met John just after finishing a very bad relationship. I was mentally abused by a guy I lived with until I kicked him out. I didn’t realise that I was abused because I did know, so now I go and talk about domestic violence. It was just like a nightmare I think if I had not told him to go I would be dead by now. He would have probably done that…..

Then I met my John. My John is an angel. Ok I whinge about him but really I’ve got nothing to whinge about.

He’s really good to me.

He would never hurt me he’s not that type of man. We’ve been together for eight years. The time’s gone really quickly.

We’re both pretty independent so we don’t get under one another’s feet. He does the outside jobs — the mowing, gardening and taking out the rubbish. I do the inside jobs sometimes he helps me but you know men it’s often quicker if you do it yourself!

The women also shared private jokes such as winking at one another when a ‘tall’ was being told. When Chris drove some of the women home after the workshops because of confidentiality, they would not talk about what they had discussed during the day, instead referring to our discussions as “secret women’s business” and changing the subject onto a different topic. Private understanding such as jokes, phrases, nicknames and a shared history are an integral part of friendships. Having, maintaining and doing activities with friends was one aspect of the women’s lives they felt was very important. Having positive friendships enriches our lives (Marie Knox and Fay Hickson, 2001, Keith McVilly, Roger Stancliffe, Trevor Parmenter and Rosanne Burton-Smith, 2006). The women spoke about two types of close friends — their partners or boyfriends and their ‘good friends’. While only two of the women, Lara and Evie, had current partners, all of the women had had boyfriends except for Kay, who hoped that she would meet someone in the future.

Part of the future for the two youngest participants, Kay and Cindy, who were in their late twenties, was to settle down, get married and have a family. Influenced by disability rights discourses, current attitudes towards people with intellectual disabilities marrying are slowly changing. In the late 1970s and early 1980s when Shirley and Evie were around the same age as Cindy and Kay, marriage would not have been option for them. Even so, both Shirley and Evie had maintained long-term relationships that lasted over a decade and until their partners’ sudden deaths.
Lara: Last weekend we went out with our friends to the country for a drive and a picnic. He belongs to a car club. They love their cars! You could eat off the bonnet but I wouldn’t dare!

He keeps that car spotless inside and out. He’s not the only one. All the car club people are proud of their cars. When we go out with the club they all stand back and look at each others’ cars and talk about them for hours.

Some of the partners are like me. They’re not really interested in the cars, but we have become good friends. I don’t mind going, really, it keeps him happy. When he’s happy it makes me happy too. You have to have different interests, otherwise you drive each other mad!

Some of our friends in the club moved to the country and that’s what got us thinking about living there. Then John’s mum died. She left him an inheritance. It was enough to buy a house in the country. We could never afford to buy something in the city. We were always going to retire to the country. We can just do it earlier now.

Some people thought I was strange letting him pick the house. They said “I wouldn’t let my husband pick my home” but it’s his money. We talked about what we wanted and I trust him. I’ve saved up and I’m going to buy the curtains and other things. I can’t believe it’s happening. I never thought I would ever live in my own home.

The death of their respective partners had created a large void in Evie and Shirley’s lives and although their partners were dead they continued to play a pivotal role in the women’s lives. Both of the women were deeply in love with their partners, and they were both coming to terms with their grief and loss. Shirley spoke about how her partner was the “love of my life” and how she didn’t feel that anyone could ever replace him. She kept a photograph of the two of them on the sideboard in her lounge room along with pictures of other people that were important in her life — family members and friends. Evie’s partner was her “soul mate” and while she was in a new relationship now she spoke about how the men were very different. Her current partner was ‘good company’ but this relationship did not have the depth of understanding or feelings she had experienced with her previous partner.

Good company was an important characteristic of friendships. While sexual preference was not discussed, all the women had clear ideas about their ‘perfect partner’ who was male, honest, trustworthy, kind and gentle. He had to be a good listener, have a sense of humour, didn’t get cranky very often and was a good dancer. These qualities were more important than good looks, although the women would prefer that he was not ‘really ugly’.

Platonic friendships were also important and the women considered themselves as ‘good friends’. Reciprocity along with feeling comfortable and able to
Friendships

Lara: I have some really good friends. I met some of them through work, the car club and other places.

I have to travel by public transport so unless John comes with me I usually don’t meet my friends at night. Working part-time is good because I can make a time to meet them during the day, somewhere close to transport. We’re all very busy so it’s nice when you can catch up.

When I move to the country it will be hard to see my friends but I use MS messenger, e-mail and the phone so we should be able to talk to one another even if we don’t see each other often. They can always visit me. We have a spare room and I can stay with them when I come to Sydney.

I’m not worried about making new friends in the country.

trust and confide in each other, having a shared history and common interests, and having someone to talk to and speak up for you were all important things that built close and lasting friendships. Friends were also people “you can go out and have fun with” Kay. “Go to parties” Shirley. And “go dancing with” Cindy.

Despite research suggesting that having stable and rewarding friendships plays a significant factor in the physical and emotional wellbeing of people, the impact of friendships on the quality of life of people with intellectual disabilities has attracted little attention (Eric Emerson and Keith McVilly, 2004).

While Evie and Cindy’s circle of friends may have been small as they had fewer opportunities to make new friends outside of work, maintaining the relationships they did have became essential. Yet there appeared to be little importance placed on this area of the women’s life in supported accommodation policy, guidelines and by their support workers. The high focus on risk management actively worked against these two women making and maintaining friendship. Research in the area of community inclusion has shown that having a community presence does not foster social networks that lead to building friendships and feelings of connectedness (Karl Nunkoosing and John Methilda, 1997).

Cindy in particular spoke of how moving from the country to the city was difficult as she had to “start all over again”. At the time of the fieldwork, loneliness was a significant issue in Cindy’s life (Kay Garvey and Biza Kroese, 1991, Wendy Booth, 1998). Separated from her family, friends and boyfriend, Cindy had found making new friends challenging and having a reputation for being non-complaint placed additional restrictions on her already limited social network. While all the women had felt loneliness at different times of their lives, they didn’t consider themselves to be
lonely people'. This would tend to support research findings that people with intellectual disabilities experience comparable levels of loneliness to that of the general public (Keith McVilly, et al., 2006).

The women had developed different strategies for combating loneliness. While Lara used the computer to stay in contact with family and friends, most of the women communicated by telephone and tried to see their friends as often as possible. Unlike the other women in the study, some of Shirley's close friendships began when she was still at school. These friendships had been maintained for over thirty years, and as close friends they had shared the best and worst times of each others' lives providing each other emotional support and understanding.

Shirley also spent one weekend in every six weeks with three of her “dearest” friends in respite care. The four friends looked forward to spending time together “looking around the shops” going on “outside picnics” or “to the café or somewhere else”. At the house where they stayed a “lady cooked for us, she cooked roasts and sometimes she cooked lemon chicken. It’s nice! …lovely!” Shirley. On the weekends Kay also enjoyed time-out relaxing with her friends. Apart from just going to one another’s homes, they went shopping, to the movies and out to cafés. Like Shirley, Kay particularly enjoyed the times when she and her friends would spend the whole day cooking. They met in the morning at one person’s home, selected the menu, went shopping for the ingredients, and after they had finished cooking they would all sit down together and share the meal they had spent the day preparing. Meeting at each others, homes promoted reciprocal arrangements. Lara had arranged this type of invitation to maintain contact with her friends when she moved to the country — she would stay at their home when she came to the city and they would stay with her when they visited her in the country. For people on a limited income, these types of arrangements provide inexpensive ways of maintaining friendships.

Other common interests the women had that formed the bases of their friendships included listening to music, going to craft and dancing lessons or to the gym. To further John’s interest in his car, he joined a car club as a way to make contact with people who had similar interests. Lara and John both enjoyed going to club meeting and activities together. Joining this car club had extended their circle of friends and talking with other members had influenced them to consider moving to the country. Just as the women made time to be with their friends, it was important for Evie to have time away from her two flat mates.

After spending a lot of time together, shopping, eating meals and watching television, having time away provides a counter-balance to their relationship (Marie Knox and Fay Hickson, 2001). For Evie, this often meant spending time alone in her room reading, or going for a walk. Having most of their social activities organised through their accommodation support provider, the three flat mates had many mutual friends. While many mutual friends widened their circle of friendships, it
also meant that they had to make individual arrangements to spend time with a mutual friend alone. The lack of privacy and few opportunities to meet with friends outside of the home added to the difficulties of maintaining friendships.

In summary, being diagnosed as having an intellectual disability at the age of 41 gave Lara a unique perspective on life. While she identified as having an intellectual disability, she did not conform to the stereotypical identity of a person with an intellectual disability. Lara was self-confident, self-assured, made her own decisions, and lived an independent life. Lara challenged herself and others to improve their lives. She saw self-advocacy as a positive way to change the lives of people with intellectual disabilities even when the process was often resisted by support workers and managers.

Unlike previous research, this study has suggested the women in this research were not ‘invisible to themselves’. While intellectual disability was a part of their self-identity, it did not define them. How they defined themselves invoked the process of experience, interacting with the social world and interpersonal relationships. Friendships were one of the most important things in their lives. All the women had ‘best friends’ and most had had ‘intimate friends’ that they shared their lives with. Living on a limited income, a lack of privacy and maintaining contact made keeping old friendships and making new ones difficult. Yet despite some or all of these difficulties, the women had a range of relationships, from acquaintances through to close friends.

Friendships are seen as one of the keys to maintaining a good quality of life. For people with disability, having an ‘optimum quality of life’ is a goal of disability policy in NSW (Ageing and Disability Department, 1998a). In the area of friendships, more work needs to be done in building and maintaining a wide range of meaningful relationships.
The last word

Lara: When I first went into the workshop I was still married to my son’s father. I realised then that I was lucky. I thought to myself “I am married. I have a son and a home. It may be housing commission but it’s still a home. I am Okay! Look at these poor buggers. What have they got?”

I learnt from that place that I’m on top of the world.

Now I have a good man. I am getting a lovely house I can call my home. I have two beautiful grandkids and a lovely son. I am not too happy with my daughter-in-law at the moment, but I’m not worried about it. That’s their life. I have nothing to complain about. I am happy. I have a fantastic job. What have I got to complain about?

Figure 50 - Self portrait, 2005, Lara. Pencil, Size A3.
Janette Welsby

OUR STORIES: WOMEN, LIFE & INTELLECTUAL DISABILITY

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You’re The Voice

We have
The chance to turn pages over
We can write what we want to write
We gotta make ends meet before we get much older
We’re all someone’s daughter
We’re all someone’s son…

You’re the voice try and understand it
Make a Nose and make it clear
Whoa oh oh
We’re not gonna live in silence
We’re not gonna live in fear

This time
We know we all can stand together
We have the power to be powerful
Believing we can make it better

9. YOU’RE THE VOICE — FINALE

His research journey began with a single story that sparked my interest to learn more about the lives of women with an intellectual disability. As I travelled, I learnt from the participants about the complexities of their lives. I read Australian disability policy and regulations, and learnt the official perspective of intellectual disability and how this discourse shaped the lives of the women. I reviewed some of the large body of literature on intellectual disability from researchers in Australia and abroad. Although this literature was constructed from diverse perspectives, I found many commonalities as well as differences. I recognised that we all see the same world through different eyes and this makes our individual perspectives unique. My perspective is not un-biased. I did not set out to be neutral. I wanted these women’s stories to touch your lives, tug on your heart strings and make you smile.

This research tells the stories of ordinary women who often lived in extraordinary situations. As Cindy, Kay, Evie, Shirley and Lara shared their personal experiences, they connected with the life stories of each other and with me. Some of our stories may resonate with you; others may not be your experience. Re-telling our stories here we connect with you and become part of your stories. Just as ripples from a pebble dropped into a pond move out across the water each time these stories are re-told they move beyond this research, making a discursive space for alternative stories about women’s lives to be heard.

People with intellectual disabilities are often described in negative terms or in tragic stories of abuse and neglect. Many historical stories of people with
intellectual disabilities are written in medical records or institutional notes, so often the personal stories of these people’s lives are missing (Dan Goodley, 1996, Dorothy Atkinson, et al., 1997, Maureen Gillman, et al., 1997). Constructing history from historical records often fails to recognise the contribution people with intellectual disabilities have made to Australian society. Very few archival accounts describe people with intellectual disabilities as workers, taxpayers, citizens and consumers.

This research set out to explore the lives of a small group of women with an intellectual disability, in order to understand what was important to them and gain an understanding of their lives from their point of view. Like many women, maintaining and nurturing the relationships they had with life partners, family members and friends played a significant part in their lives. Earning enough money to live and to be able to save so they could afford to purchase small extravagances for themselves, such as lipstick, CDs, hairdressing or dinners out was also important. Most importantly, the women liked to be able to buy gifts for the people they loved at Christmas, birthdays and other special occasions during the year.

The women in this study enjoyed the company of good friends, going to parties, dancing, meeting new people and living their lives as independently as possible. They didn’t like having to rely on other people, being abused or spoken to rudely. The women objected to being treated differently and although they knew their rights, they were not often in a position in which they could exercise them. Having little control over their lives often created a disparity between what was important to the women and their lived experience.

**Thesis Review**

The opening chapter of this thesis outlined the evolution of this research project. Chapter two positioned the research in relation to existing theories and models of disability and detailed my rationale for using a post-modern feminist perspective to explore the women’s stories. Chapter three introduced Evie, Lara, Cindy, Kay and Shirley through their artwork and own words. This Chapter
privileges the women's voices and recognised and respected them as women and experts in living with an intellectual disability.

Chapter four outlined the research design and approach. Important elements of the design included recruitment, ethical considerations and the logistics of running the art expression workshops. The Chapter also described the iterative processes involved in developing a creative arts approach to data collection for researching with participants who have an intellectual disability. This included a consideration of the participants' limited financial situations, their travel and support arrangements, and the specific requirements for their physical environment. Specifically, it is common for many people with an intellectual disability to use less formal forms of communications such as oral traditions in their day-to-day lives rather than more formal forms such as written records (Dorothy Atkinson, 1997, Dorothy Atkinson and Jan Walmsley, 1999). This was true for the women in this research in that while they could all read, they had difficulties writing.

The data collection process revolved around five art expression workshops so that the women could express themselves and share their experiences in different and creative ways in a safe, relaxed environment. A number of one-on-one interviews were also undertaken for those women who could not come to an art workshop or to clarify information about the experiences they described in the art workshops. Other forms of data collection were pictorial records of the art workshops and art works. These photographs were downloaded and viewed by the women at end of each workshop. Looking over the photographs became a part of the day's reflection, and the women took this opportunity to delete any photographs they did not want to be included in the research. A further source of data was the research diaries that recorded my research journey. These diaries also provided a running record of the group's interactions and were an invaluable record as the art workshops were not audio- or video-recorded in order to promote spontaneity.
As a feminist, as discussed in Chapter five, my research approach was underpinned by my desire to ensure that there was reciprocity in the relationships. For example, by participating in the five workshops that were facilitated by Moi, an experienced artist and art teacher, the women were introduced to a range of artistic media and methods they could choose to use to express themselves; any artwork they wanted to take home was mounted and they were given a pictorial record of their participation in the research process as a memento of the time we shared.

The level of reciprocity was enhanced in having Moi as the workshop facilitator. This allowed me to actively participate in the research process and reduced some of the power imbalance between researcher and researched. It also allowed me to put myself in the research and reflect upon the multiple roles that I held. Although I had planned extensively to meet the needs of the participants in providing a safe and nurturing experience and place to speak, I neglected to allow myself the same considerations, leaving me unprepared to deal with the emotional and physical impacts of the research. These impacts were profound and fundamental to (in)forming my post-modern feminist epistemological and ontological stance. This also emphasised the necessity of privileging the women’s voices alongside my own, as evident in this thesis.

The three data Chapters proffer insights into different aspects of the women’s lives. They detail the minutiae of Cindy, Lara, Evie, Kay and Shirley’s day-to-day lives in relation to their work, living arrangements, self-identity and relationships. The Chapters included a very personal, often intimate perspective of the experiences of different women as shared in the workshops and interviews.

Chapter six gave an overview of the women’s position in the employment market, and provided a detailed analysis of their level of income. It highlighted how people with intellectual disabilities are often exploited in the employment market, which places them in a no-win situation. The Chapter explained how the pro-rata wage system often meant they had little opportunity to increase their
earning capacity to a level where they could move off the Disability Support Pension and the supplementary benefits. It highlighted the limited opportunities the women working in business services had compared with the women working in open employment. For example, the women working in open employment had a high level of autonomy in planning their working day, and their employers supported them to fulfil their career aspirations through career progression, annual salary reviews, training and formal education. The women in business services, however, had few or no prospects of moving off the assembly line or shop floor, even though business services is positioned as a stepping stone to open employment.

Chapter seven provided a discourse analysis of the state and federal government disability policy and regulations that relate to supported accommodation. This analysis revealed three competing discourses: human rights; managerialism; and risk management. A discourse of risk management subsumes the discourse of managerialism and human rights. The risk discourse positions the women as ‘always at risk’, thereby providing a justification for the constant surveillance and control exerted over their lives. Although disability policy clearly articulates the rights of the women to live independently and have choice, the chapter reveals the contradictions and complexities that accompany living with the label ‘intellectual disability’ and living in supported accommodation.

Life according to Lara is presented in Chapter eight. It details how Lara navigates between what she perceives as her parallel worlds – the ‘normal world’ and the ‘world of intellectual disability’. Her stories about intellectual disability reflect these dual worlds, and I have used them as a trigger to critically explore self-identity and intellectual disability. The Chapter also examined the importance the women placed on friendships and relationships, and it highlights some of the difficulties they experience in maintaining them.

In Chapters six, seven and eight, the women’s experiences are positioned within the context of wider society. This is done in order to convey a practical
understanding of the women’s daily lives, and to gain insight into the lived reality of what it means to be a woman with an intellectual disability living in a major capital city in contemporary Australian society.

THE Methodological Contribution
There are a number of parallels between my research journey and the lives of the participants. Using non-traditional research methods and research participants has been an interesting experience, and it often placed me on the margins of academia. Exclusion is an interesting concept and I have often felt I was a round peg in a square hole as my topic and method did not fit nicely into a box; it crossed disciplines and pushed boundaries.

I have experienced academics who have called my research “not methodologically sound” because of my choice of participants and methodology. In their opinion, people with an intellectual disability were unreliable research participants as they tell lies. Any data I collected, they said, should be validated by another person – someone without an intellectual disability. The construction of ‘truth’ in my data was usually raised as an issue. Yet when I asked them how they verified that the data they collected was always ‘truthful’ they couldn’t, or claimed it was not a problem with their choice of participants. I learnt to be a bit cheeky, and would pose questions such as: if they were researching survivors’ experiences of domestic violence would they speak to the perpetrator to verify the number of times they actually hit their partner? Often the people who queried the validity of my research were mortified I would even suggest this idea.

What this taught me is that researchers are never un-biased. We are all influenced by stereotypical ideas and cultural myths about certain groups of people. We make value judgements about people’s lives, often based on little information. As social beings, we do this every day and our attitudes, beliefs and upbringing colour our world. I recognised that I needed to be vigilant in my

48 This comment is not a reflection on my supervisors. From the very beginnings of this research project both Moira and Debbie have supported me to take the road less travelled.
awareness of my own particular biases and assumptions. I incorporated
reflexivity and journalling into my research practices to help me unpack and
explore some of my preconceived ideas about women and intellectual disability.
Adopting a post-modern theoretical stance where a real, tangible fixed notion of
truth gave way to an idea of something less static and more dialogic and
dynamic allayed some academics’ concerns about the soundness of my data.

Even so, my feminist theoretical stance was also questioned. I soon learnt that
in some academic circles, feminism was similar to other ‘f’ words such as
Foucault, and should not be uttered in public! This brought out my
stubbornness, and I realised that within this work, some things I considered
integral to the research I was not prepared to change. I learnt that this was okay
provided that I was able to justify my position. I reviewed the literature on
disability research to establish and critique the main theoretical positions
against post-modern feminism to see if I had the adopted the best theoretical
position for this research.

After I had decided my research participants and chosen theoretical
perspectives, academics then began to raise concerns about getting the
research proposal through ethics. People with an intellectual disability were
seen as a ‘vulnerable group’, and I was constantly advised to do research on
people that were seen as ‘less problematic than my target group’. Moira
Carmody was away at the time and I worked closely with Debbie Horsfall on my
ethics application. What I learnt from Debbie was to follow my own instincts, be
precise and demonstrate that I had taken the time to think through the ethical
and logistical concerns, as well as any possible difficulties that could arise when
researching with people with an intellectual disability. To everyone’s surprise
(including my own), my ethics application was approved without changes or
queries. The knowledge I gained in this stage of my research journey was that
having to go through the ethics process helped me to define and refine my
research. It highlighted the impracticability of using Photovoice as a method for
this research. This led me to look at other creative ways of doing research and
how to place the needs of my participants at the forefront of the research design rather than my own.

During the fieldwork, I learnt that this approach was not always practical when it came to collecting data. Letting the participants decide where they would like to be interviewed resulted in conducting interviews a few weeks before Christmas, around lunchtime, in noisy shopping centre cafes. This was fraught with difficulties: little privacy; constant interruptions; and transcription nightmares. In the art workshops, I learnt that the women did not always conform to the stereotypical beliefs about people who have intellectual disabilities, such as that they are compliant and childlike in their thinking. This took me beyond the superficial into a discursive space (or world) that was complex, rich and challenging.

This research sought to disrupt fixed ideas about people with an intellectual disability and research. Within our society, being artistic is traditionally seen as biologically determined. Artists are seen as talented or gifted — notions that are not normally associated with people with an intellectual disability. For many of the disability workers I approached in the recruitment stage of the research, and for some of the women themselves, thinking about themselves as artistic was exigent. This was also the case for some academics, particularly those with a fine arts background, where crafting is important to the integrity of the work. Within my method, crafting is of little importance. Using creative arts as a data collection method also pushed boundaries for many academics who, to my surprise, were very positivist in their ideas about what constituted 'real research'. Art in academic research is often located within 'fine arts' or 'art therapy' or 'arts-based education' where the focus of the research is often practice-based. When using visual arts in research, the focus is usually to draw out what the art says, and/or what can be said about the art. This research differs significantly, in that art practices were used as a way to draw out stories; the focus was on the story and not on the artwork.
All forms of visual art are not simply visual; they are both textual and visual. They are textual in the sense that what is seen, whether or not in ‘words’, is present in the form of signs. What is seen (visual) and what is written (textual) does not have to correspond; rather, they are disjunctive and do not necessarily have to rely on one another. It is this disjuncture or disruption in the space between the visual and the story that captured my interest and makes this research different.

**The Significance Of The Research**

In telling the women’s stories, the research illuminated the multiple experiences of the women as they moved between worlds defined by policy and yet lived very idiosyncratically. This research raised ethical issues for researchers, policy-makers and disability workers by highlighting the impact government policies and attitudes to support have on the women’s lives — in particular their opportunity for autonomy. For example, workplace practices often trapped the women into dependency through poverty. Although people with intellectual disabilities no longer live in large-scale residential institutions, what I found was that living in a community location does not guarantee independence nor normalisation, despite the promises of individuality and choice. For **Evie** and **Cindy** who lived in small group homes, often their every move was controlled — having no direct access to their income, limited lifestyle choices such as where they could shop, who they could become friends with, and where and with whom they could live.

I found that when asked, the women in my research had a lot to say. They analysed their own lives and the lives of others in a discussion of their view of the world and what was important to them. There is a tendency within research (and policy) not to actively seek out this section of the population in selecting participants. This has resulted in their voices being marginalised. Although my research is important, as it provided a way for five women to tell their stories, it also perpetuated the cycle of social exclusion. Some of the women, particularly those who worked in business services and also lived in supported
accommodation, lived and worked in social isolation. The problem of often working in a closed environment, the lack of access to transportation, monitored communication and having a limited income also impacted upon the women’s ability to make and maintain friendships and engage with the community.

This research is based on the lives of five women and their experiences. While some of their stories may be similar to other women who have an intellectual disability, they are not reflective of all women’s experiences. Further research is needed to explore more extensively the lives of other women and it is for this reason I have not made policy recommendations. The recent move to person-centred planning in NSW is an important step towards focusing on the individual needs of a person using healthcare and other services, however, without change the neoliberal ideas and the dominant discourses of risk management and managerialism within current disability policy and funding models will continue to erode the human rights of people with intellectual disabilities. The importance of education and training of support workers and policy makers becomes critical in ensuring social justice and social change continues to occur in the lives of people with disabilities.

People with an intellectual disability are part of the community, and as researchers, we need to look at finding ways of ensuring that our research practices include them. I recognise that this is not without its difficulties, for example, the communication difficulties that can arise from researching with people with intellectual disabilities. For people with severe and profound intellectual disabilities, very little research has actively sought their point of view. Finding creative ways to do research that incorporates other forms of communication becomes paramount for people who may have difficulties with oral or written skills and cognitive abilities.

While I have been doing this research I have found it difficult to find any published history on the lives of people with intellectual disabilities who live/lived in New South Wales. As large-scale institutions have been closed for some twenty-five years unless research is urgently conducted that documents the oral
history of the people that lived in these places, their personal stories will be lost. Leaving history to be reconstructed and examined through medical and official records often fails to tell the personal stories of people’s lives.

This thesis highlights the need for further research in Australia that outlines the impact that neoliberal managerialist principles, embedded within disability policy, has on people with intellectual disabilities who use government-funded services. The current focus on risk management within supported accommodation policy has resulted in clients having little independence and few opportunities for making real and meaningful choice in their lives. Further research in this area is needed to bring about positive social change.

The dissemination of the results of this research has been ongoing throughout my candidature. I have attended and presented papers at postgraduate and international academic conferences for example Isolation, Disconnection, Solitude and Seclusion in a Connect World December 2006 in Tasmania. After examination, the findings of this research will be presented to agencies, service providers and policy makers at Australian disability sector conferences. These Australian based regional conferences, such as the NSW Support Workers Conferences, attract people working within the disability sector. I have also presented the finding of my research at public forums such as the Stop Domestic Violence Day at Penrith, NSW in December 2008 and through guest lecturing at the University of Western Sydney.

It is anticipated that articles based on the finding will be submitted for review to Disability and Society, The British Journal of Learning Difficulties and The Qualitative Report. I have also co-authored two edited book chapters (Debbie Horsfall and Janette Welsby, 2007, Lisa Armitage and Janette Welsby, 2009). This thesis upon completion will be submitted to Australian Research Online a repository of Australian university and government research as well as the Australasian Digital Thesis Program. These two databases will hold a digital version of this thesis which can be accessed worldwide via the web thus disseminating my research to an international audience.
**Epilogue**

At the beginning of this journey, I set out to learn about the lives of women — women who have an intellectual disability — women who were invisible to me. What I learnt was that these women have the same dreams, hopes, worries, joys, sorrows and concerns as most women. They spend their lives doing the same everyday things that make up the fabric of life – cooking, cleaning, caring, nurturing, and working. They live ordinary lives often in extraordinary circumstances and are at times forced to inhabit narrow spaces between tightly controlled and monitored boundaries. Their lives were often defined for them by a label that permeated their life opportunities — opportunities I used to take for granted — where I can work, live, entertain, shop, travel as I please. By opening a window into a previously shuttered space, this thesis demonstrates that these women are also sisters, mothers, wives, friends, students, lovers, jokers, workers, trainers, contributors, and survivors.
Figure 51 - Your window out of my research.

CLOSING WINDOWS

Travel out though this window

a swirl of colour and imagination

constantly moving and changing

of feminist post-modern research

stories making connections

onto your own thoughts and reflections

of stories, art and inquiry

lives that are different yet familiar

out to a world of new possibilities

JANETTE WELSBY (2008)
WORKS OF ART

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APPENDIX A — ORGANISATION INFORMATION

18th July, 2005

Address

Dear…………………………,

“MY JOB” – WHAT SOME WOMEN WITH AN INTELLECTUAL DISABILITY HAVE TO SAY ABOUT WORK.

Further to my telephone conversation with you in regards to my PhD research I am writing to provide you with further information and to ask you if you would have two-three possible participants who would be interested in taking part in this research project about workplace experiences of women with an intellectual disability.

WHAT IS THE RESEARCH ABOUT?
The research aims to explore the workplace experiences of women with an intellectual disability through painting, sculpture, drawing, music, movement and storytelling.

WHAT WILL THE PARTICIPANTS BE REQUIRED TO DO?
Each participant will be asked to agree to take part by signing a written consent form which is attached to their information sheet. Taking part in this research project is purely voluntary and it involves being able to meet once a week for approximately three months.

Once a fortnight participants will be asked to talk on a one-on-one basis with me about what their art represents in relation to their experience of work. These informal interviews will take about one hour and will be held at a time and place that best suits the participant. The other part of the research consists of five different art expression workshops that will be held every alternate Saturday at UWS Parramatta Campus from 10am to 3pm. Lunch will be provided. A prepaid Taxi will pick up and return home all participants. I hope to commence the research the second week in October 2005.
Workshop 1 - 15th October: This meeting is to meet and start to get to know the other women in the study. I will have already spoken to the women we will have some areas that they may like to explore over the coming workshops. This workshop will focus on “Who I am” and will explore this theme through various style of self-portraits.

Workshop 2 - 29th October: will be held at the NSW Art Gallery. The gallery will be used to look at different works of art to explore how art can be used to communicate a thought.

Workshop 3 - 12th November: In this workshop movement will be used as a form of expression. This includes photography, shadow and charcoal drawing and discussion around a theme selected by the participants.

Workshop 4 - 26th November: Using free form clay modelling and still life painting and drawing this workshop will explore various aspects of their work.

Workshop 5 - 10th December: participants will choose some of their work to incorporate into a collage. This workshop is designed to explore the dynamic and multi dimensional lives of each woman.

As this is a small scale study 6-10 women I am trying to ensure that women who work in a range of different employment options and who come from different cultural backgrounds have the opportunity to participant in the research. You need to be aware that even if you have some potential volunteers they may not be selected to participate.

WHY IS THIS RESEARCH IMPORTANT?
It provides an opportunity for the participants to reflect, explore their own feelings, to express them and tell their story in a variety of different ways.

CONFIDENTIALITY
All discussions about their art and experiences of work that they choose to discuss will be recorded on blank cassette tapes and kept in a secure location by the researcher. The interviews will be totally confidential, no participant will be identified and all the data will be coded to ensure anonymity. In addition any participant is free to withdraw their consent to participate at any time without question including at any time during the interview or workshop process. If a participant chooses to withdraw at any time their tapes, transcripts and art work will be returned to them. Any publications that result from the research will not identify the participants in any way. Sometimes talking about workplace experiences and feelings can raise emotional issues for participants and all participants will be given the contact details for local counselling services if the need arises.

WHO AM I AND HOW CAN YOU CONTACT ME?
My name is Janette Welsby. I am a student at the University of Western Sydney and this research is part of a Doctor of Philosophy (Mark Deal). My supervisor is Debbie Horsfall tel: 02 4736 0093. This research has ethics approval from the University of Western Sydney a copy of which will be forwarded to you in the post. I can be contacted on 02 4736 0188 or 0412 002 132 should you have any questions about this research.
COMPLAINTS OR RESERVATIONS

This study has been approved by the University of Western Sydney Human Research Ethics Committee. If you have any complaints or reservations about the ethical conduct of this research you may contact the Ethics Committee through the Research Ethics Officers on telephone number 02 4736 0883. Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

Thank you for your interest in this project and I look forward to speaking with you in the future.

Yours faithfully,

Janette Welsby
HDR Candidate
The Social Justice and Social Change Research Centre
APPENDIX B — PARTICIPANT INFORMATION

“MY JOB” – WHAT SOME WOMEN WITH AN INTELLECTUAL DISABILITY HAVE TO SAY ABOUT WORK.

I am writing to ask you if you would like to be a participant in a research project about your workplace experiences.

WHAT IS THE RESEARCH ABOUT?
The research aims to explore the workplace experiences of women with an intellectual disability through painting, free form sculpture, drawing, movement and storytelling.

WHAT WILL I BE ASKED TO DO AND HOW MAY IT EFFECT ME?
Taking part in this research project is voluntary. It involves being able to meet once a week for about three months.

One meeting will be every second week to talk on a one-on-one basis with the researcher about your experience of work and what your art represents. These informal interviews will take about one hour and will be held at a time and place that best suits you.

Secondly to attend five different art expression workshops that will be held every alternate Saturday from 10am to 3pm. You do not have to know about art to be part of the research. All the materials, lunch and a transport to pick you up and take you home will be provided. The Saturday workshops will be held at the Parramatta Campus of the University of Western Sydney in room EMG06. Because the university is large and it is easy to get lost your transport will drop you at the security office and I will meet you there.

Workshop 1: October 15th This workshop is to meet and start to get to know the other women in the study. The theme for the first week is “Who I am” and we will do this through different types of self-portrait.

Workshop 2: October 29th will be held at the NSW Art Gallery. We will look at how art can be used to tell a story or a thought.
Workshop 3: November 12th In this workshop we will use movement as a form of expression. This includes photography, shadow, charcoal drawing and discussion.

Workshop 4: November 26th Using free form clay modelling, still life painting and drawing in this workshop.

Workshop 5: December 10th This workshop will use some of your work and other materials to make a collage to express your experiences of work.

As I am trying to ensure that women who work in a range of different employment options and who come from different cultural backgrounds have the opportunity to participate in the research, you need to be aware that even if you volunteer you may not be selected to participate.

**WHY IS THIS RESEARCH IMPORTANT?**
It provides an opportunity for you to reflect, explore your own feelings, to express them and tell your story in different ways.

**IS WHAT I SAY CONFIDENTIAL**
All discussions about your art and your experiences of work that you choose to discuss will be recorded on blank cassette tapes. The tapes will be used as an oral record and sections of it may be transcribed to form part of my thesis or used as part of the published findings of the study. The original tapes will be kept in a safe secure place by the researcher. Part of confidentiality is your privacy. This means that you will choose a pen name to keep anything you say confidential and so that you cannot be identified. If for any reason you do not want to stay in the study you can stop at any time without question, including at any time during the interviews or workshops. If you choose not to continue any tapes of your interviews and your art work will be returned to you. Any publications that result from the research will not identify you in any way. Sometimes talking about workplace experiences can raise issues for participants and all participants will be given the contact details for local debriefing, counselling, advocacy and legal services if required.

**WHO AM I AND HOW CAN YOU CONTACT ME?**
My name is Janette Welsby. I am a student at the University of Western Sydney and this research is part of a Doctor of Philosophy (PhD). My supervisor is Debbie Horsfall 02 4736 0093. A Doctor of Philosophy (PhD) is a degree that is achieved by carrying out a program of research on a particular topic and writing it up as a research paper. This research
has ethics approval number HREC 05/140 from the University of Western Sydney. I can be contacted on 02 4736 0883 or 0412 002 132 should you have any questions about this research.

**COMPLAINTS OR RESERVATIONS**
This study has been approved by the University of Western Sydney Human Research Ethics Committee. If you have any complaints or problems about the ethical conduct of this research you may contact the Ethics Committee through the Research Ethics Officers telephone number: 02 47 360 883. Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

Thank you for your interest in this project.

Janette Welsby
10/09/05
Consent Form

“MY JOB” – WHAT SOME WOMEN WITH AN INTELLECTUAL DISABILITY HAVE TO SAY ABOUT WORK.

I, ........................................................................................................

agree to participate in this research project. I understand that the research includes informal interviews and art expression workshops that participation is voluntary, that I do not have to answer any questions that I do not want to and that I am free to stop coming at any time during the research period. I understand that what each person talks about in the workshops are private and should not be talked about unless they say that it is OK to do so.

Signature                                            Date

........................................................................................................

Other information:
In case you become sick, upset or you need help. Would you be able to supply the name and telephone number of a person that could be called if required?

Name:..............................................  Telephone.....................

We are supplying lunch at the fortnightly workshops. Would you please list any food or skin allergies or things you do not or can not eat e.g. seafood?

........................................................................................................

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APPENDIX C — DISABILITY SERVICES AND RESOURCES

Abuse and Neglect Services

Disability Services Abuse and Neglect Ph: 1800 880 052
24 hour hotline for reporting abuse and neglect of people with disabilities using government funded services. Anyone can call the Hotline to report cases of abuse or neglect or to find out more about the service. The Hotline is open from 8am to 8pm across Australia, seven days a week. Cases of abuse and neglect can include physical, sexual, psychological, legal and civil abuse, restraint and restrictive practices, or financial abuse. It can also include the withholding of care and support which exposes an individual to harm.

Dympna House Ph: 9797-6733
For survivors of sexual abuse

Advocacy Services

Self Advocacy (Sydney) Ltd Ph: 9622 3005
Self Advocacy organisation run by and for people with Intellectual Disability. They provide information and support to individuals and groups to promote awareness of their rights and responsibilities within the community. This organisation supports people who want to develop their skills and confidence so they can speak out and make decisions that will effect their own lives.

City & Inner West Disability Advocacy Ph: 9212 2020
The Individual Advocates at CIWDA will help you to make sure that your rights are recognised and respected. An advocate will "stand beside" you and support you so you can make your own decisions and get what you need. We help people to stand up for their rights, for example, when people have problems with housing, immigration, school, work and disability services.

Multicultural Disability Advocacy Ph: 9891 6400
Advocacy service in NSW available specifically to people from a NESB with disability, their families and carers. MDAA aims to promote, protect and secure the rights and interests of people from a NESB with disability and their families and carers in NSW.
### Counselling Services

**Lyn Glaser**  
*Ph: 9235 3127*  
Monday, Wednesday and Thursdays  
Clinical psychologist with over twenty years experiences in private practice and has worked with people with intellectual disabilities.

### Relationships Australia  
*Ph: 1300 364 277*  
Offers resources to couples, individuals and families to help enhance and support relationships.

### Court Support Services

**Criminal Justice Support Network**  
*Ph: 1300 665 908*  
Recruits and trains volunteers to support people with intellectual disability who need to attend a police station or court as alleged offenders, victims or witnesses. 24 Hour telephone assistance to people in police detention, service providers, advocates etc, training, and liaison with other services.

### Women’s Domestic Violence Court Assistance

Bankstown 02 9709 5622  
Blacktown/Mt Druitt 02 9671 9126,  
Inner West 02 9744 1866  
Liverpool 02 9601 6988  
Newtown 02 9559 2899  
Parramatta/Ryde 02 9893 8866  
Penrith 02 4731 5098  
Assist women to use the court system to obtain Apprehended Violence Orders (AVO's) ensure that women applying for AVO's are legally represented in court provide women with the emotional support, advocacy and information they need when they are applying for an AVO provide women with appropriate referrals so that they can take action to deal with the consequences of domestic violence.

### Consumer Services

**Office of Fair Trading**  
*Ph: 13 32 20*  
Consumers of everyday goods and services can contact us for information on their rights and responsibilities and assistance with resolving disputes. People who are renting homes, buying or selling property or living in strata scheme property can turn to us for information and assistance.
Appendix

**Discrimination Services**

The NSW Disability Discrimination Legal Centre  
**Ph: 1800 800 708**

Tuesdays, Wednesdays and Fridays 9.30am to 12.30 pm  
information designed to assist people with disabilities, their friends,  
family, carers and associates, in understanding disability discrimination  
legislation. We aim to provide accurate, timely and easy-to-comprehend  
information on: Disability discrimination legislation, your rights, points to  
consider before making a complaint of disability discrimination, the  
process involved in making a complaint of disability, discrimination and  
other organisations that may be able to assist you.

**Domestic Violence Services**

Domestic Violence Advocacy Service  
**Ph: 9637 3741**

Monday, Tuesday, Thursday and Friday 9.30am - 4.30pm  
Provides a free confidential legal service for women experiencing  
domestic violence. The service provides casework services, education  
and training for service providers and is actively involved in relevant  
policy and law reform.

**Domestic Violence Line & Women’s Refuges**  
**Ph: 1800 656 463**

24 hours, seven days a week. The Domestic Violence Line provides  
telephone counselling, information and referrals for people who are  
experiencing or have experienced domestic violence. DoCS Domestic  
Violence Line makes referrals to women's refuges and explains what  
they are and what they do. It also makes referrals to family support  
services, counselling, the police and courts, lawyers and hospitals. It  
helps with transport, emergency accommodation and other relevant  
support.

**Financial Advisory Services**

Consumer Credit Legal Centre  
**Ph: 1800 808 488**

Financial counselling information, advice and referral is available 9.30 to  
12.30pm and 1.30 to 4.30pm Mondays to Fridays, to consumer debtors.

**Government Services**

Dept of Ageing, Disability & Home Care  
**Ph: 8270 2000**

Disability Support and Assistance with local disability services.
Dept of Family & Community Services Ph: 1300 653 227
Provides policies, income support and assistance for families and their children, senior citizens, people with disabilities, carers and community groups. The Office for Women provides policies and programs for women.

Disability Complaint Service Ph: 9319 6549
If a person with a disability wishes to lodge a complaint about service they have received.

Health Services

Blacktown Women's & Girls' Health Centre
Monday - Friday 9:30am - 4:30 pm Ph: 9831 2070
Centre Services: group work - support & lifestyle etc, Counsellors - long and short term. Medical doctor, Nurse practitioner, Masseuse, Podiatrist and Naturopath

The Bessie Smyth Foundation Ltd Ph: 9649 9744
Monday - Friday 9:30am - 5:30pm
Centre Services: decision-making counselling in regard to a pregnancy, abortion information, referral advice and advocacy, pre- and post-abortion counselling and Brokerage Fund to provide financial assistance on a pay-back-by-instalment basis to allow women to proceed with a termination of pregnancy operation as soon as possible.

Legal Services

Intellectual Disability Rights Service Ph: 9318 0144
Community legal centre in New South Wales who works with people with an intellectual disability to exercise and advance their rights. Legal advice and information is provided for people with an intellectual disability or others acting on their behalf within NSW.

Women's Legal Resources Limited Ph: 9749 5533
Provides a voice for women in NSW and to promote access to justice, through the provision of legal services, law reform and community legal education, particularly for women who are disadvantaged by their social and economic circumstances. Services provided include telephone advice, referral to sympathetic solicitors and services, legal information, workshop on legal issues for women, training for community workers and critiques and advocacy about how the law affects women.
Legal Aid

Ph: 9219 5000
Legal Aid provides free advice for most legal problems. Family law advice is available without an appointment at our head office in Sydney. To make an appointment on other matters or at another location, call your nearest Legal Aid office.

Law Access

Ph: 1300 888 529
NSW wide telephone information, referral and advice service open from 9am to 5pm Monday to Friday. All calls are answered by information officers who can explain: legal aid policies and services how to apply for legal aid how to get help with your legal problem. LawAccess also gives referrals to other services and will answer simple legal questions. Family and civil law advice is available from LawAccess lawyers if a caller can’t get into a legal aid office because of the following reasons: disability distance severe disadvantage the matter is considered urgent.

Sexual Assault Services

Rape Crisis Centre
Ph: 9819 6565
A state-wide 24 hour telephone crisis, support and referral service for women who have experienced sexual violence.

Sexual Assault Service
Westmead Sexual Assault Service (24hrs) Ph: 9845 5555
Blacktown/Mt Druitt Sexual Assault Service Ph: 9881 8700
Northern Sydney (Royal North Shore 24hrs) Ph: 9926 7580
Bankstown Community Health Centre Ph: 9780 2777
Liverpool/Fairfield (Liverpool Hospital 24hrs) Ph: 9828 4809

Victim Support Services

The Victims of Crime Website
Ph: 1800 633 063
24 Hour support and referral that provides practical information for victims of crime and service providers assisting victims about counselling and support services police investigations and court processes obtaining compensation domestic violence and sexual assault victims rights.

Enough is Enough
Ph: 9542-4029
Counselling service is about support, understanding and empowerment. We believe that people who have experienced the impact of crime, violence, road trauma and antisocial behaviour on their lives can be
empowered to move forward and regain control of their lives in a positive way. Assistance offered counselling, advocacy, information, court support, referrals, education, conferencing, behavioural management and critical incident debriefing.

**Immigrant Women’s Speakout Assoc  Ph: 9635-8022**
For migrant & refugee women who are victims of violence. Counselling, bilingual workers

**Lesbian and Gay Anti-violence Project Ph: 9206 2116**
The AVP takes reports of violence from victims and witnesses, refers to other services, provides advocacy where appropriate and develops community safety initiatives.

**Workplace Services**

**NSW Working Women's Centre  Ph: 1800 062 166**
Provides information, advice and assistance to women throughout NSW about issues at work. WORKWISE, all kinds of information about your rights at work - from pay and conditions, to discrimination and dismissal. MUM @ WORK, contains information about rights at work for women with families - from pregnancy and parental leave to discrimination.

**WorkCover  Ph: 13 10 50**
Information about health and safety at work

**Department of Industrial Relations  Ph:13 16 28**
Information about conditions at work
APPENDIX D — ART WORKSHOPS

Workshop One: Who I Am

9.30 – 10.00am Set Up Room

10.00 – 10.10am Participants Arrive and Welcome
Introduce myself and Moi Moi Tan
Introduce each other
Where to find/use Tea, coffee, water & toilets
Talk about the project.
Go over ethics: particularly that this is voluntary. This means that you do not have to do anything you do not want to do. That you can leave at any time during the day or at any time over the project. It’s OK to say no or not answer any questions. Go over confidentiality and how I will be using what they say, the artwork and any photographs.
Ask permission to use a camera to document the project.
Answer any questions

10.10 – 10.30am Purpose of workshop 1 and morning tea
Today’s workshop is to get to know one another better and explores identity. This is done through three exercises that look at identity in different ways. The first is about using a made up face as a non-threatening prop to talk about myself and to start getting use to expressing what art means, symbolizes or represents to them.
The 2nd exercise is about looking at Who I am
The 3rd exercise is about self portrait
Give out aprons/art smocks

10.30 – 11.15pm Brainstorming Activity
Use white Board to brainstorm themes the women would like to talk about and explore through art over the next 4 workshops.
Talk about the different art mediums that we can use.
Talk about visit to the Art Gallery as an alternative workshop.

11.15 – 12.15pm Constructing a face
Construct a face using pictures from newspaper/magazines.
Discussion about art work:
What is it about the picture they like?
Why is that important to them?

12.15 – 1.00pm Lunch

1.00 – 1.45pm Silhouettes and discussion
Option 1: One person places their face on the table with a chosen piece of A4 coloured paper another person traces around it. The face or a number of copies of the silhouettes are cut out and mounted on cardboard. May include words, symbols,
pictures to describe who I am ie sister, friend, worker, gardener, shopper, music lover etc. (reminiscent of 19th Century black silhouettes).

Option 2: Using a piece of white A2 paper one person places their face, shoulders & hand on the table while another person traces around their silhouette in pencil. The person being drawn needs either to sit or kneel on the floor so as to lie as flat as possible for a side profile. For a face front the person being outlined needs to lie face down on the paper or stick the A2 piece of paper to a wall and trace around their outline. The person whose profile it is then fills in their own features using their sensors. For example to draw their ear: For the length, the top of a person’s ear is usually in line with the corner of their eye and the bottom is near the corner of their mouth. The distance from the corner of their ear is done by using a finger or wrist etc as a measurement guide and ear features are drawn by touch.

Discussion: Open discussion about general information about myself ie where I come in the family, my siblings, what I like to do etc

1.45 – 2.30pm Self portrait- me in the mirror
Option 1: A person selects a mirror (either held or on table) and looks at themselves for a moment then draws what they can see of themselves in the mirror.
Option 2: Same as above except that they look into the mirror and draw themselves without looking at the paper.
Option 3: Think back to the first time you looked at you in the mirror this morning and quickly draw yourself from memory.
Discussion: Open discussion see what emerges

2.30 – 3.00pm Afternoon tea and reflection discussion
Ask them how they felt about the day.
What did and didn’t work
What changes they would like
What they learnt about themselves
Download photographs and delete any they do not want to be used.
Remind them I will call them at a time they dictate to tell them about the arrangements for the next workshop.
Thank them for coming and participating.
Workshop Two: Art Gallery of NSW

5.30 - 6.00pm  Meet in Gallery Foyer / morning Tea
Reaffirm ethics: particularly that participation is voluntary. This means that they do not have to do anything they do not want to do. That they can leave at any time during the day or at any time over the project. It’s OK to say no or not answer any questions. Go over confidentiality and how I will be using what they say, the artwork and any photographs.
Ask permission to use a camera to document the project.
Answer any questions
Discuss what we are going to do today
Where to find the toilets and where to meet if we get lost
Catch time, put any large bags in lockers and use facilities if necessary.

6.00 – 7.00pm  Walk Through 20th Century Australian Gallery
Discuss of work as an art subject - Weaver Hawkins (United Kingdom, Australia b.1983 - d. 1977) Morning Underground 1922 90.1976
Abstract/portrait- Grace Crowley , The Artist and His Model 1938 61.1975
Art as portraying emotion - Roy de Maistre (Australia, United Kingdom b. 1894 - d. 1968) Conflict 1932 OA24.1960

7.00 – 7.45pm  Lunch in Gallery Cafe

7.45 – 9.00pm  Walk Through Yiribana Aboriginal & Torres Strait Islander Gallery
Assemblage – Lin Onus
Fruit bats 1991 395.1993.a-c

20th and 21st Century International Gallery
Contemporary Gallery
Reflection in car going home
**Workshop Three: Friendship & Family**

10.00 – 10.30am  Welcome, Catch up, Birthday Cake & Today's Workshop

Catch up
Where to find/use Tea, coffee water & toilets
Talk about the project.
On going ethics: Participation is voluntary. This means that they do not have to do anything they do not want to do. That they can leave at any time during the day or at any time over the project. It's OK to say no or not answer any questions. Go over confidentiality and how I will be using what they say, the artwork and any photographs.
Ask permission to use a camera to document the project.
Answer any questions
Discuss what we are going to do today

Today's workshop explores the body as form of expression and the discussion centres around family and friends. All the art expression activities are done quickly to stimulate conversation and infuse movement into work.
Give out aprons

10.30 – 11.00pm  Rubbings

Option 1: Place items (leaves, torn or cut out cardboard, textured paper etc) under an A2 piece of paper. Using crayons rub over to create a 2D effect.
Option 2: Go outside and use grass or tree trunks as a texture for rubbing

Discussion about art work and friendship:
Option 3: Using the cut out figures proceed with the rubbings as in option 1 except move the paper slightly between rubbings. This produces a different effect and introduces the notion of movement into the rubbing.
Discussion on Friends.

**Shadow Pictures for use in afternoon**

During the morning each participant goes outside and using their body casts a shadow on the ground. Another person take a picture of the different shadows. The photos are then downloaded, printed and enlarged or reduced on a photocopy machine. For use this afternoon

11.00 to 11.30  Adding ink.

Option 1: This activity adds another layer to the rubbings. Hold a spray bottle that has been filled with watered down food colouring, dye or ink around 20-25cm from the rubbing spray a light mist of ink onto the rubbings. A number of different colours can be used. The interaction with the crayons produces a luminous and iridescent lustre to the art work adding another dimension.

11.30 to 12.00  Ink Abstracts

Option 1: Food colour dye or ink is watered down and put in a spray bottle. Leaves etc are placed on a paper and holding the ink bottle around 20cm from the paper lightly spray the item using different colours. The leaf can either be lifted off the paper to leave an empty space or another piece of paper can be gently pressed on top of the leaf to produce an imprint of the leaf.
Option 2: A small drop of coloured ink is placed onto a thick piece of paper. The drop is then rolled around or blown to create an abstract pattern on the paper.
Option 3: Draw a small amount of ink into a straw and blow it gently onto a piece of thick paper creating an abstract pattern.
Option 4: Use all the above techniques.
This work can be built on in the fifth workshop

12.00 – 1.00pm      Lunch

1.00 - 1.30pm      Body Sculpture. Get from theatre of the oppressed
One person volunteers be the sculptor and others in the group
Discussion: Open discussion see what emerges

1.30 – 2.30pm      Shadow Silhouettes
Option 1: Tape a number of A2 pieces of white paper to a wall. Using the overhead projector a person casts a shadow onto the paper. Another person draws around the shadow.
Option 2: The same setup as option one however using the body sculpture idea from the previous activity a number of people are placed into position between the overhead projector and the wall. When the sculptor is happy with the shadow that is cast they quick trace around the projection onto the paper stuck on the wall.
Cut out, tear or draw symbols of friendship and family ie, hearts, hands, handshake, hug, kiss, birthday cake onto the silhouettes
Discussion: Open discussion see what emerges

2.30 – 3.00pm      Afternoon tea and reflection discussion
Ask the women how they felt about the day.
What did, didn’t work and why.
What they learnt about themselves and others in the group.
Download photographs and delete any they do not want to be used.
Remind them I will call them at a time they dictate to tell them about the arrangements for the next workshop.
Thank them for coming and participating.
WORKSHOP FOUR: MY WORK

9.30 – 10.00am  Set Up Room

10.00 – 10.30am  Welcome, Catch up, Birthday Cake & Today’s Workshop
Catch up
Where to find/use Tea, coffee water & toilets
Talk about the project.
On going ethics: Participation is voluntary. This means that they do not have to do
anything they do not want to do. That they can leave at any time during the day or at
any time over the project. Go over confidentiality and how I will be using what they
say, the artwork and any photographs.
Ask permission to use a camera to document the project.
Answer any questions
Discuss what we are going to do today
Today’s workshop is to explore our working lives using free form sculpture and still
life painting.
Give out aprons and gloves.

10.30 – 12.00pm  Free Form Clay Sculpture
Option One: Free form (use hands/small tools) to produce a sculpture about work.
Sculpture can be abstract or real life.
Option Two: Use clay to make sculptures of the things you use at work eg telephone,
morning tea, cup, workmates etc
Discussion: Open discussion about why we work.

12.00 – 1.00pm  Lunch

1.00 – 2.30pm  Still Life Drawing/painting
Option 1: Look at your sculpture and with a large brush and strokes paint its image
onto A2 paper using one colour.
Option 2: Arrange a collection of pieces on a table.
Option 3: Take a number of items from your handbag, arrange them & draw.
Take the mono painting from the previous activity and introduce colour.
Discussion: Talk about what we do at work

Alternative: Make a series of story boards about your typical day at work starting from
when you get up to when you get home.

2.30 – 3.00pm  Afternoon tea and reflection discussion
General Discussion about the activities
Download photographs and edit.
Remind them I will call them at a time they dictate to tell them about the
arrangements for the next workshop.
Thank you for coming and participating.
**Workshop Five: Colláge**

9.30 – 10.00am  Set Up Room

10.00 – 10.30am  Welcome, Catch up, Birthday Cake & Today’s workshop

Catch up
Where to find/use Tea, coffee water & toilets
On going ethics: Participation is voluntary. You do not have to do anything you do not want to do. That they can leave at any time during the day or at any time over the project. It’s OK to say no or not answer any questions. What is said is confidential and how I will be using what they say, the artwork and any photographs. Ask permission to use a camera to document the project.

Answer any questions
Discuss what we are going to do today
Today’s workshop is a reflection workshop. The multi layered individual

10.30 – 12.00pm  Activity 1.  Colláge

Using artwork from previous weeks make a collage to produce a multi layered work.

12.00 – 1.00pm  Lunch

1.00 – 2.30pm  Reflections

Free form work using any or all of the art material. This art expression is a reflection over the previous workshops and what is important to them in their lives.

2.30 – 3.00pm  Afternoon Tea, Mounting & Photograph Work

Reflection discussion over the workshops
What they liked the best and least and why
Mount work they want to keep
What changes they think would have improved the workshops
Take a group photograph
Download photographs and edit. Look over all the photographs and edit
Thank them for coming and participating. Give back art work and art materials for them to take home.