Rights, Camera, Action!

A collaborative exploration of social barriers to self-determination with people labelled with learning difficulties

© Janice Maree Ollerton

A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy

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Acknowledgements

My heart-felt thanks go to the Photo-voice project team for joining me on this journey and allowing me to sojourn with them for so long. While my name is on this thesis I am very conscious that you all have made an enormous contribution. You are a remarkable group of people and I am very proud to have worked with you. I especially thank Gill Oxley for her expertise, counsel and generous donation of time over the past four years.

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Thank you all.
Statement of authenticity

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.

Signed .................................................................

Date ..................................................................
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## Abbreviations

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<tr>
<td>AHRC</td>
<td>Australian Human Rights Commission</td>
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<td>Break Thru</td>
<td>Break Thru People Solutions</td>
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<td>Convention</td>
<td>Convention on the Rights of Persons with Disabilities</td>
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<td>The Department</td>
<td>Government Department responsible for running Group Homes</td>
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<td>DEWR</td>
<td>Department of Employment and Workplace Relations</td>
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<td>DSS</td>
<td>New South Wales Disability Service Standards</td>
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<td>IPAR</td>
<td>Inclusive Participatory Action Research</td>
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<tr>
<td>OECD</td>
<td>Organization for Economic Co-operation and Development</td>
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<tr>
<td>TTW</td>
<td>Transition-to-Work Program</td>
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<td>Universal Declaration</td>
<td>Universal Declaration of Human Rights</td>
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<td>UWS</td>
<td>University of Western Sydney</td>
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Summary

There is a considerable body of literature about people labelled with learning difficulties but limited research undertaken by or with them. In this thesis I describe an Inclusive Participatory Action Research endeavour in which people labelled with learning difficulties explored social barriers limiting their self-determination. The thesis proposes that people so labelled are unacceptably disadvantaged by ableist social structures and disablist practices. Participating in the social research described herein, became a way of challenging such practices, dismantling disabling barriers, exposing myths of incompetence and building the self-determination skills of the research team members.

Taking the social model of disability position, the claim of unacceptable disadvantage was founded on experiential evidence that people disabled by society are not permitted opportunity for self-determination equivalent to that enjoyed by other members of society. This dictated that the research be essentially rights-based; in particular, it was founded upon the principle that people labelled with learning difficulties have rights: the right to self-determination, the right to be included in research that concerns them and the right to an inclusive research approach with accessible research methods and outcomes. As a consequence, the research required new ways of doing disability research.

Informed by the dialogic strategies of Paulo Freire, an Inclusive Research approach was melded with Participatory Action Research to provide an inclusive research methodology (IPAR). Creative methods such as Photo-voice (where photography and narrative are used to express that which can be difficult to verbalise), poetry, metaphor, journaling and patchwork were combined with traditional qualitative research methods, such as textual analysis and interviewing, in new and innovative ways to make the research process accessible. Using the camera, conceptually complex theories and procedures, including ableism, textually-mediated social behaviour and institutional ethnography, were rendered comprehensible to the research team. The abstract was made concrete through the photographic text. Anchoring the analysis in the United Nations’ Convention on the Rights of Persons with Disabilities provided grounds upon which perceived injustices were assessed and challenged.
The research knowledge created promoted action. Self-advocacy and citizenship were means of investigating and challenging disabling barriers. Through the exercising and development of self-determination skills the research transitioned from a facilitated endeavour to a project which was self-funded and self-directed by the team, all labelled with learning difficulties. In terms of a research outcome this event transformed the social and material relations of the research, qualifying for that utopic Disability Studies goal of emancipatory research.

In terms of personal outcomes and achievements I have been changed by this research. Many of the assumptions I brought to the study have been unsettled and unacknowledged stereotypes dismantled. Feedback from my co-researchers, their families and disability service providers, indicates that participation in this research has also been life-changing for my colleagues. It has contributed to increased confidence, pride and feelings of self-worth for everyone involved. Opportunity to support one another to challenge oppression and engage in social action contributed to improved quality of life for a small community in Western Sydney and to human flourishing.

For my Photo-voice co-researchers, undertaking social research provided opportunities to publically and professionally exhibit their photographic work. They met with corporate executives, NSW Education Department officials and Members of Parliament. They wrote to the Australian Human Rights Commissioner and instigated an internal investigation into a Government Department. The team contributed to the Photo-voice website and shared their research findings across Australia in venues such as corporate board rooms, school classrooms, university Human Rights lectures, as well as disability Expos, academic conferences and the largest disability service consumers’ conference in the southern hemisphere. These achievements are highly significant and worth celebrating.

Using IPAR the Photo-voice team promoted disability rights. Accessible research methods were developed using the camera to expose disabling practices and illuminate ableism. The camera has also provided a means by which we can disseminate our work in print, online and in power point presentations. Collaboratively we took action to address injustices and generate positive social change. Endeavouring to shed light with moving pictures, our motto was

Rights, Camera, Action!
Prologue

The dignity of risk

What if you never got to make a mistake?
What if your money was always kept in an envelope where you couldn’t get it?
What if you were never given a chance to do well at something?
What if you were always treated like a child?
What if your only chance to be with people different from you was with your own family?
What if the job you did was not useful?
What if you never got to make a decision?
What if the only risky thing you could do was to act out?
What if you couldn’t go outside because the last time you went it rained?
What if you took the wrong bus once and now you can’t take another one?
What if you got into trouble and were sent away and you couldn’t come back because they always remember you’re “trouble”?
What if you worked and got paid 46 cents an hour?
What if you had to wear your winter coat when it rained because it was all you had?
What if you had no privacy?
What if you could do part of the grocery shopping, but weren’t allowed to do any because you weren’t able to do all of the shopping?
What if you spent three hours every day just waiting?
What if you grew old and never knew adulthood?
What if you never got a change?

(Anonymous, 2006)
Thesis overview

What if everything about you was investigated and written by someone else? This is frequently the experience of those labelled with learning difficulties. This thesis describes a collaborative research endeavour in which people labelled with learning difficulties were supported to investigate for themselves what they considered were the social barriers limiting their self-determination. The thesis proposes that people so labelled are unacceptably disadvantaged by ableist social structures and disablist practices which limit their self-determination. Participating in social research was one way of challenging the legitimacy of ableism/disablism and of voicing their discontent.

I distinguish between the words disability and impairment. For reasons explained in Chapter 2, I have adopted New Zealand’s national distinction between disability and impairment, as it seems to me to be more progressive and recognises that “Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments. Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have” (New Zealand Office of Disability Issues, 2001).

For the purpose of this research I also use the term learning difficulty rather than intellectual disability (which is generally used by Australian disability service providers and their funding bodies (NSW Department of Community Services, 2007)). In this way I avoid associating the notion of disability with my co-researchers. Learning difficulties is also preferred by many people within the People First movement (People First, 2008). People labelled with learning difficulties have complained that “In the past we used to be called labels like mentally handicapped, mentally retarded, intellectually handicapped, or mentally subnormal. We didn't like these labels as they kept us down. We choose to use ‘learning difficulties’ ourselves. It is a label which doesn’t hurt us as much as those above. Jars should be labeled not people!” (Central England People First, 2000).

Motivation for the research grew from my dissatisfaction with the Australian Government’s Welfare-to-Work reforms (DEEWR, 2007). Following UWS Human

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1 People First organisations are run and controlled by people labelled with learning difficulties.
Research Ethics Committee approval, the Penrith Photo-voice project (affectionately referred to as simply Photo-voice by the research team) unfolded in four stages. Stage 1 was acquiring Photo-voice skills (Wang, 1999, 2005b) and collecting photographic data on social barriers. (For clarity and emphasis I hyphenate Photo-voice throughout this thesis.) Stage 2 involved the analysis of our photographic data and the articulation of the research problematic. Stage 3 was the beginning of our social action. Stage 4 saw the group evolve from a facilitated research project into an emancipatory, self-funded, self-determined project.

The inclusive nature of the research provided a supportive environment in which the team, consisting of five people aged 18-26, one experienced Photo-voice practitioner and me, could critically explore their reality of disablement in relation to their self-determination, apprehend that reality, expose and name it. In doing so the group participated actively in their own liberation from disablement. They were able to not merely adapt to an inequitable world in which they lived but to intervene in that world and instigate positive social change. The process of naming and challenging disabling social barriers to self-determination was also a means of building the self-determination skills of the research team members.

The inclusive nature of the research provided authority for the group to actively engage in a large part of the strategic planning of the research, data collection and analysis. Furthermore, as part of their naming rights, the research team provided their own pseudonyms (Bart, William, Andrew, James and Anne), consenting for these, along with their photos and photos of themselves taken by others, to be included in this thesis. They have therefore shared control of how they are represented in the thesis. Due to the information exposed during the research, when necessary a subgroup of the participants has been further encoded as Alex, Brendan and Chris (including italicisation) to completely de-identify individuals from those depicted in the photographs, providing an additional layer of privacy and protection. The first use of other pseudonyms will be indicated by bold type.

Throughout this document, Photo-voice sources given as (Name, date) or (Transcript/Field notes/Minutes/Correspondence, date) indicate that I have written evidence (notes or transcripts of tapes) on file. Permission to use photographs and disclose information has been obtained as necessary.
This thesis, entitled Rights, Camera, Action!, is divided into three parts.

Part 1 – Rights includes Chapters 1 to 5. Chapter 1 is the rationale for the research, noting that my three key areas of research motivation stemmed from my vocational, educational and spiritual experiences. I name these areas and the need for collaborative research as relevant to my concern that people labelled with learning difficulties were unacceptably disadvantaged by ableist social structures and disablist institutional practices limiting their self-determination. Chapter 2 outlines the three main social theories informing the research. I begin with social constructionism, introducing my epistemological position and the way I interpreted the construct of learning difficulties. This is followed by an examination of ableism/disablism, which leads naturally to a discussion of the social model of disability. The social model was seen as a means by which ableism could be exposed and disabling barriers identified and challenged.

In Chapter 3 I explore human rights. I consider the inadequacy of the United Nations' Universal Declaration of Human Rights as an instrument for promoting the rights of people with impairments. The United Nations' Convention on the Rights of Persons with Disabilities is then examined along with its relevance to my research. After broadly considering the contemporary notion of human rights the discussion turns specifically to the right to self-determination in Chapter 4. An historical review of the construct of self-determination is presented, along with an outline of self-determination theory and models used within the field of special education. Part 1 of the thesis concludes with Chapter 5 arguing the right to inclusive research methodologies. Following an introduction to both Inclusive Research and Participatory Action Research I develop a melding of these methodologies in a research approach, Inclusive Participatory Action Research (IPAR).

Part 2 – Camera reveals how photography was an intrinsic research component. The discussion in this section of the thesis considers the research methods or tools utilised in the study and introduces Stages 1 and 2 of the research project. Spanning Chapters 6 to 8, Chapter 6 begins with a metaphorical camera bag containing the research tools. In packing the camera bag I discuss its contents including the merits of Photo-voice as an inclusive research method along with its theoretical underpinnings. Risk is presented as an essentially human experience.
Preparations required to take on and minimise risk are explained and ethical considerations are raised along with the research methods used to address these. Chapter 7 figuratively loads the film into the camera, outlining further preparations that were required prior to the study, including promotion of the project and recruitment of helpers and participants. Chapter 8 takes you on location with the Photo-voice team, cameras in hand. This photographic section of the thesis reviews Stages 1 and 2 of the four-staged process. Stage 1, data collection, explored a range of social barriers. Stage 2 articulated two specific research problematics for further investigation. These were identified as Public Transport and Rules that Restrict Us.

Part 3 – Action! reflects on the ways our small group of critical social researchers and agents in self-advocacy acted upon the world, challenging ableism and declaring their rights, to bring about positive change in the life of a specific group member and the lives of others who have been similarly labelled. Chapter 9 records one aspect of Stage 3 of the research, how the Photo-voice project investigated the Sydney public transport system. Utilising institutional ethnographic strategies to uncover the textual mediation of everyday activities our group identified ableist social practices which exclude people with limited literacy in the public transport system. Actions taken by the group to address this issue are outlined. Our actions led to important outcomes in self-advocacy, citizenship and self-determination.

Chapter 10 is entitled “Rules that Restrict Us: advocacy/action and analysis”. Stage 3 of the research also involved exploring the barrier Rules that Restrict Us. This barrier particularly concerned our research colleague (whom I have named Alex). A background to Alex’s situation is given and our research findings on this barrier. I tell the story of our group’s advocacy actions to challenge the barriers and the difficulties we faced. An analysis of the research is also presented.

In Chapter 11 I discuss a creative hermeneutic analytical tool developed in order gain an understanding of the degree to which the social action of Stage 3 was collaborative. Piecing together symbolic patches of actions, I developed an analysis tool that was accessible to the group and added rigour to my work.

Chapter 12 introduces Stage 4 of the research wherein the group decided to
become self-determining and self-funded. Transitioning from Inclusive Participatory Action Research to fully-qualified emancipatory research, I look at the group’s actions which changed both the material and social relations of the research project. This includes a review of funding strategies, knowledge production and means employed for the dissemination of research findings to the research team’s audience of choice. I tell of how the Photo-voice group travelled to Victoria, Australia, and presented at the largest consumer-based disability conference in the southern hemisphere, producing beautiful travel journals on the experience, using their Photo-voice skills.

Finally, the Conclusion looks back on what was achieved and forward to areas for further investigation. It speaks of possibilities for development of this politically conscious and enthusiastic group of social activists.

I trust that as you read this thesis, wherein I have endeavoured to openly expose my foibles and fears, the research contradictions and our many achievements, you will also be arrested by the joy that has permeated this research and the hope that has sustained us.
Part 1 presents my view of things. Beginning with the research rationale in Chapter 1, the theoretical foundations of the research are established in Chapter 2. Ableism/disablism is presented as a key research concern and foreshadows my discussion on human rights and disability rights in Chapter 3. The research was founded upon the assumptions that people have a right to be included in research concerning them. They have a right to self-determination (Chapter 4) and a right to inclusive research methodologies (Chapter 5).
Chapter 1 – Rationale: Naming Influences

“To exist, humanly, is to name the world, to change it.”

“I recognized that the actions of men and women take place within the time-space continuum in which ideas are generated. I have also recognized the impossibility of ignoring the historical, cultural, ethical, racial, and class conditioning to which we are subjected. Neither realization allows me to forget the ontological reason for my decision to fight in favour of the liberation of the oppressed.”

Paulo Freire (Freire, 1996, p. 69; Freire & Macedo, 1996, p. 164)

1.1 Introduction

In this chapter I name the significant influences on my decision to undertake the research presented in this thesis. I discuss my vocational background and my growing discomfort as I perceived a diminishing of rights for people who used disability employment services in Australia and my role in that process as an employee within the industry. My educational background is relevant as it awakened a political consciousness in me that, like Freire (quoted above), I am unable to forget or ignore. This has informed both the political and methodological approach to the research. Also explained is where this PhD is situated on my spiritual journey. My Christian frame of reference factors into the research rationale since a researcher’s values inform their choice of research topic, their motivation, the subject matter and the location of the research (Carspecken, 1996).

My response to these influences was a desire to collaboratively name and change the world.
1.2 Naming vocation

“And there stirs in me a little of the same anger... when I remember the countless times I have seen disabled people hurt, treated as less than people, told what to do and how to behave by those whose only claim to do this came from prejudice and their power over them.”

(Hunt, 1966, p. 14)

I have worked with people labelled disabled for almost thirty years. In 1981, the International Year of the Disabled Person, I was appointed a Disadvantaged Person’s Officer (DPO) within the Commonwealth Employment Service (CES). Although my clients included ex-offenders, indigenous jobseekers, migrants with language difficulties, the long-term unemployed and people with impairments, that year there was a particular Departmental push to prioritise the placement of people with impairments into employment. My position as a DPO was thought of, and referred to, as the Disabled Person’s Officer. From the start of my career in the employment industry I have always worked with people with impairments.

During the 1990s, while living in Great Britain, I worked for eighteen months in a very different industry. I was employed in a special school for children with profound and multiple learning difficulties. This experience had significant impact on my life and created a keen interest in the field of disabilities. During my experience at Ty Gwyn Special School I became increasingly aware of and appalled by the lack of control people with impairments had over their lives.

I returned to Australia in 1999. During my absence significant changes had occurred within the Australian employment industry. The CES had been disbanded and the employment industry restructured (Madden & Hogan, 1997). Under the Commonwealth Disability Services Act 1986 (Australian Government, 2006) employment services for people with impairments fell into two main categories: open employment services and business services (formerly called sheltered workshops). Clients of business services, assessed as not open-employable, were employed by the same organisation that provided the employment support (Anderson & Wisener, 1996). Open employment services supported clients to gain and retain employment in the open labour market with an employer not funded under the Act. I re-entered the Australian employment industry as a disability employment consultant with an open employment service,
run by the NSW Spastic Centre. This position combined my newly gained experience of working with people with significant impairments with my employment consulting background. I have been employed in the disability employment assistance industry since 1999.

My clients have had a variety of physical, sensory, mental health and cognitive support needs. Although I have enjoyed working with the vast majority of my clients I have generally found the most rewarding relationships to have been with people labelled with learning difficulties. This is because it seems to me that things are so much tougher for them than they are for other clients. For one thing, they very rarely think that they are disabled and so wonder why they must attend a specialist service for people with disabilities. I wonder this too. I wonder why people have to wear a label they don’t agree with in order to get the support they need. But since they can’t go to mainstream services because someone has labelled them disabled, and if they haven’t been able to find employment on their own, disability employment assistance services have their place. Supporting someone labelled with learning difficulties to break into the labour market is a great way of dismantling stereotypes and demonstrating to employers, and the wider community that, actually, they’re not disabled after all.

Over the past five years the nature of the disability employment industry has changed. Change can be destabilising and is often unsettling as people desire to maintain equilibrium (Gardner-Cardani, Yonkoski, & Kerestes, 2007). I was particularly unsettled by the changes. I suspect that the reason I was so disturbed stemmed from my developing critical consciousness. Industrial changes were occurring just as I was embarking on tertiary studies in adult education. Whatever the cause, my life was being significantly affected by change over which I had no control and had been given no say. Lewin’s Change Theory (1951) states that there must be motivation for change before change is generated. However, motivation for industrial changes came from the Federal Government rather than from within the disability industry. Changes were imposed from the top-down rather than developed democratically from the bottom-up.

Following the 2004 Australian federal election the responsibility for disability employment assistance was transferred from the Department of Family and Community Services (FaCS) to the Department of Employment and Workplace
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This move is considered to be one of the most significant changes to be made in the industry for many years (Micali, 2006). As a worker in the industry I saw the change of the responsibility from FaCS, whose focus was to support and assist people, to DEWR, whose focus was to get people off welfare and into jobs, as alarming. It introduced a new culture and different priorities to the industry. Under FaCS the social inclusion strategies within my job had a broader focus than merely employment. I assisted people to set life goals, of which employment may be just one of many. Under DEWR all activities were to be explicitly employment related. If people had housing needs, financial problems or perhaps felt isolated, an employment consultant’s role was to “refer them on” (Ollerton, 2005).

Another change which I found destabilising occurred in 2005 when DEWR introduced a new funding system to the disability employment industry called Case Based Funding (Department of Family Housing Community Services and Indigenous Affairs (FaHCSIA), 2008). Under the previous block grant funding system organisations were allocated a set amount of funds with which to achieve a minimum client placement target. In contrast, Case Based Funding is a fee-for-service model whereby fees are paid to service providers calculated to meet the individual needs of each client. To calculate what those needs are DEWR formulated the Disability Pre-employment Instrument and Disability Maintenance Instrument. These instruments were designed to measure the level of impairment-related support that the service would be required to purchase, or provide, in order to assist a client to reach and maintain an employment outcome (Department of Employment and Workplace Relations (DEWR), 2008). There are four levels of funding. Clients who are measured with the lowest scores translate to the lowest funding level i.e. Level 1. “Higher scores are distributed along the continuum to the highest scores at Level 4” (DEWR, 2008, p. 1). Disability employment services introduced various assessment processes for measuring impairment and support needs in order to generate evidence supporting the data they recorded into the Disability Pre-employment Instrument and Disability Maintenance Instrument. The funding, though calculated on an individual’s needs, does not have to be specifically allocated to particular clients and can be distributed across the

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2 DEWR has subsequently been re-named DEEWR (Department of Education, Employment and Workplace Relations). For the purposes of this thesis I will refer to the Department as DEWR.
organisation. It is therefore in the organisation’s best financial interest to paint the
darkest picture of a client’s impairment support needs in order to achieve a higher
score and gain greater funding. The assessment processes implemented by
organisations deliberately construct clients as deficient and needy.

I was alarmed by such an overt deficit focus and deeply troubled by its
manipulative ability to construct certain types of clients for the organisation’s
benefit. I felt that the new funding model was dehumanising and unethical. Prior
to these industrial changes the vision for the industry had been to maximise a
person’s potential and to celebrate abilities rather than concentrate and gather
evidence on clients’ impairments. The funding changes angered me. The new
funding formula obligated services to look at clients as people with problems. It
was the antithesis of a resistance to labelling. It fanned a growing compulsion
within me to fight for the liberation of the oppressed (Freire & Macedo, 1996).

In December 2005 the contentious Disability Support Pension (DSP) Bill, which
had previously stalled in the federal parliament, was successfully passed (Micali,
2006). This Bill introduced more changes. Prior to the Bill participation in a
disability employment assistance program was voluntary. Jobseekers registered
for assistance because they were motivated and wanted to find work. On 1st July
2006 changes in the eligibility criteria for the DSP were introduced making it more
difficult for people to qualify. Those who no longer qualified were required to apply
for the less financially generous New Start Allowance. The OECD has criticized
this particular change as it financially disadvantaged people with impairments
(OECD, 2007). Not only was New Start Allowance less money, but in order to
receive income support New Start recipients must demonstrate that they are
actively seeking work because they fall under mutual obligation requirements. I
felt that organisational culture, which was founded on industry standards
underpinned by principles of client choice and the right to self-determination, was
severely compromised by the imposition of mutual obligation. DEWR introduced
mandatory Activity Agreements outlining client obligations. These contracts

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3 Mutual obligation is based on the principle that those people receiving income support must not only seek
work but also, after six months on payment, undertake additional activities which contribute something to
their community -Guide to Social Security Law, (Department of Families Housing Community Services and
Indigenous Affairs, 2010).

4 On 1st July 2009 the Australian Labor government re-named Activity Agreements as Employment Pathway
Plans. This document is still subject to mutual obligation but has an expectation of greater client input.
replaced the previously used voluntary, client-centred and client-drafted Employment Action Plan. The Employment Action Plan was a document which facilitated client decision making and choice. The Activity Agreement on the other hand was a DEWR document generated online. Consultants impose generic activities to which clients must agree and the document requires minimal client input. Financial penalties can be imposed if people fail to comply with Activity Agreements. Employment consultants are obliged under Social Security Law to inform Centrelink of breaches of the Activity Agreement. The introduction of compulsory job-searching requirements not only changed the culture of the employment assistance program, it negatively affected the motivational levels of clients.

Making so many significant changes was detrimental to staff morale in my workplace and generated a feeling of powerlessness throughout the organisation (Ollerton, 2005). The prescriptive requirements of DEWR regarding how often clients were to be seen and the threat of desktop monitoring by the Department made staff apprehensive that Big Brother was watching. In order to comply with DEWR regulations I observed that clients appeared to become pushed around by their employment consultants - told they must go to this interview, sign this form, undertake that assessment, attend that training session. In many cases, and often with good intentions, jobseekers were treated like objects to be acted upon rather than subjects with agency in their own lives (Lather, 1991).

In 2006 I decided something needed to be done. Freire (2004) speaks of people as a “presence in the world”. This presence is not neutral but political, full of possibility and hope. I recognised that I was not just an object of history to be pushed along by the events around me but equally I was a subject of history. Part of my responsibility as a human, and to develop that humanity within me, was to read the world in which I live, to critically understand the reality around me and to apprehend the ways things are so that they can be denounced, reimagined, re-created, renamed and the world rewritten (Freire, 2004). My presence in the world could not be neutral. In such an oppressive environment my role as a human being was not to adapt to these changes but, as Freire suggests, “to intervene as [an] active subject” (2004, p. 60) in the world.

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5 Centrelink is the Australian government agency responsible for the administration of welfare services.
I decided I would not be complicit in the Government’s punishment of its most disadvantaged citizens. Nor would I participate in measuring, objectifying and constructing types of people in order to generate higher funding levels for my employer. I chose to undertake this PhD while maintaining one day per week employment within the industry. I still needed a job, but I also wanted to maintain a positive influence in my workplace. I ceased being an employment consultant and took on the role of staff mentor and disability awareness trainer within my workplace in an effort to cultivate a critically reflective corporate culture.

1.3 Naming education

“How do our very efforts to liberate perpetuate the relations of dominance?”

(Lather, 1991, p. 122)

As the Australian employment industry changed during the 1990’s, so too did the role of an employment consultant working with people with disabilities. In 1999 I found employment consulting also included on-the-job training. I had little formal training to assist me in that task and was encouraged by my employer to undertake further education. I began with a TAFE course, a Certificate IV in Assessment & Workplace Training. This was followed by a degree in Adult Education and a research Honours degree as part of my professional development within the organisation. My educational journey over the past nine years has been personally and professionally transforming. The first subject I took as an undergraduate, Critical Thinking, challenged me to “de-inevitabilise” the things I took for granted (Hacking, 1997, quoted in Dowling & Dolan, 2001, p. 23). I began questioning basic assumptions I had made about society and the labour market, stereotypes I held about certain client groups and how the organisation I worked for approached employment support.

Reflecting on the social constructionist notion (more about that in Chapter 2) that society can be understood as an organic phenomenon developing and changing in concert with its citizens, I found myself in a contradiction. My experience working within the disability services industry, whose ontological paradigm views service

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6 I have made my views very clear to management who are well aware of the social model influence that explicitly permeates my training sessions. Like a voice in the wilderness I offer staff a different view to consider.

7 NSW Institute of Technical And Further Education.
users as people with problems in need of assistance to fit in to society, was challenged by my experience as a student. Education introduced me to different paradigms of thinking. What if disability wasn’t the client’s problem? What if disability was a social problem and as a cog in the disability services industrial machinery, I was part of that disabbling process?

Ward and Flynn (1994) have noted that disability research has traditionally been positioned within the positivist paradigm, with its unquestioned assumptions about value-free objectivity, thinking that the social could be studied in much the same way as the natural sciences. This approach also assumed that the beliefs of the researcher and their research approach and methods were quite independent of the causal explanations and knowledge produced. However, in the 1960s and 70s disability research moved into a more interpretive paradigm. Erving Goffman’s (1963) work in symbolic interaction was highly influential. “Everyone cited it” (Thompson, T. L., 2000, p. 5) and some researchers, for example Robert Edgerton (1967), began to listen to the research subject’s experiences. Researchers including Peter Berger and Thomas Luckman (1967) started to recognise that knowledge was socially constructed. The subjects of social research were acknowledged as different to that of natural research as they were not passive objects but active participants. Some researchers began to look for meanings rather than causes and it was realised that the knowledge and understanding gained from the research was very much influenced by the researcher’s own values (Carspecken, 1996). However, in spite of their differences the social relations of the research were the same. These two paradigms maintained a power imbalance between the expert researcher and the powerless research subject.

I recognised and accepted, that life around me was socially constructed and that I had a role in the construction process. My difficulty arose as I recognised the destructive nature of the construction of my clients as impaired objects who must conform to the meaning and role disability services ascribe to them. I saw myself as being fashioned to be an oppressor deliberately constructing stereotypes and I did not want to be part of that construction process.

Reflecting on the language of the industry I was unsettled to recognise that while promoted as a specialist employment service my workplace was actually a
Rights, Camera, Action!

segregated service, part of what Goggin refers to as Australia’s “social apartheid” (Goggin, 2008, p. 1). The contradiction in the human services rhetoric of social inclusion, where the means of inclusion was via segregated services, became very apparent. The knowledge that I was part of a social apartheid system that excluded people with impairments was disturbing. Just as troubling was the fact that I had not questioned this before. I had never before considered that my clients were not permitted (not eligible) to seek assistance in mainstream job centres because they were labelled disabled. Systematic segregation went unchallenged (Goggin & Newell, 2005). Without assistance from employment services such as that which I worked for, my clients might never find a job, yet participating in a disability employment service perpetuated their marginalised and stigmatised role in society. This dialectic situation needed to be reviewed.

I had previously examined existing opportunities for people with impairments to exercise self-determination within a Disability Employment Assistance service in Sydney, Australia (Ollerton, 2005). The Australian Government’s Welfare to Work Initiative and the introduction of Case-Based Funding were significantly affecting service delivery (Micali, 2006). The industrial change from voluntary to compulsory job seeking (with punitive consequences for those who were unable to meet their activity agreements) was a disturbing erosion of client choice. I believed it created fear (loss of income is a very real threat) and undermined client self-determination. My research findings uncovered a multiplicity of barriers to self-determination embedded within organisational policies and procedures. A sense of fear of change concerning the Welfare to Work reforms and powerlessness to prevent further undermining of the NSW Disability Service Standards (DSS) (NSW Ageing and Disability Department, 1998) pervaded the organisation from the top down (Ollerton, 2005). Compromise was seen as unavoidable by management in order to win tenders and for the organisation to retain and develop their place in the industry.

I was deeply concerned by the research findings. They seemed to be but the tip of the iceberg. If powerlessness was the general experience of disability employment service users within one organisation, I wondered at the extent of oppression and injustice that they must encounter throughout society. I could not do nothing. “Washing one’s hands of the conflict between the powerful and the
powerless means to side with the powerful, not to be neutral” (Freire, 1985, p. 102).

Compelled by a sense of political urgency to expose the silent oppression within the disability services industry, I wondered if disability service users also thought the industry was oppressive. Certainly, the literature in Disability Studies supports my observation, but it is written by academics (see for example Emerson et al. (2009)). Those who identify as disabled academics, such as Vic Finkelstein (2002), do not speak from the experience of a person labelled with learning difficulties\(^8\). What do those people think about disabling social barriers? Was I colonising the experience of people labelled with learning difficulties by imposing my interpretations upon them? Recognising my complicity in the oppression of segregation I wondered if exposing the oppression was an additional act of oppression by naming the world for others.

Reluctantly I saw that positioning myself as the patron wanting to rescue the powerless was merely replacing one form of oppression for another. But how could something be done about oppressive social practices if nothing was said? How could I break these oppressive structures within which I found myself and work for positive social change? The response to these questions needed to be the provision of an opportunity for people to explore their own world and name their social barriers for themselves, if indeed they thought that they existed. I could offer my assistance and support along the road to emancipation.

It was my aim to not only establish a research environment in which people could look for and possibly name their social barriers to self-determination but also to provide support for people to actively reduce the oppressive impact of the barriers and hopefully remove them. A person’s level of self-determination is affected by the degree to which their environment provides opportunities for them to practise self-determination and exercise their skills of self regulation, self-realisation, autonomy and psychological empowerment (Wehmeyer & Schwartz, 1998a; Wehmeyer & Bolding, 2001). People with learning difficulties tend to have poorly developed self-determination skills and their lives are often largely controlled by others (Wehmeyer & Garner, 2003). This has been described as living “on other

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\(^8\) An exception perhaps being The Rev’d Canon Dr Christopher Newell A.M. who left a sheltered workshop before taking up university studies (Newell, 2008).
people’s terms and by other people’s rules” (Shapiro, 2001). I hoped that a collaborative research project would be an opportunity for people labelled with learning difficulties to determine their own terms and rules and to exercise self-determination.

I was motivated to explore the issue of social barriers to self-determination further, in the spirit of emancipatory learning and liberatory pedagogy (Mezirow, 1990; Freire, 1996). I wanted the people concerned to share control of the process in order to be emancipated. I also saw this as an opportunity to create an environment that would raise people’s consciousness and occasion the exercising of self-determination in order to build skills with people. I could undertake a research project wherein people could discover if they were affected by social barriers, and if so, could have an active rather than passive role in the research. “In the world of history, of politics, of culture [we] apprehend not simply to adapt but to change” (Freire, 2004, p. 60). The research had the very real promise of liberation and empowerment for all of those involved.

1.4 Naming spirituality

“He has told you, O man, what is good; And what does the LORD require of you but to do justice, to love kindness, And to walk humbly with your God?”

(Micah 6:8)

During my first weeks of the PhD program Professor Stuart Hill explained to my cohort of social science students that action in research was

- informed by a research plan which was
- informed by one’s creativity and imagination which was
- driven by their passions which were
- motivated by their values, beliefs and hopes for the future.

(Field notes, 26/3/06)

He stressed that it was fundamental to research to examine one’s values, beliefs and hopes so that researchers may be sure of their foundations. This encouraged me to consider why, as a Christian, I felt compelled to investigate self-determination for people with disabilities.
I recognised that people with impairments live under oppression. I saw that an economic rationalist motive to reduce welfare dependency was causing my clients to lose considerable control over their lives. Reflecting on these discomforting thoughts I also considered what it was that God requires of people (quoted above: “to do justice, to love kindness, And to walk humbly with your God” Micah 6:8). I decided that the current state of affairs for people labelled with learning difficulties was not justice and it was not kindness. My desire to explore social barriers to self-determination was intrinsically linked to my relationship with God and a desire for a just society. My socio-political involvement in research which takes a stand against social inequality and injustice was not just a Freirean notion but part of my Christian responsibility (Dayton, 1990; Douglas, 1990; Evangelical Ministries to New Religions, 2006).

I also believe that I have a responsibility to be salt and light in the world (Matthew 5: 14-15). These practical Christian metaphors found their application to my project in the following intentions:

Salt – adds flavour to the environment (as does diverse perspectives and changed social relations to disability research). It stops corruption (as can challenging injustice) and it heals hurts (which can come from dismantling oppressive structures and instigating positive social change).

Light – illuminates the world by exposing darkness (such as discrimination and injustice and by providing information so that people can make informed choices).

1.5 Naming collaboration

“No need to hear your voice. Only tell me about your pain. I want to know your story. And then I will tell it back to you in a new way. Tell it back to you in such a way that it has become mine, my own. Re-writing you, I rewrite myself anew. I am still author, authority. I am still the colonizer, the speaking subject, and you are now the centre of my talk.”

(hooks, 1990, pp. 151-152)

Literature in the field of Disability Studies is scathing of the oppressive way in which people labelled with learning difficulties have been objectified through disability research and excluded from the process (Oliver, 1990, 1992; Barnes & Mercer, 1996; Swain, 2004). In response to the disability rights movement’s call
for “nothing about us without us” (United Nations, 2004) and in light of Freire’s (1982) insistence that people should be engaged as researchers in matters about themselves, I appreciated that the PhD project had to be collaborative. Rather than take the maternalistic stance of championing the cause of others my aim was to support people in championing their own cause, if indeed they thought they had one. Although it is well documented (see for example Mark Rapley (2004)) that people with the label of learning difficulties are frequently and in numerous ways excluded from society, and my own observations confirmed an undermining of their self-determination by Government policies, I did not want to colonise the research group’s interpretation of the social or name their world for them. Perhaps that which seemed so obvious to me was not at all the way they read the world. I was aware of the danger of disability research being a form of oppression in itself. I did not want to manipulate people to write my story as theirs (that is, the way I see the world) nor to dehumanise them by writing their story for them.

“In dialogic action there is no place for the conquering of people on behalf of the revolutionary cause” (Freire, 1996, p. 149).

Instead I wanted to work alongside people in a dialogic environment that was cooperative, that gave the research group the authority to name the world and write their own story on their own terms. An inclusive research strategy, explicitly designed to avoid disabling social relations where a researcher does research on the participants, was required (Priestley, 1997). An approach where people do things together was deemed most appropriate, for their liberation as much as for my own (further elaborated in Chapter 5).

Jan Walmsley (2004) stresses that researchers working with people labelled with learning difficulties need to consider the interests of the people in their research. At the very least they should demonstrate its relevance, showing how what the research team does matters to people labelled with learning difficulties and helping them access the outcomes of their work. Following these recommendations would be a way of light shedding and salt shaking. Working collaboratively with people to challenge oppressive situations would provide an authentic learning experience that Myles Horton claimed was essential for adult learning (Horton & Freire, 1990). It was also a tool for liberation (Freire, 1996).
1.6 Conclusion

My desire to undertake this research has been moulded by my life experiences – named as vocational, educational and spiritual. My beliefs and values have been strongly moulded by my education and an awakening of my own critical consciousness. Observing unchallenged injustices has forged my passion to undertake this research, and to research in collaboration with those disabled by these injustices.

These were my influences and also my biases. My rationale was (inevitably) politically motivated and value-driven. Being politically discomforted by the industrial changes occurring around me and morally motivated by apparent injustices I chose to explore the research from a critical emancipatory position. More generally however, Marcia Rioux (1994) claims that disability is a social status not a medical condition. She demands that the disability research agenda include the political implications attached to such a status. The critical emancipatory paradigm provides a platform for research which is inherently and explicitly political, where empowerment and reciprocity are central (Habermas, 1972).

Whatever my motivations, self-determination is a human right. Therefore, social barriers to this human right for people labelled with learning difficulties are worthy of investigation.

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Chapter 2 introduces the social theories underpinning the research. Ableism and disablism point to a discriminatory social system that favours some people above others while the social model of disability demands politically motivated research for positive social change. Social constructionism supports both these theories and suggests things could be otherwise.
Chapter 2 – Social Theories

“The five statements above are insights from people who took part in the Photo-voice research project. They express some of the critical social issues that people labelled with learning difficulties face in Australia today, issues to do with restrictive practices, discrimination and internalised oppression. These social barriers to self-determination stem from ableism/disablism and the socially constructed status of disability.
2.1 Introduction

Chapter 2 covers the main social theories underpinning the research. Beginning with social constructionism I sketch its background before discussing the relationship between language, knowledge and power within discourses. This is followed by reflections on the social construction of normalcy and of learning difficulties.

I then explore ableism, that silent, unchallenged assumption upon which Australian society functions, and its alter ego disablism. Definitions are provided for these two concepts which form part of the philosophical bedrock of my research. I consider issues surrounding ableism and suggest a means of interrogating it.

Thirdly I recommend the social model of disability as a useful tool for illuminating ableism and interrogating disablism. It begins with an explanation of Australia’s national understanding of the term disability, how it is defined as a medically-based problem in legislation, and how disability is generally understood by those, like me, who work in the disability services industry. The medical model of disability and its influence is explained, followed by the epistemological differences between it and an alternative paradigm for viewing disability, the social model of disability. Discovering the social model of disability has had a significant effect on my life. I discuss how it exposed my own ableist assumptions and unquestioned work practices and also how ubiquitous disablism was throughout society. While it is not without its limitations the social model does offer a means of turning the researcher’s gaze in a different direction and can be applied in inclusive research by people labelled with learning difficulties.

2.2 Social constructionism

It is widely recognised in the social sciences that society is a dialectic phenomenon created by people and upon whom it continuously acts (Berger & Luckmann, 1967). Society cannot exist without people because it is the people who produce societies. In a very real way, societies also produce (or construct) the people in them. In the following section I discuss social constructionism and where it has come from, the construction of normalcy and of people labelled with learning difficulties.
2.2.1 Background to social constructionism

Social constructionism developed within the context of the intellectual movement referred to as postmodernism. Postmodernism is characterised by a questioning and rejection of the fundamental assumptions of modernism. One such assumption promoted in the human sciences was that phenomena could be analysed semiotically (through a system of signs) because the various aspects of the world were underpinned by rules or structures. Those holding this view are called structuralists. Notable structuralists include Ferdinand de Saussure (1974; 2010), who introduced structuralist theory to linguistics and founded the field of semiotics. Lévi-Strauss (Lévi-Strauss, 1963a, 1963b; 1969) applied Saussure’s theories to anthropology, reducing the notion of culture to a system of symbolic communication. Structuralists in psychology, such as Piaget and Freud, claimed underlying psychic structures could account for psychological phenomena (Burr, 1995), while Marx postulated that social phenomena could be reduced to economic structures, such as class, and superstructures such as ideological and political practices (Althusser, 1996).

Structuralists believed that there were all embracing theories, grand narratives, to be discovered through the analysis of structures (Burr, 1995). From a structuralist perspective, people labelled with learning difficulties are objectified with observable characteristics, classified and regarded as other in terms of a grand narrative of deviance and deficiency (Goodley & Rapley, 2001; Roets & Goodley, 2008).

The intellectual movement that developed out of structuralism, rejecting the notion of structures and rules underpinning the different features of the world, is called poststructuralism. Burr (1995) has noted that “the terms ‘postmodernism’ and ‘poststructuralism’ are sometimes used interchangeably” (p.13). Postmodernism rejects that the world is comprised of hidden structures or that it can be understood in terms of grand narratives. Instead, it emphasises pluralism, a multiplicity of situation-dependent ways of life. It is upon this background of postmodernism that social constructionism has grown.

Social constructionism can be traced back to the work of Comte, Durkheim, Mead and Foucault. However, during the 1970s it was especially brought to the fore in
social research through Feminism’s interrogation of gender as a social construct (Garner, 2007). Social constructionism has been a key concept used in the critical analysis of disability in the social sciences. Disability is recognised as a socially constructed identity category, similar to race and gender (Garland-Thomson, 2008).

For the social constructionist all aspects of society are the products of individuals interacting within that society’s culture (Garner, 2007). The meanings and purposes ascribed to people, actions and things are created in collaboration with others and are dependent upon the society in which they are found (Berger & Luckmann, 1967; Gergen, K. J. & Gergen, 2004). Rather than a system or structure Berger and Luckmann claim that society is a fluid and symbolic construction of loosely connected activities. It is held together by negotiated ideas, shared meanings and a common language (Seidman, 2008). Reality is not a fixed state but is socially constructed in an ongoing and dynamic process as people act upon their interpretations of the world. Particularities of human variations are instilled with social meanings. Many of those meanings are constructed from narratives which justify disablism and actively disadvantage some people more than others.

Social constructionism is the antithesis of essentialism (the belief things have an essence which can be defined, categorised and understood in the same way by all rational people). Traditionally, disability research into learning difficulties has taken an essentialist stance with the assumption that learning difficulties was an internal pathology located within the person. In this thesis I propose that learning difficulties is a social construct imposed upon one group of people by others. Rather than an essential characteristic of a person or an internal, diagnosable, medico-clinical affliction such as measles (Ferguson, Ferguson, & Taylor, 1992; Rioux & Bach, 1994; Rapley, 2004), learning difficulties is just a label. To press the point, as Biklen and Burke have clearly noted, people are not born mentally retarded. They only "become" mentally retarded on the basis of their performance on intelligence tests and adaptive behaviour scales" (2006, p. 167).

Although the reality or truth of learning difficulties as a fixed pathology may appear
to be obvious to those who accept it as truth, it is an invention of our particular culture and society. It is a truth belonging to the knowledge of a particular set of discourses (discussed in further detail below). This does not discount the differences and difficulties that some people do appear to have with cognitive functioning, or their need for support. However, my claim is that this is difference not impairment and certainly not disability.

Some of the fundamental building tools of social constructions are language, power and knowledge. An interest in these implements gives social constructuralism shared understandings with poststructuralism. While this thesis does not have scope to provide a full description of poststructuralist thought, some consideration is required in order to clarify my understanding of the relations between language, power and knowledge. A poststructuralist discussion on language, power and knowledge invariably draws upon the concept of discourse. This too will be addressed.

2.2.2 Language

The objects of our consciousness, things we see, think about and describe, are all constructed through language. Structuralism claimed that the meaning ascribed to a word did not intrinsically reside in the object/concept but in the reference made to its difference to other objects/concepts (Burr, 1995). For example, the word dog only had meaning when difference could be distinguished between dog and some other object/concept (for example, a table). Structuralists, such as Saussure (1974; 2010), believe that once a signifier (term used to describe an object/concept or sign) is attached to the object/concept being signified, this relational meaning is fixed. People of the same language can therefore use the same word and understand its meaning because of the fixed meaning (Burr, 1995).

The difficulty with this theory is that the meanings of words do change over time. Gee (2005) reminds us that the meanings of words are not general and can have specific meanings in different contexts of use, which can vary in different social and cultural settings. The words cool, sick, mad and awesome all have very different meanings for some people, yet to others these words are adjectives used to describe the same thing - really good fun.
The changing meanings of language have been the interest of poststructuralists. They refute claims of fixed rules and meanings arguing that meanings are always temporary, context-dependant and contestable (Burr, 1995). Gee (2005) recognises language is not only a communication tool but is fully integrated with all the elements that appear in social practice. Language is a social phenomenon, occurring between people, whether they are chatting, writing a thesis or filling in a form (Burr, 1995). Through language we negotiate social activities, social relationships, social identities and social institutions. Fairclough (1992) notes that when changes in language occur these are linked to changes in wider social and cultural processes.

Language and context have a dialectical relationship. Gee explains their interconnectedness in the following way:

“Language has a magical property: When we speak or write we craft what we have to say to fit the situation or context in which we are communicating. But, at the same time, how we speak or write creates that very situation” (2005, p. 10).

The dialectical relationship of language and context has been described by Gee as bootstrapping each other into existence over time. Gee (2005) identified seven ways language actively constructs the world. Firstly, it is used to denote significance, as we apply meaning and value (or lack of it) to things. Considering the language of “The Crutch and Kindness League”, a philanthropic organisation of the late 19th century (Montague, 1969, p. 375), the significance attributed to league-members was enhanced by the juxtaposition of crutch (associated with negatively valued connotations of dependence and impairment) and kindness (associated with positive connotations of selflessness and generosity).

Secondly, language is used for recognition as we take on certain roles or activities. Drawing on the previous example, the activities undertaken by members of The Crutch and Kindness League are interpreted as kind and good by association with the title of the league. Similarly, actions undertaken by the Guild of The Brave Poor Things, established in 1894 (Mantin, 2009), could be interpreted as being noble and accomplished under suffering (because the members are considered to be both brave, as they face difficulties, and poor things to be pitied). Mantin provides some wonderful examples of charitable language used by the Guild which demonstrate how we speak differently when undertaking different activities.
One example from 1897 described members as “pathetically grateful for kindness” (p. 15). This highly value-laden phrase not only emphasises the significance of the actions in the description of the kindness-recipient’s response, it also demonstrates Gee’s third use of language, which is to construct identities. From the example above the givers of kindness have identities of benevolence and the recipients of kindness have pathetic identities.

Fourthly, language is used to signal the kind of relationships we have with each other. The choice of language and the way it is conveyed can indicate various relationships. The Crutch and Kindness League title clearly articulates a powerless/powerful relationship.

The fifth way language is used in social construction concerns politics (the distribution of social goods) and the intention to convey a perspective on their distribution. Drawing again on the examples above, the title of The Crutch and Kindness League appealed to Christian sympathies in Victorian Britain, encouraging the social good of kindness to “crippled’ children” (Borsay, 2002, p. 106). Here language is used to indicate what is good, appropriate or the ways things should be.

The sixth use of language concerns the communication of connections or relevance (or not) of one thing to another. Situations are not necessarily inherently connected but language is used to construct relevance or connections. The organisational title Guild of The Brave Poor Things, inspired by Juliana Horatio Ewing’s (1885) fictional character of a “crippled boy” who dreamt of being a soldier (Mantin, 2009) delivers military connotations and the associated positive social values of the time to the organisation. The futility of such dreams for the “poor things” connects the organisation to a tragedy model of disability paradigm.

For a more contemporary example, Australia’s Prime Minister recently stated

"I think on a debate like asylum seekers people should feel free to say what they feel. And for people to say they’re anxious about border security doesn’t make them intolerant" (Julia Gillard quoted in The Australian Institute, 2010).

This statement connects issues of asylum seekers with national security and racism when these three issues are not necessarily connected.
Finally, we use language to privilege or "disprivilege" certain sign systems and forms of knowledge. Gee (2005) explains that there are many forms of sign systems used. These include different languages (for example, English, French, Japanese), different ways of speaking (for example, academic jargon, public servant acronyms, hip hop artists’ rhyme), and the use of different communication systems (for example, equations, charts, images). We use language to promote different knowledge and belief claims within these sign systems. The sign system used on the Cerebral Palsy Foundation’s website is a set of rolling images of children and young people with crutches or in wheelchairs. These communicate neediness. Coupled with the text “There is no known cure” (Cerebral Palsy Foundation, 2010, emphasis in the original), language is used to implicitly point readers to the medical sciences for cures and thereby privileges medical knowledge.

Changes in both the language and the active way it is used reconstruct and transform the contexts in which the language is used. In understanding the function of language Gee (1990) claims that it is helpful to consider “that it is not individuals who speak and act, but rather that historically and socially defined Discourses speak to each other through individuals” (p. 145). Gee distinguishes the term discourse (lower case ‘d’), which is understood to represent extended conversations and the speech community wherein they take place, from the word Discourse (capital ‘D’), which will be discussed below. This is a helpful convention for separating the two concepts which I have adopted.

2.2.3 Discourse

The meaning of Discourse within poststructuralist literature can be slippery (O’Farrell, 2010). While discourse is concerned with language, Discourses are much more than language (Gee, 2008). Poststructuralists claim that language is manufactured in Discourses (Burr, 2003). Since language is vital in the expression of ideas and meaning making (Seidman, 2008) and develops from Discourse, it is important to gain an understanding of what is meant by Discourse.

Gee (1990) provides a clear definition:

“Discourse is a socially accepted association among ways of using language, of thinking, feeling, believing, valuing, and of acting that can be used to identify oneself
as a member of a socially meaningful group or ‘social network’, or to signal (that one is playing) a socially meaningful ‘role’" (p 143).

Also likened to an “identity kit” (Gee, 2008, p. 155) Discourse, describes a way of being in the world, influencing everything from our language, dress and actions to our values, thoughts and beliefs. For the poststructuralist, what people do and say does not portray a personality trait or provide a glimpse of who they are as people. Rather, actions and language are manifestations of Discourses within which people participate and have their origin in the discursive culture in which they live (Burr, 2003).

Michel Foucault (1979; 1983; 1988a, 1988b, 1994) has been an influential thinker on Discourse, transforming the concept from its linguistic roots and applying it to the social sciences. Foucault saw Discourse as inherently epistemological, informing the way we understand the world. More than just informing our understanding Foucault (1972) proposed the constitutive notion of Discourse. This views Discourse as actively constructing and constituting the world as we know it. A Foucauldian approach to Discourse has been criticised for over-emphasising the predominance of Discourse in shaping the breadth of meaning in particular cultures, and for claims that Discourse colours the details of people’s everyday lives (Denzin & Lincon, 2005). Dorothy Smith (1990) spoke of the need to consider the “dialectics of [D]iscourse and the everyday” (1990, p. 202). Applying feminist theory to Foucauldian thinking she warns of assuming that Discourse will always over-ride and determine the values of women. Smith reminds her readers that women are active, skilled and make choices, highlighting that within Discourse “there is play and interplay” (p.202).

Discourses are inherently ideological (Gee, 2008). Ideology in this sense refers to the taken-for-granted everyday truths about the world, held by particular groups of people. They are “systems of ideas” (van Dijk, 2007, p. 110) which work to form particular group identities, aims, actions and values. Foucault rejected the notion of ideology⁹ (in particular Marx’s theory of ideology) for the reductionist approach taken to the relation of power and knowledge (Foucault, 1980). However, other social constructionists, such as Gee (2008), Fairclough (2001) or van Dijk (1995) note the role of ideology in Discourse. Gee also refers to ideologies as cultural

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⁹ For a more comprehensive discussion on Foucault and ideology see Hall, (1997, pp. 13-75).
models. Social constructionists claim that meaning is always situated in specific socio-cultural experiences and practices (Gee, 2000a, p. 195). People make sense of the world through their cultural model, or ideology, developed through their cultural communities. Ideology is an unchallenged social theory of the everyday person, by which they organise and understand their everyday experiences, and make meaning of life and language. Ideologies do not have to be logically consistent or complete, but are shared understandings within a community, acquired, confirmed, changed and perpetuated through Discourse.

Knowledge and Discourse are inseparable (Lyotard, 1984). Both are intrinsically tied to the language we use to produce them, because “language provides the basis for all thought” (Burr, 2003, p. 62).

Discourse is not free. Foucault argues that

“In every society the production of [D]iscourse is at once controlled, selected, organized and redistributed according to a certain number of procedures, whose role is to avert its power and its dangers, to cope with chance events, to evade its ponderous, awesome materiality” (1972, p. 216).

Foucault claims those who define the language also control our understandings, our knowledge. Discourse is therefore tied to systems of power insofar as the elite are able to maintain power by defining the meanings of language. The power to define is one of the organising and controlling procedures referred to above. Controlling knowledge and how things are understood includes controlling what can be said, where and by whom (Foucault, 1972).

Foucault asserts that if Discourse controls what can be said by whom, then it also controls what cannot be said and whose voices are excluded (Foucault, Marchetti, Salomoni, & Davidson, 2003). Discourses are embedded with power relations that maintain control. This point is significant in a disability rights-based thesis. An example of how this is played out in practice can be seen in the application of technologies of exclusion utilised by schools (Ferri & Connor, 2005). Such technologies include labelling, performance testing, tracking and special education. These are but a few of the tools by which the Discourses of education and psychology collaborate to construct some children as other and perpetuate an imposed and unchallenged identity of them. These technologies are designed,
applied and interpreted by those constructed as experts. Following the expert’s instructions is common sense as their diagnoses are regarded as truth. The experts (for example, psychologists, special education teachers, physicians) are rarely challenged. They are examples of the elite who hold positions of power because of their control of language and knowledge.

Foucault called such tools “technologies of power” (1979, p. 23). The examples above are technologies of disciplinary power. Foucault’s Discipline and Punishment (1979) outlines three simple instruments of disciplinary power “hierarchical observation” (pp. 170-177), “normalizing judgment” (pp. 177-184) and “the examination” (pp. 184-192). The application of these instruments in numerous social institutions such as the armed forces, prisons, hospitals, schools or factories, is now an intrinsic social practice, and is a form of social control. Unchallenged labels are imposed upon a student as a result of expert (hierarchical) observation. Their seating in a classroom may heighten their visibility and the teacher’s control of the child’s behaviour. The unquestioned process of tracking the student’s progress records information needed for making normalising judgments. This, along with unchallenged assessments and unquestioned examinations produce a particular kind of knowledge about the student which is also unchallenged and accepted as truth. This knowledge defines who is regarded as normal or abnormal.

Foucault notes that a technology of power is accepted within the Discourse

“only as a condition that it masks a substantial part of itself. Its success is proportional to its ability to hide its own mechanisms” (1988a, p. 86).

The social practice of labelling, assessing, tracking and segregating children into special education is accepted within the Discourse as a normal, beneficial process, thereby disguising the power relations controlling and coordinating the school experience.

Gee (2008) points out that Discourse defines its own account of acceptable criticism. It is opposed to self-scrutiny and internal criticism. Voicing alternative viewpoints to those proposed within the Discourse defines someone as actually being outside the Discourse (Gee, 2008).
2.2.4 Power and knowledge

Discourse is the face of knowledge. It has been described as historically and culturally located systems of knowledge with the power to construct subjects and the worlds in which they live (Foucault, 1988b). Power and knowledge are therefore intrinsic features in Discourse. They are the other two building tools intimately linked to language which are fundamental to social constructionism. Again, Foucault features as a key contributor to this discussion (1983; 1988a, 1988b, 1994). Reworking Francis Bacon’s famous aphorism “knowledge is power”, which viewed knowledge as the instrument of power and both as separate entities, Foucault’s work on the archaeology (1972) and genealogy (1979) of knowledge sees the phrase inverted and the concepts reformed into a single notion he coined power-knowledge.

Foucault sees knowledge, that common-sense way of viewing the world by a particular culture (which some view as ideology), as inherently tied to language and Discourse, both of which are essential to power (1972). Power is not a thing possessed by the powerful, but is understood as relational and an effect of Discourse (Foucault, 1983). Rather than viewing power as a repressive force affecting society from the top-down, Foucault sees power percolating from the bottom up in capillaries of power entwined in the relationship between the subject and subjected. Power is omnipresent, operating at every level throughout society, rather than being the localised property of the State (1979; Flynn, 2005). Power relations are unavoidable because they are interwoven and “rooted deep in the social nexus” (Foucault, 1983, pp. 222-223).

Power “needs to be considered as a productive network which runs through the whole social body” (Rabinow, 1984, p. 61). It produces knowledge. In the example above, particular knowledge about students was produced through the instruments of disciplinary power, which in turn, produced an individual, the special education student. This identity was constructed to suit various vested interests (Foucault, 1979). It is underpinned by an ableist ideology. The knowledge produced will cause people (teachers, parents, the student) to speak and act in

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10 Common sense assumptions (knowledge) developed within the Discourse are cultural models or ideology. Ideology employs “common sense assumptions in the service of sustaining unequal relations of power”, (Fairclough, 2001, p. 84).
particular ways according to the Discourse within which the knowledge was developed. No one will force them to do this. It is the effect of power-knowledge within Discourse. Power-knowledge relies on acquiescence based on ideological assumptions of the accepted knowledge (Fairclough, 1992).

Power-knowledge is the power to create hegemonies of knowledge (Judd, 2006). Foucault’s (1983) work provides an analysis of the complex social techniques and methods fundamental to hegemony. Foucault draws upon Gramsci’s (Gramsci, Hoare, & Nowell-Smith, 1971) notion of hegemony - where relations of domination are based upon consent rather than force, and are virtually invisible. It involves the naturalisation of practices and their social relations as a matter of common sense. Freedom from coercion is an interesting feature of the working of power-knowledge and one of the ways Discourse hides its mechanisms.

Language, Discourse, power and knowledge are a complex set of interrelated tools fundamental to social constructions. So intrinsic to the fabric of our daily lives are they that we unwittingly wield them every day as we construct and are constructed by the societies we live in. One particular social construction to which I would draw your attention now is that of normalcy.

2.2.5 The social construction of normalcy

Before considering the social construction of learning difficulties it is useful to consider the social construction of normalcy, thereby establishing a context. It also serves as a reminder that just as there is no such thing, no “object of scientific understanding and intervention” (Trent, 1994, p. 6), as learning difficulties, neither is there such a thing as normal.

In a critique of normalcy Davis (1995) identifies that the social problem lies not with the person with impairments but with the way that normalcy is constructed, expected and enforced. The ideology of ableism accepts the concept of normal as a reality, creating problems for anyone unable to meet society’s ableist expectations. Such a person poses a challenge to commonly held assumptions about what people should be like. Paul Hunt (1966) recognised his identity in society – as a person with physical impairment – was perceived “as unfortunate, useless, different, oppressed and sick” (p. 146).
In keeping with Oliver’s (1990) historical argument, Davis (1999) notes how people with impairments were viewed differently in pre-industrial Europe to today. He claims that prior to the mid-nineteenth century “Western society lacked a concept of normalcy” (1999, p. 37). Instead the accepted paradigm was of a human ideal. Davis (1999) notes that if a society has the concept of an ideal then everyone falls short of that standard and lives in varying degrees of imperfection. In such a society impairments are not viewed as absolutes but as features on a descending continuum upon which all people sit. This speaks of a particular kind of accepted knowledge.

Davis suggests that the development of statistics introduced a new knowledge and seriously challenged the existing social knowledge. The bell-curve, or normal curve, as it was earlier known, introduced the notion of norm. Under this paradigm most people fall under the umbrella of norm. Those who fall on the edges of the curve are, subsequently, categorised as abnormal.

The industrial revolution and the introduction of factories led people labelled with learning difficulties and those with impairments which affected their work productivity quotas, to be singled out as deviants as they did not match the expectations of an average worker. The need for time keeping, production maintenance, literacy and numeracy meant that people who had at one time found an economic niche no longer had a socially useful or productive role (Ryan & Thomas, 1987; Oliver, 1990). Walmsley (1994) suggests that in societies where literacy is uncommon, those who are unable to read or write do not stand out as they do in Western cultures today.

Industrialisation and the rise of capitalist economies, plus the science of eugenics in the 19th century and the emerging notion of normal, all contributed to the development of what is commonly called the social construction of disability (Davis, L. J., 1999). Trent (1994), looking at learning difficulties in North American, also confirms the importance of the social economy in the construct. He notes that where society had been accepting of the “feeble-minded” prior to the 1819 financial crisis, the economic hard times saw significant social attitudinal changes towards them occur as they began to be viewed “with a mixture of curiosity, [and] anxiety” (p. 10). However, after the American Civil War (1861-1865) history records the emergence of the negatively viewed, socially
constructed, identity of “idiots” as something to be feared.

Statistics and the notion of normal are also tied to eugenics, as its focus is a population that can be normed (Davis, L. J., 1999). Eugenics, which literally means “normal genes” (MedicineNet, 2001), seeks to improve the human species by selective breeding. Based on Darwin’s theory of evolution, eugenics pursues the perfect body in the quest of a perfect society. The consequence of this perspective is a division of the population into that which is considered standard and non-standard, normal and abnormal. The aim of eugenics is for the State to attempt to “norm the non-standard” (Davis, L. J., 1995, p. 30), or eliminate the abnormal.

In the early 20th century the medical and educational professions, the so called “judges of normality” (Foucault, 1979, p. 304), embraced the development of intelligence quotient (IQ) testing as a new statistical form of bricks and mortar for constructing the normal. Scheerenberger notes that mental retardation refers to

> “significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behaviour, and manifested during the developmental period” (1987, p. 218).

By calculating quantities of normalcy\(^\text{11}\), any departure from a set normalcy quotient makes abnormality possible. The new category of abnormal people also came with a set of peculiar subgroups called idiots (scoring < 30), imbeciles (30-50) and morons (50-70). Prior to the construction of the labels these discursively categorised people (idiots, imbeciles and morons) did not exist. Rapley (2004) has noted that while the individual categorical words have history the meanings attached to them were significantly reconstructed when they were apprehended and applied to intelligence testing. This highlights the fluid nature of socially constructed meanings. It also signals to me hope that social constructions can be renegotiated. In the following section I discuss the social construction of learning difficulties and the implications of this for people upon whom that label is bestowed.

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\(^{11}\)Linneman (2001) notes that prior to the mid-nineteenth century the word norm was simply used to describe a carpentry tool.
2.2.6 The social construction of learning difficulties

In this section I discuss the social construction of learning difficulties. I claim that the problem for people labelled with learning difficulties lies in the social relations of language, power and knowledge and not in their heads. Bogdan and Taylor have argued strongly that

“Mental retardation [sic] is, in fact, a socio-political not a psychological construction. The myth, perpetuated by a society, which refuses to recognize the true nature of its needed social reforms, has successfully camouflaged the politics of diagnosis and incarceration” (1982, p. 15).

Trent has described learning difficulties as a

“construction whose changing meaning is shaped both by individuals who initiate and administer policies, programs and practices, and by the social context to which individuals are responding” (Trent, 1994, p. 2).

Learning difficulties is not a thing. It is a label resulting from the knowledge produced within a particular Discourse underpinned by an ableist ideology. It is applied to specific people identified by the technologies of power. Although learning difficulties is the preferred term of the People First organisation (People First, 2008), it is still an othering label, a technology of exclusion, the application of which frequently goes unchallenged. The label emphasises the perceived limitations of a person and disregards their abilities. Once named, the construct is reified and accepted as truth.

Phil Smith claims that labels such as learning difficulties are deliberately applied to people in order to establish boundaries “between the normate and the freak” (2005, p. 88). The taxonomies of difference established through labels are the means by which the disability services industry maintains a “privileged, ableist, white class that oppresses those perceived as freaks” (p. 88). Taxonomies of difference also serve the disability industry’s economic goals by ensuring service users. Deborah Metzel (2005) points to the classification of people by such labels as a means of social and economic control which is tied to highly regulated funding and services.

Labels are a form of language devised and applied by others and over which the people thus described have little control (Rapley, 2004). The meanings
associated with the labelling language within the specific sociocultural context, not only determines access to services, but also how people are treated. Janette Welsby and Debbie Horsfall (2006) have noted the historical positioning of people labelled with learning difficulties as untrustworthy, unreliable and generally incompetent. Dan Goodley and Mark Rapley concur:

“It is assumptions and ways of talking about disability that are crucial to the production of persons as incompetent” (2002, p. 127).

Assessment of competence is invariably linked to the construct of learning difficulties (Edgerton, 1967; Seigert & Weiss, 2002). Assessments produce a particular form of knowledge within the Discourse in which they are implemented. This is knowledge interpreted by the powerful (such as doctors, psychologists and educators) about the powerless (Ferri & Connor, 2005). Knowledge plays a key role in constructing learning difficulties.

Powerful social relations have ensured the influence of only certain and protected knowledge - that which is authorised to reconstruct meanings and apply the labels (Cocks & Allen, 1996; Gee, 2008). The privileged knowledge is articulated through language. This language is authorised and frequently goes unchallenged. The authority invested in such language makes it very powerful (Dreyfus, et al., 1983). For example, when terms such as acquiescence bias, (which presupposes that some people are incapable of valid testimony), are pronounced by the holders of privileged knowledge, it has the power to silence people on the assumption that their testimony is invariably unreliable (Goodley & Rapley, 2002) whether or not that assumption is accurate.

Authorised language has the power to perpetuate ableist ideologies. These can have enormous impacts upon the lives of those whom it labels and determines what actions will be taken by and for them. For example, the knowledge gained from the results of a psychologist’s IQ test may result in the sanctioning of institutionalisation, loss of family life, reduced freedom, programmed treatment and the regulation of all areas of a person’s life for the rest of their life.

Language is communicated in many ways and its influence on the social construction of learning difficulties is multi-layered. The social knowledge of learning difficulties develops as members of society interact with language through
the world around them (Cocks & Allen, 1996, p. 282). Buildings, such as special schools (which segregate and heighten the status of other), negative stereotypical representations of learning difficulties through the media, stories of the burden of care and cost of people labelled with learning difficulties to the public purse are all ways in which language communicates on the topic of learning difficulties to the general community. The Discourse within which they are situated informs what members of society understand learning difficulties to be and how they respond to it. This response is very often negative. Phil Smith (2005) notes that rates of abuse and violence against people labelled with learning difficulties are significantly higher than those in the general populations. He points to the ideologies of eugenics and stigmatisation, casting people labelled with learning difficulties as being less than human, as justification for some members of the general population to enact atrocities upon them.

Since the knowledge and the way it is presented is essentially evaluative, people represented as other are assigned less social value than those who are in a position to judge and evaluate (Cocks & Allen, 1996; Philo & Metzel, 2005). The evaluation and subsequent relegation of someone to a constructed diagnostic category has significant consequences. Despite Edgerton’s (1967) recognition of the destructive nature of the label mentally retarded over forty years ago, supported by a raft of subsequent research (see for example Finlay and Lyons (2005), Hayden and Neils (2002), Rapley (2004) and Snell and Voorhees (2006)), this term was not changed by the American Association of Mental Retardation (AAMR) until 2007. Here it was acknowledged that

“the term mental retardation does not communicate dignity or respect and, in fact, frequently results in the devaluation of such persons” (Schalock, R., Luckasson, & Shogren, 2007, p. 119).

It must be asked why those in positions of power maintained this label for so long?

Learning difficulties has become a reified category, which has resulted not only in the concrete forms of oppression found in the well documented history of disability (see for example Ferguson (1994), Cocks, Fox, Brogan and Lee (1996), Wehmeyer, Bersani & Gagne (2000), Rapley (2004)), but also, as Licia Carlson (2001) observes, in various forms of conceptual oppression. These include the marginalising (and effectively silencing) of people labelled with learning difficulties
from mainstream scholarship in philosophy and Disability Studies. In particular, Carlson (1998) notes the exclusion of the perspectives and experiences of women with learning difficulties from feminist scholarship.

People labelled with learning difficulties also experience marginalisation from within the disability movement. Negative social attitudes towards learning difficulties have led to people being ostracised, as Jane Campbell notes:

“People without learning difficulties in the [disability] movement still fear being lumped together with us. Being put together with what society see [as] the ‘stupid, thick, mental and mad’, would reinforce the stereotype that disabled people are incapable” (1997, p. 88).

The languages of power and the manner in which knowledge is presented disguises the fact that the powerlessness of people labelled with learning difficulties is not generally the result of any intrinsic limitation. Instead, their powerlessness comes from being weighed in the slippery scales of socially valued characteristics and found wanting. In a society that values intellectual ability people deemed to have lower intelligence (which is itself a social construct) are seen as being of less value. In a capitalist society that measures worth with material output less productive workers are assessed as being of less worth. The evaluative language used in connection with people labelled with learning difficulties (terms such as slow-learner, incompetent, special needs, mentally retarded) pretends to be descriptive. However, it is value-laden and assigns those upon whom it falls into devalued social roles (Cocks & Allen, 1996; Shier, Graham, & Jones, 2009). Wolfensberger, has noted that “devaluation…is not something which is inherent in the person” (1992, p. 2). Instead, the devaluation of people labelled with learning difficulties comes from the language used to evaluate them as being of less value than other members of society.

2.2.7 Attitudes towards people labelled disabled

The epidemiologically orientated, positivistic research of the diagnosticians of abnormality (including many medical and healthcare professionals and educational specialists) is implicitly interested in deviance from identified social norms. Medical modelists regard abnormalities as personal attributes and seek to fix the person through remediation, finding a cure or applying a means of correcting the
identified impairment (Linneman, 2001; Ferguson & O’Brien, 2005). The person’s difference is constructed as a personal problem. Derrick Armstrong has warned that the label of ‘learning difficulties’ has been constructed “for managing and controlling a ‘troublesome’ minority” (2002, p. 333). Control is systematically organised through Governmental policies and programs. For this reason, significant difficulties are encountered by people labelled with learning difficulties when they endeavour to reconstruct the label by not conforming to its stereotype. Fred Spedding’s moving account of his efforts to advance his civil rights through self-advocacy illustrates this point (Spedding, et al., 2002).

The management and control strategy has given rise to whole industries developed around efforts to cure diseases, repair dysfunction, improve learning or to modify behaviours in individuals. As previously noted above, when the problem is defined as an individual rather than a societal inadequacy, it belongs to the person not the society. The individual is the one viewed as in need of fixing. Lack of therapeutic progress is also frequently understood in terms of the individual rather than the system (Ferguson & O’Brien, 2005). The professionals involved in restorative interventions are often protected from criticism because their actions are authorised by the classification of the impairment rather than the outcome. From my own experience in the disability employment industry it is very common to hear that some clients are “too hard” to place in a job, rather than considering that it is the task of finding the job in a restrictive and disablist labour market that is “too hard” or that the skills of the employment consultant are inadequate.

Along a similar blame the victim line of argument, Paul Longmore12 writes of “disability as transgression” (Longmore quoted in Zames Fleischer & Zames, 2001, p. 4). He describes the ableist social expectation of impairment as a predicament that must be managed and endured in private (or between you and your physician) but which people can eventually overcome if only they will try harder. To remain incapacitated must, in some way, be their own fault. This distorted social logic is rather like blaming someone for losing the battle against cancer for not fighting hard enough. Constructed in this way, some labelled people strive not to transgress social norms and will go to great lengths to be

12 Longmore had polio as a child, resulting in lifelong impairments. As a disease from which some people recovered, he claims that it was considered that to have not successfully vanquished this blight transgressed social values and wholesome Americaness (Zames Fleischer & Zames, 2001).
perceived as normal (see for example French, S., 2004). Goffman called it “passing” (1963, p. 73) and Edgerton described it as a “cloak of competence” (1967, p. iii).

Furthermore, people labelled impaired or with learning difficulties are constructed as needy. Ferguson and O’Brien (2005) note that the desire to help those in need is generally accompanied with an expectation of gratitude. Such an expectation reinforces an inherent power imbalance and establishes “the bargain” (Longmore quoted in Zames Fleischer & Zames, 2001, p. 4) – help becomes contingent upon the receiver’s gratitude for the giver’s generosity.

2.2.8 Summary

The history of the construct of learning difficulties can be read as one dominated by language, power and knowledge. Complex power relations exist between individuals, groups and social institutions. This section has discussed how language and knowledge can be both powerful and used by people with power. In a society underpinned with an ableist ideology, structured for the benefit of those without impairments and without due consideration for those with different levels of ability, people become seen and constructed as other. In the section to follow I look more closely at the concepts of ableism and disablism and their impact on Australian society.

2.3 Ableism and disablism

“The true focus of revolutionary change is never merely the oppressive situations which we seek to escape, but that piece of the oppressor that is planted deep within each of us and knows only the oppressor’s tactics, the oppressor’s relationships.”

(Lorde, Audre, 1984, p. 123)

2.3.1 Introduction

Ableism is one of the most “entrenched and accepted isms” (Wolbring, 2009) with which we live today. But what is ableism and what is disablism? After discussing the confusion often engendered by these terms and clarifying meanings I suggest ways of interrogating them. Ableism is presented as the root source of disabling social barriers. I also discuss dominant group privilege of those considered non-disabled, along with unquestioned ableist social structures. This section prefaces
discussion of the social model of disability (2.4) which will provide an effective lens by which to identify ableism and disablism in society so that political and social practices can be changed and a more inclusive society constructed.

2.3.2 Defining ableism and disablism

Ableism

Ableism is a phenomena so unquestioningly embedded in Australian social practices that Fiona Kumari Campbell has described the world as “compulsively ableist” (2006, p. 2). Ableism is influential, silent and universalising (McLean, 2005). Davis (2002) notes that ableism is an unquestioned belief that underpins and is protected and maintained by our social policies, structures and institutions. But it is a term that requires clarification. Writers in the field of Disability Studies and special education have variously referred to the concept of ableism using the words ableism and disablism with apparently interchangeable meaning (Rauscher & McClintock, 1996; McLean, 2005). This can cause confusion. Though often paired together, ableism and disablism are very different things. Vera Chouinard has defined ableism as “ideas, practices, institutions and social relations that presume ablebodiedness” (1997, p. 380). Ableism’s presumption of ability consequently “privileges ‘species typical abilities’ while labelling ‘sub-species-typical abilities’ as deficient, as impaired and undesirable” (Wolbring, 2008). Laura Rauscher and Mary McClintock have described ableism as “pervasive” with “[d]eeply rooted beliefs about health, productivity, beauty, and the value of human life” (1996, p. 198). These values are perpetuated by the media and work to create an environment that is frequently unwelcoming and often hostile to people whose ability levels (whether they be physical, mental, cognitive, and sensory) are not deemed to be “socially acceptable” (1996, p. 198). This summary of ableism paints a picture of how ableist notions assist in constructing what is socially acceptable. In constructing the acceptable such ableist attitudes consequently “construct persons with disabilities as marginalised, oppressed and largely invisible ‘others’” (Chouinard, 1997, p. 380).

Disablism

Fiona Campbell has defined disablism, as “a set of assumptions and practices promoting the differential or unequal treatment of people because of actual or
presumed disabilities” (2008a, p. 152). This definition sees disablism as deliberate discrimination. Disablism is not confined to people with “actual or presumed” impairments. Australian research has shown that disablism also extends to the other members of families in which someone has an impairment (Jarrett & Llewellyn, 2008).

2.3.3 Interrogating ableism and disablism

Thomas Hehir (2002) has noted that before progress towards social equity can be achieved there must first be an acknowledgment that ableism exists. The social model of disability along with critical disability theory can be applied as a strategy for exposing ableism and the discriminatory systems that stem from it perpetuating disabling social barriers, exclusion and oppression. People who are unaffected by impairments are frequently unaware of the ubiquitous influence of ableism in society (McLean, 2005). This lack of awareness includes lack of consciousness of the way ableist normativity has been institutionalised into western culture. Ableist normativity refers to the way in which Discourses (which include technologies, programs, curricula, and policies, as well as everyday activities) present as normal a particular way of appearing, acting and being. This way of being represents what it is to be fully human (Baker, B., 2002). Fiona Campbell notes that such an understanding maintains “the distinction between ableness and disabledness” (2008b) through the construct of normalcy.

The social model of disability and critical disability theory challenge the taken-for-granted nature of normalcy, ideologies and beliefs. They offer a means by which we can question and disturb the dominant and hegemonic non-impaired identity and develop a critique of ableist thought. Cheryl van Daalen-Smith (2006) has linked the same ideologies of greed, power and societal hierarchy that sanction injustices based on gender, race, class, sexual orientation with those that also authorise discrimination based on ability. An interrogation of ableism and disablism is a way of highlighting what these ideologies are and how they are perpetuated in social practices.

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13Discrimination with particular reference to those with learning difficulties has also been called “handicapism” (Bogdan, R., Biklen, Blatt, & Taylor, 1981, p. 238). However, for consistency disablism is used in this thesis for ability-based discrimination.
2.3.4 Dominant group privilege

Ableism privileges the interests of the non-impaired and therefore tends to render the existence and concerns of people with impairments or learning difficulties as invisible or the focus of benevolence. At the same time the benefits of not having an impairment are equally invisible and go unchallenged and unacknowledged. This makes the non-impaired person a beneficiary of the disabling classification system which oppresses others (McLean, 2005). The phenomenon of dominant group privilege and systemic, unearned advantage at the expense of minority groups, was identified by Peggy McIntosh (1988) in her feminist review of white, male, heterosexual, privilege. McIntosh recognised that concentrating on the plight of the oppressed was inadequate for explaining the perpetuation of oppression and instead focused attention on the benefits and privilege enjoyed by the oppressors. She explains,

“I did not see myself as racist because I was taught to recognize racism only in individual acts of meanness by members of my group, never by invisible systems conferring racial dominance on my group from birth” (p. 2).

In a similar way, invisible ableist systems of privilege also confer dominance on the able-bodied/minded. By only looking for “individual acts of meanness” or situations of oppression, you never actually acknowledge the “colossal unseen dimensions” (McIntosh, 1988, p. 4) of privilege, which goes unchallenged. Just as an “obliviousness” (p. 4) to white advantage or male advantage maintains an inculturated myth of meritocracy and that opportunity is available to all citizens, so too does an obliviousness to ableism. An interrogation of ableist social barriers can expose the unwarranted and unchallenged privilege of ablebodiedness.

The social model of disability parallels this line of thought having identified the privileging of the interests of the non-impaired as the characteristic of an oppressive society “which takes little or no account of people who have impairments and thus excludes them from mainstream activity” (UPIAS, quoted in Oliver, 1996b, p. 25)\(^\text{14}\). While the social model is a means of exposing disabling barriers, it also offers a way by which to interrogate ableism, focusing on the benefits of maintaining ableist systems.

\(^\text{14}\)For a detailed history of the Union of the Physically Impaired People Against Segregation (UPIAS) and the development of the Social Model of Disability see Shakespeare (2006).
2.3.5 Systemic ableism

The problem of ableism/disablism is not individually based. Ableism (and the disablism that stems from it) is not something which can be simplistically reduced to a trait or attitudinal problem of prejudiced people (Davis, L. J., 2002). Ableism results from political and social practices. Davis (2002) claims it is one aspect of a far-reaching cultural and ideological change stemming from modernisation. He calls for a move away from a victim/victimised perspective as this position leaves little room for agency. Instead, if ableism is viewed in terms of political and social practices then these practices have the potential to be changed through political processes.

Australia is an ableist nation. The National Disability Strategy Consultation Report, 2009, testified that there was still widespread misconception in Australia that people with impairments are “a danger, a burden, and a threat” (National People With Disabilities and Carer Council, 2009, p. 11), and that they “would be better off in institutions with people of their own kind” (p. 11). This overt expression of desired exclusion of people with impairments betrays a lack of respect and recognition of human dignity for people with impairments. In the following section I introduce the social model of disability and discuss how looking at disability differently can be an effective means of illuminating ableist assumptions and disabling practices.

2.4 The social model of disability

“Until the concept of disability disappears and is replaced by a society that is structured to support everyone’s life relatedness and contribution—until that day my life and opportunities and the lives of every other person who carries the label ‘disabled’ depends on the goodwill of people in the human service system. Goodwill is no substitute for freedom.”

(National People With Disabilities and Carer Council, 2009, p. 1)

2.4.1 Introduction

This section of Chapter 2 provides an overview of the social model of disability and explains how the social model has come to be the way by which I conceptually view disability. To establish a context I discuss the current Australian notion of disability and commonly accepted models of this term including the medical and
social models. The North American and British social model approaches are then reviewed. A critique of the social model including an indication of its relevance to my research concludes the section.

2.4.2 The medical model of disability

In Australia the concept of disability is predominantly understood using a medical model and promoted in terms of functional deficit. The Australian disability service providers are obliged to adopt the definition of disability held by their funding bodies. Disability services in Australia are funded through either the State or Federal Governments (Roth, 2007). Both Governments refer to the Australian Disability Discrimination Act, 1992 (Australian Government, 1992) which defines disability as:

“(a) total or partial loss of the person’s bodily or mental functions; or
(b) total or partial loss of a part of the body; or
(c) the presence in the body of organisms causing disease or illness; or
(d) the presence in the body of organisms capable of causing disease or illness; or
(e) the malfunction, malformation or disfigurement of a part of the person’s body; or
(f) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
(g) a disorder, illness or disease that affects a person’s thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour”


This Act presents disability as a medical problem located exclusively within the individual. Pathological and problem-based assumptions underpin this conception of disability. They impose the presumption of biological or physiological inferiority on people with impairments (Hahn, 1986). Terms such as malfunction, malformation, disfigurement, disorder and disturbed are ableist and value-laden. Such language reveals that disability is viewed as individual and inherently negative (Campbell, F. K., 2008b). It is the language of the medical model of disability.

The medical model of disability is the dominant and generally unquestioned way of understanding disability. The medical model of disability is also called “the individual model” or “the personal tragedy theory of disability” (Oliver, 1996a, p.
31) and assumes illness and impairment are “abhorrent and undesirable” (Oliver, 1996a, p. 20). From this standpoint, people with impairments in Australia and other western nations have frequently been viewed with fear, contempt, pity, horror or distrust and have been subjected to exclusionary, over-protective and patronising behaviours (Barton, 1996). However, over the past three decades the concept of disability has been explored and different ways of understanding disability have emerged. Mike Oliver’s critique of the medical model, which began in 1983, has encouraged others to look more closely at its influence.

Mike Oliver (1983) was the first theorist to make the binary distinction between an individual or medical model of disability and a social model of disability (Giddens, 2006, p. 281). Oliver’s work (for example Oliver, 1983, 1986, 1990; Campbell, J. & Oliver, 1996) has been highly significant in the field of Disability Studies, highlighting the difficulties within a medical understanding of disability (Thomas, 2004). The medical model of disability locates the problem of disability within the person. For people born with perceived impairments the identification of the problem of disability occurs early in a child’s life. Fiona Place notes that “within minutes” of her healthy baby’s birth

“he received a tentative diagnosis – whispers and murmurs placing a virtual sticker on his forehead... he’d already been judged, already been found wanting” (Place, 2008, p. 1).

The segregated schooling of people labelled with learning difficulties and impairments is a social practice underpinned by the medical model of disability. Rather than admitting a child perceived as having special needs is prohibited from attending a mainstream school because of systemic structures or institutional resourcing issues, the point of prohibition is located within the child (Slee, 1997; Baker, B., 2002). Their exclusion is blamed on their impairment, so that it is their fault that they must attend a special school. The medical model assumes impairment renders a person dependent upon medical professionals or specialist teachers and contributes to what Barton refers to as the “dependency model of disability” (1996, p. 8).

The tragedy status attributed to impairment assumes it is a dreadful thing of which

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15 For a comprehensive anthology of literature comparing and critiquing models of disability see Nick Watson’s collected works Disability (2008, 2009).
people are victims. The association of impairment with tragedy is said to stem from “non-disabled assumptions of what it is like to experience impairment” (Oliver, 1996a, p. 21) in spite of substantial evidence challenging these assumptions (Silver & Wortman, 1980). The idea that impairment must involve some form of “loss or ‘personal tragedy’” (Oliver, 1996a, p. 21) has led to a fix-it mentality. Rehabilitation and medical treatment are considered to be the reasonable source of a cure to eradicate the problem. Bernadette Baker describes this approach to disability as an “outlaw ontology” (2002, p. 665) where impairment is seen as something “outside the normal” (2002, p. 674), the diagnosis and remedy of which must be hunted down to be rid of the problem of disability. The medical model of disability focuses on the need for the individual to get better, to strive to be more normal and for the individual to fit in with society. For this reason Oliver (1996b) actually refers to it as the individual model. However, it is most commonly termed the medical model in much disability literature (see for example Albrecht, Seelman & Bury (2001)) and for this reason I too have adopted the term.

2.4.3 Doing disability research Downunder

Australia’s national ontology of disability is the medical model. We do have a number of noteworthy disability researchers interested in a social understanding of disability (see for example Meekosha & Dowse, 1997; Armstrong, 2002; Bleasdale, 2003; Rapley, 2004; Goggin & Newell, 2005; Mantle, 2008; Campbell, F. K., 2009). However, considerable disability research coming out of Australia remains focused on an individual, medically based, understanding of disability (for example Bittles, et al., 2002; Klotz, 2004; Leeder & Dominello, 2005; Jackson, O’Connor, & Chenoweth, 2006; Hayes, 2008; Riches, Parmenter, Llewellyn, Hindmarsh, & Chan, 2009). Much Australian disability research (such as that coming from the Australian Institute of Health and Welfare) defers to the World Health Organization’s (WHO) International Classification of Functioning, Disability and Health (ICF) when defining disability (Riches, et al., 2009).

The ICF is a highly complex framework used for conceptualising and categorising

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16 It should be noted that Oliver has emphatically stated that “there is no such thing as the medical model of disability, there is instead, an individual model of disability of which medicalisation is one significant component” (1996b, p. 31).
disability. It is made up of three components (each further broken down in numerous domains) relating to:

- body functions and structures of people (and impairment thereof)
- activities people do (and activity restrictions)
- factors in their environment which affect these experiences.

The Australian Institute of Health and Welfare states “[t]he key criteria for defining intellectual disability are: significant impairment in intellectual functioning; difficulties in adaptive behaviour; and manifestation in the developmental period” (2008, pp. 5-6). Despite its reference to the ICF this definition focuses on functional impairment (both intellectual function and adaptive behaviour) but makes no reference to the ICF definitional component of environmental restrictions to participation. This indicates a possible confusion in the application of the ICF with regards to “intellectual disability”, an inconsistency of application of the ICF definition and a falling back onto the comfortable interchange of the terms impairment and disability.

The ICF is the WHO’s second attempt to describe disability following fierce criticism and the rejection of its previous classification instrument by the international disability movement (Hurst, 2000; Williams, G., 2001). Much of the criticism of the ICF and the medical model of disability centres on the fixation with pathology and the failure to address the social disadvantage experienced by people with impairments. This is the crux of the difference between the medical model and the social model of disability. A failure to consider social disadvantage is also a failure to recognise, critique and challenge the ableist structures that perpetuate this disadvantage.

The revised ICF, introduced in 2001, incorporates a social element to the definition of disability, a significant concession by a medically dominated organisation. The United Nations more explicitly recognised the social origin of disability by transferring the problem of disability from the individual into the community when it declared

“[t]here is no universally agreed definition of disability. It is now considered a socially created problem and not an attribute of an individual” (UN Chronicle, 2004).
The social model of disability underpins the Convention on the Rights of Persons with Disabilities (the Convention) which recognises

“that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (United Nations, 2006).

Although Australia is a signatory to the Convention it has not yet reviewed the way it defines disability in legislation.

The idea that disability is a social issue, closely linked to human rights and oppression rather than impairment, made sense to me (Oliver, 1992; Barnes & Mercer, 1997; Morris, 2001; Finkelstein, 2002). It resonated with my increasing and uncomfortable awareness of client powerlessness and their declining opportunities for decision making and choice (at least within my industry of employment assistance). I could see how industrial changes and service practices were actually disabling people. An environment with limited opportunity to exercise choice is an environment with limited opportunity for self-determination to develop and flourish (Wehmeyer & Garner, 2003). Therefore, a lack of opportunities to make decisions and choices creates a situation that inhibits (because it does not encourage), and therefore disables, the development of self-determination skills.

2.4.4 Discomforted by disabling practices

With a dawning awareness of the social model of disability I began to notice social structures and practices that might be considered disabling. I had never before questioned the necessity for the disability industry, nor asked why it is that doctors, whose job it is to assist the sick, are the ones who decide who has access to disability services. Looking at the world through the social model I became uncomfortable with an increasing awareness of exclusionary practices everywhere I looked. I wondered if Wolfensberger (1989) was correct in his assertion that the human services industry’s unspecified function was the creation and maintenance of large numbers of dependent and devalued people for the purpose of securing employment for others. Rather than a specialist employment service I recognised my workplace as a segregated service.
I reflected, “What are the barriers faced by people with impairments and how are they so very different to those faced by long-term unemployed people?” They too are a highly disadvantaged and socially devalued group (Davidson, 2002). Why does the industry I work in call its clients people with disabilities (highlighting impairments) when the intent is to capitalise on their abilities? Why was there a focus on supporting the client to fit into the workplace rather than challenging discriminatory attitudes and exclusive workplace practices? I was challenged to look more closely at what the social model of disability had to offer.

2.4.5 The social model of disability

“In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society.”

(UPIAS, quoted in Oliver, 1996b, p. 25)

There are differing views of the social model of disability within the Disability Studies community. Barnes (2003) and others, such as Oliver (1996b), have argued that it is not a social theory but merely an “heuristic device’ or an aid to understanding” (Barnes, 2003, p. 6). However, while I call it a model, it is nevertheless an organised system of knowledge that can be applied to various social contexts in order to discern what is disability. For the purposes of this thesis I recognise the social model as a theory - a way of understanding disability.

Having clarified that semantic issue, there are also differing views within the Disability Studies field internationally on what the social model is. In the United States (US) the independent living and disability rights movements of the 1970s were significant influences on emerging interest in the link between disability and society. Berger and Luckmann’s (1967) social-constructivist view is credited by some as “the harbinger of the social model of disability” (Braddock & Parish, 2001, p. 44). The social model of disability is also referred to in the US as the “minority group model of disability” (Williams, G., 2001, p. 134). Much of the US research draws upon a Marxist analysis of disability which renders it, along with rehabilitation, a commodity within a human services industry functioning as a commercial enterprise (Wolfensberger, 1989; Oliver, 1996b; Albrecht, et al., 2001). This understanding is combined with a political appreciation stemming from the US
civil rights movement.

In spite of an explicit call for social reform and an awareness that learning difficulties (commonly termed mental retardation in the US) is a social construct, Oliver (1996b) has criticised the US approach to a social model of disability for its failure to challenge the notions of individualism or consumerism, upon which capitalist societies are founded.

The British version of a social model of disability grew out of a neo-Marxist opposition to Fabianism$^{17}$ and the paternalistic welfare state (Oliver, 1996b). The British social model was initially cultivated by grassroots organisations of people who identified themselves as disabled (including academics and activists) and had experiential as well as intellectual knowledge of disability (Barnes & Thomas, 2006). It takes a more materialist approach than the US social model of disability. The British social model developed a binary distinction between the notion of disability and impairment. This approach to understanding disability has a strong reliance on a radical structuralist epistemology. Highlighting economic, environmental and cultural barriers faced by people with impairments, it is also referred to as “social oppression theory” (Oliver, 1998, p. 1446). The British social model spells out material disadvantages within social structures such as

“inaccessible education, information and communication systems, working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities, and the devaluing of disabled people through negative images in the media-films, television and newspapers” (Barnes, 2007).

The social model of disability has had two significant outcomes (Shakespeare & Watson, 2001). Firstly, it supported the disability rights movement’s strong philosophical and political commitment to the removal of disabling social barriers. Secondly, the epistemological paradigm shift enabled people with impairments to reconceptualise disability and see that it is not their fault. This has been an opportunity for consciousness raising for people with impairments allowing them to consider the exclusionary and oppressive social structures and environmental

$^{17}$Fabianism – a highly influential form of English socialist thought from the 1880s to present day. Fabians envisage social development slowly moving from capitalism to socialism through benevolent, bureaucratic intervention (Cole, 1961). All British Labor Prime Ministers have been members of the Fabian Society along with other influential thinkers such as George Bernard Shaw, H.G.Wells, Oscar Wilde and Sidney Webb (Fabian Society, 2010).
barriers (Goodley & Tregaskis, 2005). Disability is a problem of social oppression and people with impairments and those labelled with learning difficulties are an oppressed minority group (Shakespeare & Watson, 2001).

The social model (which takes the blame of disability from the person and places it on society) has been a liberating concept for many people with impairments (see for example Hevey, quoted in Oliver, 1996a, p. 27). It directly connected with the experience of people with impairments. Liz Crow found relief through the social model, describing it as

“the proverbial raft in stormy seas. It gave me an understanding of my life, shared with thousands, even millions, of other people around the world, and I clung to it. This was the explanation I had sought for years. Suddenly what I had always known, deep down, was confirmed. It wasn’t my body that was responsible for all my difficulties, it was external factors, the barriers constructed by the society in which I live” (1996, p. 206).

Although my research has included a rights base and has been influenced to a degree by North American disability researchers, nevertheless, it has been the British writers who have dominantly informed my practice. This may unconsciously stem from the fact that I have worked in an industry in which the medical model is deeply embedded and because I have found the British critique of the medical model, particularly by Oliver (1990), unsettlingly convincing and personally enlightening. Perhaps more influential, though, has been an awareness of the way in which the British social model has positively contributed to the lives of many people living with impairments, who have become politically empowered (McClimens & Taylor, 2003).

I began my higher research degree with a desire to make a difference, uphold the cause of the oppressed and support people to speak out against injustices. The social model was a means of both illuminating and articulating injustices. It is, therefore, the lens of the “British social model” (Shakespeare, 2006, p. 9) of disability through which my research has been conducted. It is not however, without its critics.

### 2.4.6 Criticisms of the social model

A common criticism of the social model, particularly from within the disability
movement, is that it does not go far enough (Shakespeare & Watson, 1997; French, S., 2004) and is too simplistic as it does not take the human body and impairment into account (Crow, 1996). Social modelists are strident in declaring that impairment has nothing to do with disability and “disablement is nothing to do with the body” (Oliver, 1996b, p. 35). This is seen by some as inadequate. Sally French (1994b) argues that the social restrictions imposed upon her because of her vision impairment are not ameliorated by the principles of the social model. Michael Bury (1988) claims that the dismissal of impairment is an unhelpful, over-socialised and over-politicised view of disability. Bill Hughes and Kevin Paterson suggest that by ignoring the body the social model “actually concedes the body to medicine and understands impairment in terms of medical discourse” (2006, p. 92).

In response to criticism that the social model ignores the bodily existence of impairment, Oliver (1996b) has stressed that the social model does not attempt to deal with the personal restrictions of impairment because impairment is not its topic of consideration. The social model is intended as a means of conceptualising social barriers of disability. It is not a denial of the pain of impairment.

“Rather it has been a pragmatic attempt to identify and address issues that can be changed through collective action rather than medical or other professional treatment” (Oliver, 1996b, p. 38).

What Hughes and Paterson (2006) are seeking is an altogether different model - a social model of impairment. Although this chapter does not develop a model of impairment, it does discuss the social construction of learning difficulties and removes it from the status of impairment.

Mairian Corker and Tom Shakespeare suggest that both the "medical model and the social model seek to explain disability universally, and end up creating totalising, meta-historical narratives that exclude important dimensions of disabled people’s lives and [of] their knowledge" (2002, p. 15). Shakespeare (2006) has further criticised the social model for having had a negative impact upon disability research, including being responsible for neglect in research on impairment and its effect upon people’s lives. However, I would argue that this is the fault of researchers rather than the model. The social model simply opens a broader field
of research. Social modelists do not discourage research into the phenomenon of impairment, they emphasise the difference in their fields of inquiry. It is important to recognise that it is the view of many people with impairments that they are disabled by the imposition of physical, social and attitudinal barriers and that this should be reflected in disability research (French, S., 1994b, 1994a).

Critics of the social model have also objected to the “confrontational stance towards the rest of society” (Low, 2001) taken by social modelists. No doubt, maintaining the status quo would suit “the rest of society”. However, when those on the margins are oppressed, confrontation - which means “group action in opposition to those in power” (Farlex, 2008) - is an act of resistance and a means of engaging in debate on social issues to address power inequality. Challenging the dominant paradigm will invariably bring opposition because the redefinition of the problem of disability brings into question the whole body of research that is so interested in biological classification of disability and remediation of the condition (Rioux, 1994). Such questions are threatening. Quality of life and service delivery research is also drawn into question as it is generally based on the assumption that better service delivery models will ameliorate the condition and the effects of disability (Schalock, R.L., 2001). Furthermore, researchers who identify as disabled, have been criticised by the medical model side of this debate as being militant and self-seeking, using the social model as a means of furthering their own careers (Personal Communication, Prof. David Felce, Director, Welsh Centre for Learning Disabilities). This is a strong accusation. Colin Barnes (2001) claims that researchers supporting politically sensitive or minority group research are vulnerable to accusations of bias. He recommends naming your position from the outset and making your ontological and epistemological positions clear. A social model disability researcher who ensures her methodological strategies and data collection methods are logical, rigorous and transparent will be vindicated by the quality of her work.

Having had its genesis in UPIAS, an organisation with an explicitly physical-impairment focus, the British social model has been criticised for prioritising the issues of people with visible impairments while marginalising those with invisible impairments. These latter include people with mental health issues, hearing impairment and people labelled with learning difficulties - leaving their experience
of social oppression largely ignored within the social model debate (Chappell, 1998; Goodley, 2000; Walmsley & Atkinson, 2001; Coker & Shakespeare, 2002; Scott-Hill, 2002).

Goodley (2001) raises the concern that learning difficulties is segregated from other impairments and viewed by some as an unproblematic biological impairment. Such a view is rooted in a medicalised notion of disability where the problems of the person with learning difficulties are inherently related to their impairment rather than stemming from social barriers such as a complex welfare system, a segregated educational system or a discriminatory labour market that privileges multi-tasking and high intellectual functioning (Chappell, Goodley, & Lawthom, 2001).

The social model received further criticisms from other oppressed groups for its failure to incorporate issues of multiple-oppression such as racism (Begum, Hill, & Stevens, 1994), sexism (Morris, 1991) and homophobia (Hearn, 1991). These criticisms are well founded and the issues raised still require consideration within the context of the social model of disability.

### 2.5 Conclusion

The social model of disability is a helpful tool for revisioning disability to identify social inequity for people labelled with learning difficulties. Focusing its gaze away from the body or intellect and onto an ableist society’s disabling barriers, it does not seek to address issues of impairment. Although the social model does not provide a means of addressing all the areas of disability researchers would like, Sally French (1994b) has noted that criticisms of the social model do not invalidate it. Indeed, they have often been raised with the aim of increasing its power and usefulness. One area of usefulness is “as a springboard for analysis of the economic and social barriers experienced by the collectivity of disabled people” (Chappell, et al., 2001, p. 46). This was how I aimed to use it. Dismissing the essentialism of the medical model of disability, I took a social constructionist approach to inclusive disability research, challenging ableism and the notion of normality. Using the social model of disability my research sought to target the tools of power which construct and constrain people labelled with learning difficulties, to expose and name them and to challenge the status quo.
Encouraged by Davis (2002) I recognise that ableist political and social practices are open to change through political processes. I applied the theories outlined in this chapter to research intended to critique an ableist society and expose disabling barriers limiting the self-determination of people labelled with learning difficulties. I was motivated by issues I considered matters of human rights.

Chapter 3 introduces the discussion on human rights that continued throughout my research. In particular, Chapter 3 considers the United Nations' Universal Declaration of Human Rights and the Convention on the Rights of Persons with Disabilities, and their relevance to my research.
Chapter 3 – Disability Rights are Human Rights

“Virtually every Australian with a disability encounters human rights violations at some point in their lives and very many experience it every day of their lives.”

(National People With Disabilities and Carer Council, 2009, p. 4)

3.1 Introduction

For those labelled disabled, disability rights are synonymous with human rights, not merely a sub-category. One place to begin a discussion on rights is, nonetheless, to initially consider the broad concept of human rights. This chapter is divided into three. The first section searches out a definition of human rights and considers the relevance of human rights to social values and to the lives of people with impairments. The Australian Human Rights Commission’s definition of human rights points to key international human rights instruments. In section two of this chapter I review two of these major human rights instruments: the United Nations’ Universal Declaration of Human Rights (the Universal Declaration) (United Nations, 1948) and the Convention on the Rights of Persons with Disabilities (the Convention) (United Nations, 2006). The final section considers the foundational assumptions upon which human rights are claimed to be based, including a clarification of my own assumptions along with their relevance to my research.

3.2 Rights

3.2.1 Defining human rights

The Australian Human Rights Commission (AHRC) notes there is no universally accepted definition of rights (AHRC, 2010d). James Griffin has argued the term human rights lacks an accepted criteria, with far too little content “to be playing the central role that it now does in our moral and political life” (Griffin, 2001, p. 306). Ian Parsons says it would be “probably impossible – to generate any sort of all-encompassing, absolute definition of ‘human rights’” (Parsons, 1999, p. 6). His point is that if a person or group of people experience an issue as a human rights concern, then it is irrelevant what others might call it. Parsons suggests that a more fruitful strategy is to determine what people mean by the term. So, what do I
mean by human rights?

The concept of rights arises from certain historical processes in addition to particular cultural, social and political conditions. Rights can therefore be construed as a social practice with a history. The notion of rights can be traced back to ancient civilisations. Ober (1996) claims the idea of rights is evident in writings of the ancient Greeks. Throughout history issues of justice, ethical behaviour and human dignity have influenced the development of human societies. They contributed to Greek and Roman laws and are fundamental to Buddhist, Christian, Confucian, Hindu, Islamic and Jewish teachings (AHRC, 2010b).

The 1215 Magna Carter made explicit reference to rights. Clause 3, still in use under British law today, states

“No free man shall be seized or imprisoned, or stripped of his rights or possessions, or outlawed or exiled. nor will we proceed with force against him. except by the lawful judgment of his equals or by the law of the land. To no one will we sell, to no one deny or delay right or justice” [sic] (“Treasures in Full: Magna Carta,” 1215).

Rights in this sense relates to the notion of self-ownership and of having control over ourselves and our property. It posits the notion: I am my own person and nobody has the right to use my body or my property against my will, or to control my choices without my permission (Ivison, 2008). It is this that underpins self-determination theory (explained further in Chapter 4), and my research.

Considering rights in terms of justice and human dignity lies at the heart of social values. Although value systems vary in detail from one society to another their fundamental ideas are often very similar (AHRC, 2010a). If society sees little value in certain groups of people, then their treatment towards those people is affected (Wolfensberger, 1983; Ryan & Thomas, 1987; Wolfensberger, 1992; Barron, 1996). Unfortunately, in Australia, people with impairments experience such a sense of being considered of little value. A recent report by the National People With Disabilities and Carers Council (2009) found it is commonly believed

“that people with a disability are not able to make a significant contribution to the community, and that they are somehow not of equal value as human beings and members of the community” (p. 11).
This thesis asserts that people with impairments are valuable members of the community with “the right to have rights” (Arendt, 1958, p. 296). Indeed, the research process was in and of itself a means by which those rights could be expressed, explored and, above all, claimed.

I do not propose that rights are timeless or definite. Any notion of human rights must be recognised as historically specific and contingent (Donnelly, 2003). My rights-based research was positioned within a specific context and moment in history, as outlined in Chapter 1. Significantly, it was preceded by the Australian Government’s Welfare to Work reform package. Internationally however, the research unfolded during a time of great hope for people with impairments as the United Nations adopted the Convention. This period in history was described by Kofi Annan, Secretary-General of the United Nations, as

“the dawn of a new era -- an era in which disabled people will no longer have to endure the discriminatory practices and attitudes that have been permitted to prevail for all too long” (Annan, 2006).

Within this context the issue of rights was highly significant for the research. The following section explains how my research interest can therefore be described as disability rights.

3.2.2 Disability rights

Following the 1981 International Year of Disabled Persons, the World Programme of Action concerning Disabled Persons (WPA) was established by the United Nations in December 1982. This was a global strategy to enhance disability prevention and promote equal opportunities for people with impairments around the world (United Nations, 2010d). Significantly, the WPA “emphasizes the need to approach disability from a human rights perspective” (United Nations, 2010e).

The approach taken throughout this research sees disability from a human rights perspective and understands the word rights in terms of disability rights. Being on the receiving end of discrimination and disadvantage, being disrespectfully treated, deprived of a right or freedom because of who you are, because of your

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18 The decision to use the term disability rather than impairment in the context of disability rights was in keeping with the language in disability literature and the disability rights movement.
identity within society, are all breaches of human rights. But when those breaches are directly related to your identity in society as someone with an impairment, there can be a tendency to retreat to the safety of a human rights argument and claim your right to dignity, equality and respect based on your humanity (Parsons, 1999). This is an ableist retreat. It ignores impairment and implies that the impairment is not an important part of your worth or value. The women’s rights movement has argued that womanhood is crucial to a woman’s worth and value (Parsons, 1999), not just her humanity. It is the same for people with impairments (and any other marginalised and discriminated group), who experience discrimination and a breach of their human rights not just because they are humans, but because of their very identities.

When exploring disabling social barriers through the social model of disability we distinguished disablement as a disability rights issue. Thus, when our research team encountered a perceived breach of civil rights (for example, lack of access to public information which disabled commuters) we understood this civil rights issue as a disability rights issue because the disadvantage was notably experienced by those with impairments. When we faced a breach of legal rights, for example, restrictive practices that contravened the DSS, we saw this as a disability rights issue. It is widely recognised that the social model of disability and rights-based research are mutually reinforcing (Albrecht, et al., 2001). Therefore, when rights issues were identified, even though they may still be considered human rights, our research specifically interpreted them as disability rights.

### 3.2.3 Understanding human rights in an Australian context

Under section 3 of the Australian Human Rights Commission Act 1986 (AHRC Act) human rights are defined as:

> “the rights and freedoms contained in specific international instruments that are scheduled to, or declared under, the AHRC Act.

These instruments are:

- International Covenant on Civil and Political Rights
- Convention on the Rights of Persons with Disabilities
- Convention on the Rights of the Child
- Declaration on the Rights of the Child
• Declaration on the Rights of Disabled Persons
• Declaration on the Rights of Mentally Retarded Persons
• Declaration on the Elimination of All Forms of Intolerance and Discrimination Based on Religion or Belief” (AHRC, 2010a).

The AHRC is

“also required to have regard to additional human rights instruments where appropriate, namely:
• Universal Declaration of Human Rights
• International Covenant on Economic, Social and Cultural Rights
• Any other instrument relating to human rights that the Commissioner considers relevant (see section 46A(4) of the AHRC Act)” (AHRC, 2010a).

Given that the AHRC’s definition of human rights is so limited and relies upon broader international human rights instruments to give it depth, approaching my Australian research from a human rights perspective required some background understanding of those international instruments. In particular I found it most useful to look to the Universal Declaration and the Convention as frameworks within which to understand human rights as disability rights. The following discussion considers these two international human rights instruments and their relevance to the research.

3.3 The Universal Declaration of Human Rights

This section will focus on the context in which the Universal Declaration was established and the significance of the notion of human dignity to this instrument, followed by an exploration of its special features, significance, vision as well as its limitations.

3.3.1 Historical context

The high profile enjoyed by human rights in the 21st century is a relatively new phenomenon. Prior to the Second World War human rights abuses occurred but were rarely discussed at an international level (Donnelly, 2007). Rights have traditionally been viewed as the domestic issues of sovereign States and not the concern of other nations. As sovereign entities, States were not subject to any higher authority. The principal duty of other nations was non-intervention with the
obligation not to interfere in the internal matters of sovereign States. That position has fundamentally changed over the past sixty years, following the establishment of the United Nations in 1945 and its Charter affirming fundamental human rights for all people. The subsequent development of an International Bill of Human Rights over the next eighteen years saw human rights established in international law. A triad of human rights documents comprises the International Bill of Rights. These are the Universal Declaration (1948), the International Covenant on Civil and Political Rights (1966a), and the International Covenant on Economic, Social and Cultural Rights (1966b). Signatories to these Covenants are bound by them and obliged to promote and protect their citizens’ rights as outlined in them (Office of the United Nations High Commissioner for Human Rights, 2007).

The Universal Declaration was one of the first major achievements of the United Nations and has remained a powerful instrument which continues to have a significant effect on the lives of people throughout the world (United Nations, 2009a). When the world was confronted by the systematic elimination of millions of innocent civilians by Germany during World War II (now known as the Holocaust), the United Nations was established as an international forum in which to deal with the consequences of such atrocities. The United Nations was charged with the responsibility of ensuring that such things never happen again. The United Nations’ Charter, emphasising human rights, stated that the primary objective of the United Nations was “to save succeeding generations from the scourge of war” and “to reaffirm faith in fundamental human rights” (United Nations, 1945). While the Universal Declaration is not binding, many human rights covenants, conventions and treaties have been built on its principles (United Nations, 2009b).

### 3.3.2 Significance of dignity

The Universal Declaration is a deontological list of rights. A deontologist ascribes rights to someone based on their possessing certain attributes that warrant the special protection or recognition that can be provided by those rights. Rights can therefore be appreciated as the status of an individual and expression of their

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19 A helpful deontological image using the notion of rights as trumps is offered by Ronald Dworkin (1984). In card games a trump is a playing card that beats other cards previously played. According to Dworkin, certain kinds of rights trump other political justifications. We found the trumps concept particularly useful as will be seen in Chapter 10.
fundamental worth and inherent dignity as a person (Ivison, 2008).

The significance of the concept of human dignity in the Universal Declaration is considerable. It is the notion of dignity developed in the Universal Declaration that constitutes its universality (Dicke, 2002). It was the first declaration of rights in history to refer to human dignity and represents the most significant difference between the Universal Declaration and all other previous international agreements.

Dignity features in five different places within the Universal Declaration (including twice in the Preamble), highlighting its importance. It begins by stating

“Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world” (Preamble).

Although the Universal Declaration does not define dignity, Dicke (2002) notes that the founding functions of dignity in this document are that it is something to be recognised (“Whereas recognition…”). The Preamble calls this recognition “faith”,

“faith in fundamental human rights, in the dignity and worth of the human person” (Preamble).

The importance of this emphasis is firstly, that dignity is an assumed existential attribute irrespective of whether or not it is recognised, and secondly, that it presents the obligation to overtly recognise it. From the Preamble (quoted above) it is acknowledged that dignity is the foundation of freedom, justice and peace, and is a quality that all members of the human family have in common. Therefore “dignity is an expression of the unity of humankind” (Dicke, 2002, p. 114). I believe it is this sense of dignity that Freire’s (1996) critical pedagogy sought to awaken in people through humanisation. It is a quality of their humanity that must be recognised to fulfil their “vocation” (p. 25) as people.

### 3.3.3 Special features

Human rights, as articulated in the Universal Declaration, have a number of special features. The rights are described as being universal, equal, inalienable, indivisible, interdependent and interrelated (United Nations Population Fund, 2010).
Human rights are, literally, the rights that all people have simply because they are members of the human race. Human rights are therefore said to be held universally around the world by all humans. This is not to say that all people enjoy or recognise the universality of human rights, but that is the goal of the Universal Declaration. Human rights are also considered to be universal because they have been accepted by three quarters of the world’s States as ideal standards\(^{20}\) (Donnelly, 2003).

Human rights are equal rights since every human has the same human rights as every other human being. This characteristic is also described as inherent because the right is intrinsic to each person. Human rights are inalienable rights because people cannot stop being human. Human rights are not dependent upon how someone has behaved and cannot be taken away. Similarly they cannot be relinquished because they are founded upon the person’s humanity. Nickel (2009) argues against the inalienability of human rights but concedes that they are very hard to lose. He gives examples of the prisoner who has their right to freedom of movement temporarily taken away from them while they are incarcerated or the monk who gives away the right of movement when committing to lifelong seclusion in a monastery.

Human rights are also described as indivisible. This is because all human rights are equal in importance and are connected. This makes them interdependent. Failure to protect one right can result in the abuse of other rights. No one right, whether civil, political, social, cultural or economic, can be fully enjoyed without the others (United Nations Population Fund, 2010). Their interdependence means that taking action to fulfil one right can also lead to the fulfilment of other rights (Amnesty International, 2008). Human rights are interrelated because each one contributes to the recognition and fulfilment of a person’s human dignity through the satisfaction of their physical, psychological and spiritual needs (United Nations, 2008). For example, the fulfilment of a person’s right to health may rest on the fulfilment of their right to information, education and development (United Nations Population Fund, 2010).

\(^{20}\) The United Nations has a membership of 192 Member States (United Nations, 2009b). Human Rights can be regarded as universal, since most of the world’s leaders have undertaken international legal obligations to implement the rights set out in the International Human Rights covenants to which they are signatories.
The Universal Declaration spells out minimum conditions for human beings to live a dignified life. Even though delivery remains patchy, the Universal Declaration remains a forward-seeking vision of how the world could be. It joins moral vision with potential political practice.

### 3.3.4 Importance and vision

The Universal Declaration was unprecedented. For the first time in history a document considered to have universal value was adopted globally. It was also the first time that a brief but significant list of specific rights and freedoms for the peoples of the world had been articulated. Its development was the result of intensive negotiations and exhaustive examination with approximately 1,400 contentious rounds of voting on virtually every phrase and word in the document (United Nations, 1998). Nevertheless, there was broad-based international support for the Universal Declaration when it was adopted. Although the 58 founding Member States of the United Nations represented a variety of ideologies and political systems, diverse patterns of socio-economic development, in addition to religious and cultural backgrounds, the Universal Declaration represented a common vision of the international community. This vision pointed beyond the reality of what the world was to a deeper moral reality of what the world could become (United Nations, 1998).

The Universal Declaration carries moral weight because it was adopted by most of the international community. It has greatly informed the activities of the United Nations, influenced both national and international law and has generated wide debate on the topic of human rights (HREOC, 2009).

### 3.3.5 Limitations

The vision of the Universal Declaration, while inspiring, has made little impact on the lives of the world’s people with impairments (Despouy, 1993). This was recognised internationally by the United Nations when it stated that

“… although pre-existing human rights conventions offer considerable potential to promote and protect the rights of persons with disabilities, this potential was not being tapped. Persons with disabilities continued being denied their human rights and were kept on the margins of society in all parts of the world” (United Nations, 2010c).
It is further echoed in the words of Sir Bert Massie, Chairman of the British Disability Rights Commission:

“I do not really believe it is widely accepted that disabled people have the capacity to be equal. And for this reason we do not fully recognize disabled people’s circumstances as issues of injustice and inequality” (Massie, 2006, p. 5).

One reason given for the Universal Declaration’s impotence in this area is that it is grounded in a traditional human rights paradigm, based upon ableist assumptions and is therefore infected with disablism (French, P. & Kayess, 2008; Kayess & French, 2008). Buried within the traditional formulation of civil and political rights has been the assumption of an able-bodied right-bearer (Kayess & French, 2008). Such an assumption fails to include in the formulation of rights the provision of services (such as health and social services, which are economic and social rights) that are frequently required by people with impairments simply to survive.

The Universal Declaration espouses formal equality, an equality which treats everyone as equal. This does not recognise diversity. Equal treatment does not necessarily mean identical treatment. French and Kayess (2008) note that formal equality entrenches pre-existing patterns of social disadvantage. It draws attention to discriminatory behaviour of an individual but fails to recognise that disablist discrimination flows from the institutions and structures of society (Fredman, 2005). For example, in Australia, anyone registered and eligible to vote must not be denied the opportunity to participate in an electoral process of secret voting, according to Article 21.3 of the Universal Declaration. Stopping someone from voting would be clearly discriminatory. However, ableist institutional structures, which rely on ableist voting practices such as a dependence upon written voting cards and electoral information, makes secret voting inaccessible for some Australians with impairments. This is in breach of the Convention’s Article - Participation in political and public life, which insists that States ensure “that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use” (Article 29 j). The Australian Government’s claim that the cost of improving access to independent and secret voting is too great, denies even the Australian Disability Discrimination Commissioner, Graeme Innes, who is vision impaired, the right to a secret ballot (Hudson, 2009).

That the limitations of the formal equality model have been recognised is evident
in a movement away from formal equality by the Human Rights Committee for the International Covenant on Civil and Political Rights in favour of substantive equality. Kayess and French (2008) note that formal equality measures disregard difference and aim to assess merit by freeing people with impairments from stereotypical assumptions. This approach is problematic as it assumes merit can be objectively quantified, free from the social context in which it is located, and fails to recognise that “merit is itself a social construct” (Fredman, 2005, p. 204). It is also problematic when specifically applied to people with impairments because in order to treat people with impairments equally they may require special accommodation and therefore different considerations or treatment.

Substantive equality seeks to remedy the imbalance caused by difference. It compensates for historical disadvantage and requires alteration of the norm to better reflect human diversity. Substantive equality measures include the instigation of institutional system change - for example, designated quotas or affirmative action for minority groups to increase their participation in employment or education, or the introduction of flexible work hours to accommodate health restrictions or family responsibilities. Substantive equality measures require that States take steps to eliminate conditions that perpetuate discrimination (French, P. & Kayess, 2008). The introduction of substantive equality measures was seen by the United Nations Human Rights Committee as a pre-condition for achieving equality for people with impairments and has featured as a significant area of discussion in the Convention negotiations.

The Universal Declaration’s inability to progress the cause of people with impairments and deal with the issue of equality was ultimately the reason for drafting the Convention (United Nations, 2010c).

### 3.4 The Convention on the Rights of Persons with Disabilities

This section introduces the Convention and explores its significance both historically and for my research.

Sixty years after the signing of the Universal Declaration, the Convention was put into force on 3rd May 2008 (United Nations, 2008). While some may contend that the rights of people with impairments were already covered by the Universal
Declaration it was recognised that the rights of people with impairments across the world were being "persistently and systematically violated" (Megret, 2008, p. 495). It was clear that without "a legally binding treaty that spelled out their rights, persons with disabilities faced being legally "invisible" in their societies and even in the international arena" (United Nations, 2008). This invisibility stems from the omission of explicitly recognising people with impairments in the binding instruments of international human rights law. Not one of the equality clauses of any of the three instruments which make up the International Bill of Rights, nor any of their thematic conventions21, mention people with impairments (or disabilities) as a protected category22 (Kayess & French, 2008). Within the Convention equal or equality is mentioned 68 times (United Nations, 2006) and features as a key component of many of the Convention’s Articles.

3.4.1 The historical Convention

The Convention was historic for a number of reasons. It was the first international treaty that specifically addressed the rights of people with impairments, who it is claimed are the world’s largest minority group (United Nations, 2010b). It was the fastest negotiated comprehensive human rights treaty and the first of the new millennium, with signatures from 82 member States. This was the highest number of signatures in history for a United Nations convention23 (United Nations, 2010a).

Most significantly, the Convention was drafted in consultation with people with impairments and disability organisations, giving them a voice on the international stage on a global issue. It recognises that disability is a socially created problem, marking a paradigm shift in the way disability is viewed, evidencing influences of the social model of disability (United Nations, 2008). It embodies a conceptual change away from a welfare-based response to a rights-based approach to impairment (Kayess & French, 2008).

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21 Thematic Conventions include; the International Convention on the Elimination of All Forms of Racial Discrimination, 1965; the International Covenant on the Elimination of All Forms of Discrimination Against Women 1979; the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment 1984, and the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families, 1990.


23 As at 27/8/2010 there were 146 signatories of the Convention, of which 90 had ratified the Convention (United Nations, 2010a).
In countries that have ratified the Convention and its Optional Protocol, people with impairments have a powerful tool that can be used to ensure their Governments meet their legal obligations. The Convention does not supersede the Universal Declaration by adding new rights. It works alongside the Universal Declaration, articulating clearly an explicit, social dimension to human rights and emphasising the obligation to promote and protect the rights and dignity of people with impairments. The Convention reiterates the notion of dignity nine times throughout the instrument. It points out not only that rights should apply to people with impairments but how these rights should be applied, making it a very practical document for member States. The foundations of the Convention (discussed below) are the same as those underpinning the Universal Declaration.

3.4.2 Theoretical foundations of human rights

A number of theories have been posited regarding the theoretical foundations of human rights. In the following section I discuss some of the arguments presented historically as to why humans have human rights then consider the foundations of the Universal Declaration and the Convention.

Chris Brown has noted that

“virtually everything encompassed by the notion of “human rights” is the subject of controversy... the idea that individuals have, or should have, “rights” is itself contentious, and the idea that rights could be attached to individuals by virtue solely of their common humanity is particularly subject to penetrating criticism” (1999, p. 103).

Many champions of human rights appeal to the authority of God as the foundation of human rights. John Locke (1690), claimed rights belong to all people because all were created equal under God. Similarly, those who drafted the 1776 American Declaration of Independence or the 1789 French Declaration of the Rights of Man and of the Citizen, claimed that all people were endowed by their creator with certain inalienable rights (Yale Law School, 2008a, 2008b). While the authors of these documents wrote at a time very different from ours, and the “all” to which they refer was certainly a limited understanding of “all” (excluding slaves, women, children, those labelled with learning difficulties or the mentally ill (Ivison, 2008)), still, on face value and with twenty-first century understanding, these words stand. The authority of God is a compelling argument for some, but not everyone.
Some philosophers consider human rights as naturally given rights. A philosophy of natural rights would claim that all people have basic fundamental rights because all people are born human. Natural rights stem from the belief that it is an inherent and natural human ability to distinguish right from wrong. Philosophers who have based their theories on natural rights are also referred to as natural law thinkers. John Locke was a natural rights philosopher, as was Hugo Grotius (1583-1645). Grotius is regarded as the father of international law. Grotius was the first scholar to use the word ‘right’ to mean an intrinsic moral quality in people, which gave them certain entitlements (AHRC, 2010c). Contemporary philosopher and natural rights advocate, Allan Girwith, (1982) claims human rights are natural because they apply to all people and that they are moral rights (in the sense that they are justifiable through a valid moral principle). Natural law theorists appeal to nature and reason as a foundation for human rights. Utilitarianism and Marxism rejects natural rights (Dyck, 2005). Jeremy Bentham has contemptuously declared

“Natural rights is simple nonsense: natural and imprescriptible rights, rhetorical nonsense – nonsense on stilts” (Bentham quoted in Binmore, 1994, p. 3).

Bentham rejected the notion of natural rights claiming that rights can only be that which are legally enforceable. For Bentham there are only legal rights, not natural rights or human rights. He believed rights were to be determined by Governments and were therefore not universal but calculated and changeable (Dyck, 2005).

Christian Bay (1979) argues that human rights are not natural rights as they presuppose enforceability. Yet, they can become natural rights if behavioural sciences can demonstrate that a right corresponds to a human need. Bay insists that needs establish human rights. Arthur Dyck (2005) also proposes that human rights are founded on human need rather than nature. Dyck rationalises that human rights are “logically and functionally necessary, and universally so, for the existence and sustenance of communities” (p. 123). However, this argument falls down empirically in that many communities do exist without fundamental human rights. Take, for example, the fundamental right to “security of person” expressed in Article 3 of the Universal Declaration or the right not to be “subjected to torture or to cruel, inhuman or degrading treatment or punishment” found in Article 5 of the Universal Declaration and reiterated in the Convention on the Elimination of All Forms of Discrimination Against Women (United Nations, 1979). The global
phenomenon of violence against women shows that these fundamental human rights do not exist for millions of women around the world, yet they live in established communities where patriarchal cultural values and social structures exist which subordinate women (Meyer, 1998). Similarly, the rights of the child are not similarly enjoyed by male and female children around the world. Research from Senegal, released in December 2009, shows that in the Kolda region only 23% of girls reach secondary school, as opposed to 77% of boys (Diop & Askew, 2009). Australia’s Pacific neighbour, Papua New Guinea, confers no economic rights on its weakest citizens (including people with impairments) and there is no right of access to health and education (Talao, 2009). Within Australia itself, Governments of all persuasions have been unable to adequately address their obligations to ensure a standard of living adequate for health and well-being for Indigenous Australians in remote communities (Gordon, 2008). It can be seen, therefore, that many communities do exist without the recognition of fundamental human rights.

The appeal of human rights, as articulated in both the Universal Declaration and the Convention, is to the “inherent dignity and of the equal and inalienable rights of all members of the human family” (Universal Declaration Preamble). This too is a contentious foundation. What constitutes a member of the human family? This question is highly controversial as evidenced by the ongoing abortion debate.

Each of these foundations is subject to questioning and doubt. Alasdair Maclntyre claims that “every attempt to give good reasons for believing that there are such rights have failed” (1981, p. 67). Maclntyre discounts all the various theories that have endeavoured to ground human rights on calculations of utility or intuitions. Jack Donnelly (2003) suggests the best way forward is to accept that the root of human rights is conventional and controversial, and leave it at that. He claims that human rights “ultimately rest on a social decision to act as though such “things” existed - and then, through social action directed by these rights to make real the world that they envision” (p. 21). Human rights can therefore be regarded as statements of faith. While human rights, like all social practices, require justifications, they appeal to foundational assumptions rather than evidence.

I am content to accept human rights on faith and stand with Hannah Arendt and assume that all people have “the right to have rights” (1958, p. 296). Furthermore,
they are human rights, founded upon belief in the inherent “dignity and worth of the human person” (United Nations, 1948).

3.4.3 Whose responsibilities are human rights?

An examination of the rights enumerated under the various United Nations instruments reveals they frequently refer to rights delivered by institutional arrangements. For example, in the Universal Declaration at least three Articles refer to institutions established within a State: Article 7 – equality before the law, Article 15.1 – the right to a nationality and Article 26 - the right to education.

However, human rights are not the sole responsibility of Governments and their institutions. Many of the duties to which basic human rights refer are duties upon all people to treat one another with respect and dignity. The Universal Declaration states

“All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood” (Article 1).

As I embarked upon this research I was aware of my responsibility to uphold and promote human rights. The tenet that all people have a right to rights appears axiomatic, especially given that the notion of inalienable rights of all people has been espoused for centuries through a number of significant documents (see 3.4.2) and is enshrined in the Universal Declaration. Yet, as Hannah Arendt became aware, millions of stateless people in war-torn Europe had lost the right to rights in the mid twentieth century. Similarly, I was conscious of the gap between the rhetoric of rights and the reality in the lives of people who receive disability services. Human rights can be particularly elusive for people labelled with learning difficulties because of the lack of control which frequently characterises their lives. A recent example of this was in 2008 when the United Kingdom’s Joint Committee on Human Rights were shocked by the poor level of understanding that staff in hospitals and care facilities had regarding the human rights of patients and those in their care. Its members, MPs and peers, found that the rights of people labelled with learning difficulties were frequently breached. “Even in cases of horrific abuse, staff did not know they were doing wrong” (BBC News, 2008). Rights are related to the values by which societies live. Poor treatment of people labelled with learning difficulties reflects the limited value placed upon this group of people.
It is a serious comment on the value our society places on those requiring care when abusive behaviour is not deemed inappropriate or wrong by care givers and service providers. This points to a lack of respect for human dignity, what Freire would call “dehumanization” (Freire, 1996, p. 25), of those receiving services. From my vista of the employment assistance corner of the disability services industry, I suspected that the situation in Australia was similar to that in Britain. It warranted investigation. Human rights instruments were seen as a tool with which to identify issues and raise awareness of breaches of fundamental rights.

3.4.4 How the Convention influenced this research

In theoretical agreement with the faith statements of the Universal Declaration and the Convention, and convinced that it was my responsibility to promote and protect human rights, I used the Universal Declaration and the Convention as motivational foundations for the research presented in this thesis.

Both are inspiring documents. However I returned repeatedly to the Convention because it is a highly practical document. It spells out the motivational foundation upon which to develop my research because it recognises, reaffirms and promotes the protection of dignity and worth of all members of the human family. These were very useful words.

It is important to be reminded and to remind others, of the seriousness of the offence of discrimination. Described as a “social-evil” by Bickenbach (1999, p. 109), discrimination is wrong because it is a violation of the inherent dignity and worth of a person. A rights-focused approach to the research was intended to interrogate perceived inequalities or discriminatory practices and structures, which, as evidenced in the British example above, are often not even recognised, or perhaps are concerns about which people become desensitised.

Bickenbach (1999) has argued that a civil-rights approach to the issue of social disadvantage experienced by people with impairments can only have limited success. He claims that it is founded on the false presumption that once the issue of discrimination is resolved, the only obstacle between a person with impairments and full social participation is motivational. He points out that disadvantage and distributional injustices often still remain as they are produced by economic forces and created systematically.
Recognising the limitations of my research, I accept this argument. Nevertheless, there is merit in challenging discriminatory social structures and practices because some success is achievable which can have significant impacts on the lives of those involved and in the broader community. For example, while this research may not have removed the disadvantage of poverty for those living on a disability support pension, we did generate change through exposing restrictive practices; people gained greater control over their finances. Furthermore, the experience of exposing injustice and claiming rights gives agency to people - the power to name and to challenge, and the power to be agents of change.

The Convention influenced my research by reinforcing the importance of my work. It reminded me that even with the Universal Declaration and human rights instruments, people with impairments “continue to face barriers in their participation as equal members of society and violations of their human rights” (Convention Preamble k.) in Australia. It reminded me of the right that all people have to self-determination, by recognising the importance of autonomy, independence and being involved in decision-making within their own lives. The Convention also highlighted the need for inclusive disability research (discussed further in Chapter 5). In particular, its Preamble illuminates the importance of including people with impairments in research concerning them by making clear reference to people being actively involved in decision-making processes about policy and programs that directly concern them.

People with leaning difficulties have much to offer society, not only through diversity but also as they fulfil their own responsibilities to their communities by promoting and observing human rights. The Convention recognises that an enhanced sense of community will result when all members of the society enjoy full participation, human rights and fundamental freedoms, in addition to the anticipated production of “significant advances in the human, social and economic development of society” (Preamble m.)

And finally, the Convention recognises that disability is an evolving concept, resulting from the interaction between persons with impairments and ableist/disablist attitudinal and environmental barriers that hinder full and effective participation in society on an equal basis with others. The Convention therefore provided a philosophical foundation upon which to build the research strategy that
was aligned to my theoretical position. It also provided an analytical framework within which to interpret the research data (as discussed in 6.8.1).

3.5 Conclusion

Human rights belong to all people and yet in Australia many people with impairments experience violations of their rights every day (National People With Disabilities and Carer Council, 2009). My research was rooted in the principles of human rights expressed through the Universal Declaration and the Convention. These instruments, and particularly the Convention, were used as analytical tools and provided the research with an internationally recognised argument upon which to base rights claims.

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The right of all people to self-determination, autonomy and to having control over their lives was a key interest of the research. The right to self-determination is explored more fully in the following chapter.
Chapter 4 – The Right to Self-determination

“No cause is left but the most ancient of all, the one, in fact, that from the beginning of our history has determined the very existence of politics, the cause of freedom versus tyranny.”

Hannah Arendt (1990, p. 11)

4.1 Introduction

Self-determination is recognised as both a human right (Nirje, B.A., 1972) and an intrinsic human need (Deci, E.L. & Ryan, 1985). It is regarded as “a precious principle in a free society” (Dowson & Sailsbury, 2003) and was a foundational principle underpinning my research, which asserted the right to self-determination for all people, particularly those labelled with learning difficulties. Yet self-determination is a term used to mean a variety of things and is therefore easily misinterpreted and misunderstood. In this chapter I consider the construct of self-determination and explain a number of its meanings. Section two outlines the historical roots of self-determination, tracing its transition from the field of philosophy to psychology and on into the curriculums of special education. Along with an overview of self-determination theory, four models of self-determination are discussed. Section three of this chapter describes how my research took the construct of self-determination from special education and the medical model of disability and applied it to Disability Studies through the social model paradigm.

4.2 Explaining self-determination

The noun self-determination has two primary uses. The first is in relation to individuals and their actions that occur as a result of intentional, personal will or volition. The second use of the word applies to groups of people concerning their action in deciding their own form of government (Walzer, 2005). Both uses of the word share the same rights-based root and stem from the understanding that people (individuals and people groups) have a right to be self-governing. It is the second understanding of self-determination that underpins the United Nations’ International Covenant on Civil and Political Rights, Article 1, and recognises that

24 In a discussion on self-determination Wehmeyer (2007) notes that volition refers to making “conscious choices” (p. 5), where conscious is defined as “intentionally conceived or done, or deliberate” (p. 5).
“all peoples have the right of self-determination” (United Nations, 1966a). This reference pertains to people groups, such as cultural groups or nations. It is a collective concept that is frequently applied to individuals. Although not explicitly articulated, these sentiments are also expressed in point (n) of the Preamble of the Convention, which confirms

“Recognizing the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices” (United Nations, 2006).

This sentiment is adopted by the disability rights movement because it is grounded on the principles of freedom, authority, support and responsibility (Powers, et al., 2002). My interest in self-determination relates to that which refers to individuals because I believe everyone has a right to self-determination. But what actually is it?

Self-determination is not a thing that can be seen, touched or measured. It is a construct, described by Michael Wehmeyer (2007) as a personal disposition that can assist in explaining or predicting some aspects of human behaviour. Although you cannot see self-determination, you can observe behaviours and actions that infer self-determination and through which an extent of self-determination can be estimated. A variety of definitions of individual self-determination have been offered by researchers. Field claims it is “the understanding and ability to act on personal strengths and limitations” (2005, p. 1). Algozzine, Browder, Karvonen, Test and Wood have more specifically described it as “the combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behaviour” (2001, p. 219). Wehmeyer defines self-determination as

“acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life, free from undue influence or interference” (1999, p. 57).

This recognises not only ability, understanding and beliefs but also environmental factors that affect a person’s self-determination. I considered Wehmeyer’s definition, used in conjunction with its four discrete components (autonomy, self-regulation, psychological empowerment and self realisation, described in 4.3.3) to provide the most comprehensive and workable understanding of the construct for
the purposes of my research.

Although stereotypically it is assumed that the capacity of a person for self-determination is based on their level of intelligence, Wehmeyer and Garner (2003) have found that it is not a significant contributor to their level of self-determination. Instead, research has indicated that a major contributor to a person’s level of self-determination is the degree to which their environment permits them to exercise self-determination (Stancliffe, Abery, & Smith, 2000; Wehmeyer & Bolding, 2001; Wehmeyer & Garner, 2003).

This presents a problem for people labelled with learning difficulties as they often have others exerting control or influence over major choices and decisions. Important choices (such as where to live, how and with whom to spend their time and even what skills they should develop) that affect their quality of life are frequently determined by others, thereby reducing their opportunity to exercise self-determination (Field, S., 2005). Packer and Wright (1983) noted over twenty-five years ago how attitudes of residential staff strongly related to residents’ level of autonomy and the amount of decision-making opportunities they were permitted. Wehmeyer, Agran and Hughes (2000) have reported that a common attitude of a significant proportion of special education teachers (42% from a sample of 1200) was that they saw no benefit in teaching self-determination skills to students with profound learning difficulties. The teachers believed that the students could not become self-determined. Wehmeyer (2002) claims that this perception of students is based on a misunderstanding of what self-determination is, mistakenly equating it with complete independence and having control over every aspect of their lives. He argues complete independence is not necessary for self-determination. Wehmeyer explains that while some people may not be able to master all the skills required for difficult problem solving, they may, given the opportunity, be able to develop some skills to assist their participation in self-determination.

More recently, research has shown that even where disability service providers wanted to allow consumers greater choice options and autonomy, they were often restricted by external regulations and licensing requirements (Ollerton, 2005). Such limitations included the degree to which staff could respond to consumer preferences (Stancliffe, et al., 2000; Ollerton, 2005).
Baker, Horner, Sappington and Ard (1999) have also cited environmental factors such as paternalistic service delivery practices, over protection and prejudice as contributing to low levels of self-determination, while poverty has been noted as an environmental barrier to self-determination for people labelled with learning difficulties (Schalock, R. L., 1994; Traustadottir, Lutfiyaa, & Shoultz, 1994). Because people labelled with learning difficulties frequently rely on the welfare system for financial support, the choices for these people are limited by their financial situation (Welsby, 2010).

So, for people labelled with learning difficulties, one common barrier to, and problem of, self-determination lies not with them but with social barriers including the discriminatory attitudes of those around them. This makes self-determination a human rights issue given that “all peoples have the right of self-determination” (United Nations, 1966a).

Self-determination is a significant concept in the disability rights movement (Powers, et al., 2002). It is valued and promoted in disability literature (Wehmeyer & Schwartz, 1998a), by Government policies and industry standards (NSW Ageing and Disability Department, 1998; NSW Government, 2006; Penrith City Council, 2009) and in the core values and policies of many disability service providers (Break Thru People Solutions, 2009; Vision Australia, 2010). Schalock (1996) regards self-determination and rights as two of the eight core dimensions in quality of life for all people and explicitly for people labelled with learning difficulties.

### 4.3 Self-determination: philosophy and construct

#### 4.3.1 Historical background

Simpson and Weiner (1989) have noted that the earliest mention of self-determination in literature appears in 1683 with reference to agents who have free-will. It is a term with roots in the long-standing theological debate about free will and determinism25 (Wehmeyer, 2004, 2005). In the 17th century John Locke proposed that human actions occur as the result of personal volition rather than people being predestined or compelled to act in a particular way by God. Locke

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25 Determinism suggests that all actions are the result of preceding events; that they are by some means caused to happen (Wehmeyer, 2005).
claimed people were free to act and should therefore be permitted such freedom (linking free will with the concept of freedom and human rights). According to Locke, rights belong to all people because all were created equal under God, to live in a state of “perfect freedom” and where all “power and jurisdiction is reciprocal, no one having more than another” (Locke, 1690, II. 4). This did not mean that all people were in all senses equal. Within basic equality there was a range of inequalities, some of which resulted from birth, alliances and privilege. Nevertheless these differences did not cancel out basic equality. Locke went on to write about “that equal Right that every man hath, in his Natural Freedom, without being subjected to the Will or Authority of any other man” (ibid., VI. 54). In my opinion the sentiments of Locke’s treatise still stand.

Since the time of Locke the notion of determinism has gradually separated from the discipline of theological determinism. In the twentieth century discussions around determinants have been more natural than supernatural (or theological), focusing more on environmental or other forms of determinism. Nevertheless, the construct of self-determination still has its origins in the “free will problem” (Wehmeyer & Mithaug, 2006, p. 34) and fundamentally refers to, and gets its meaning directly from, the philosophical debates around determinism.

In the latter half of the nineteenth century, psychological questions about self-determination moved from a philosophical orientation, comparing whether or not behaviour was the effect of free will or was predetermined, to considering whether or not it resulted from internal or external forces. By the 1930s the field of personality psychology was systematically exploring self-determination with an interest in the causation of human behaviour (Wehmeyer & Mithaug, 2006).

Angyal (1941) purported that a fundamental characteristic of a living organism was its autonomy. Autonomy (which also refers to volition) is regarded as a crucial factor in healthy human functioning (Angyal, A., 1965; Deci, E.L., 1980; Deci, E. L. & Ryan, 2000).

By the 1970s personality psychology was exploring human behaviour in relation to extrinsic and intrinsic motivation (Lepper, Greene, & Nisbett, 1973; Deci, E.L., 1975). Self-determination was incorporated as a central factor in Deci and Ryan’s

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26 Thomas May (1994) also recommends autonomy is best understood as self-rule/governing rather than as autarkeia, which implies self-sufficiency and is regarded as too restrictive a definition.
theory of intrinsic motivation and laid the foundations upon which they developed Self-Determination Theory (Deci, E.L. & Ryan, 1985). Deci and Ryan’s Self-Determination Theory has been described as “the most extensive application of the self-determination construct in psychology during the past 50 years” (Wehmeyer & Mithaug, 2006, p. 31) and is discussed below.

### 4.3.2 Self-determination theory

Deci and Ryan proposed that people have an intrinsic need to be self-determining (Deci, E.L. & Ryan, 1985). Self-determination Theory deconstructs this need into a further three components which are innate psychological needs: competence, autonomy, and relatedness.

Competence refers to the need to experience yourself as effective and capable in controlling your environment and predicting outcomes, rather than ineffectual and inept (White, 1959).

Autonomy refers to the need to feel that your behaviour is self-chosen and meaningful, rather than coerced and pressured (deCharms, 1968).

Relatedness refers to the need to care for and to relate to others, being in harmony with important others, rather than alienated or marginalised (Sheldon & Elliott, 1999).

Although the right of all people to be self-determining, making their own decisions about life and the future, has long been viewed as an “inalienable right” (“The Declaration of Independence,” 1776) by adults without impairments, and as an innate human need by psychologists, a brief historical glance at how people with impairments have been treated in society reveals it has not always been recognised as a right for adults with impairments (Algozzine, et al., 2001; Stroman, 2003). The perception of people labelled as having learning difficulties (and also those with other impairments) as being competent, capable of autonomy or worthy of respect and social inclusion, is a relatively recent occurrence, and still not widespread. Powers, Singer and Sowers (1996) have noted that “disability and self-competence have traditionally been regarded as antithetical” (p. 4). Not surprisingly, discussions about self-determination theory have, in general, excluded considerations of its application to people with the label of learning.
difficulties (Wehmeyer, 2001). However, with the rise of the Disability Rights and Independent Living Movements in the 1960s and 1970s, an interest in the concept of self-determination in the lives of people with impairments has grown.

Nirje’s (1969; 1972) notion of normalization clearly articulated a place for self-determination in the lives of people with impairments. He notes

“One major facet of the normalization principle is to create conditions through which a person experiences the normal respect to which any human being is entitled. Thus choice, wishes, desires and aspirations of a person have to be taken into consideration as much as possible in actions affecting him [sic]. Thus, the road to self-determination is indeed both difficult and all important for a person who is impaired” (p. 177).

Nirje’s chapter of Wolfensberger’s (1972) classic text on normalisation is titled The Right to Self-determination. This is noted by Wehmeyer and Mithaug (2006) as possibly the first reference of the term within disability literature. Perske’s (1972) call for opportunities for people with impairments (including those with learning difficulties) to experience dignity of risk was also linked to self-determination. Dignity of risk is the right to make choices, which are sometimes mistakes but which present opportunities for people to grow as they experience the bumps and knocks that are a common part of daily life. Perske wrote that to shield people from risk experiences is to “cripple them for healthy living” (1972, p. 199), claiming there is a “dehumanizing indignity in safety” (1972, p. 200).

As an interest in self-determination began to be applied to people with impairments, including those labelled as having learning difficulties, new models of self-determination began to be developed. These are discussed below.

4.3.3 Models of self-determination

There have been four distinct models of self-determination pertaining to people labelled with learning difficulties developed over the past fifteen years which present a variety of frameworks within which to interpret the construct:

i) Abery’s ecosystems model (1994) building on Deci & Ryan’s (1985) theory, conceptualised self-determination as an intrinsic drive. Although this model does not dismiss personal characteristics of self-determination it regards self-determination as both a process and the product of an individual’s interaction with
their environment (Abery & Stancliffe, 1996).

ii) Power’s motivational mastery model (Powers, et al., 2006) is characterised by perceived competence, self-esteem, maintenance of a locus of control and the internalisation of goals and rewards (Wehmeyer, 2001). This model encourages the reduction of learned helplessness and promotes self-efficacy expectations.

iii) Mithaug’s self-regulation model (Mithaug, 1996; Wehmeyer & Mithaug, 2006) presents self-determination as self-regulated problem-solving that is markedly free from external influences.

iv) Wehmeyer’s functional model (1999) recognises four essential functional characteristics. These characteristics emerge through the acquisition of component elements (detailed in Wehmeyer & Mithaug, 2006). They are:

Autonomous behaviour – acting according to his or her own interests or preferences, free from undue external influence or interference (Wehmeyer & Schwartz, 1998b);

Self-regulated behaviour – making decisions about what skills to use in particular situations, examining the task at hand, formulating and enacting a plan of action. It includes goal-setting and problem-solving (Wehmeyer & Schwartz, 1998a; Wehmeyer, 1999);

Psychological empowerment – acting in accordance to the “beliefs that they have the capacity to perform behaviours needed to influence outcomes in their environment and, if they perform such behaviours, anticipated outcomes will result” (Wehmeyer & Schwartz, 1998a, p. 5);

Self-realisation – knowing what you do well and acting accordingly. It includes acting with a reasonably accurate knowledge of his or her weaknesses as well as strengths so as to capitalise on this knowledge in a beneficial way (Wehmeyer & Schwartz, 1998a). Incorporating self-realisation and psychological empowerment as essential characteristics recognises the importance of both cognitive and behavioural contributions to this theoretical framework (Wehmeyer & Mithaug, 2006).

I found each of these models helpful in informing my approach to the research.
However, Wehmeyer’s functional model combines a number of features of the other three models. His definition of self-determination relates to Abery’s ecosystem model which recognises the environmental impact of undue influences or interference on decision-making. Undue influences or interference directly promote learned helplessness, linking Wehmeyer’s definition to Power’s motivational mastery model. Furthermore, Wehmeyer’s functional model incorporates Mithaug’s self-regulation model, recognising self-regulation as one of the four key characteristic of self-determination. It was Wehmeyer’s model which I utilised in my research when supporting the team to identify those things which they felt were social barriers hindering their self-determination.

4.4 Shifting the paradigm

Research in the field of self-determination for people with the label of learning difficulties has traditionally been the domain of professionals and not the people about whom the research was written. In general, participants in self-determination research are recruited via referral from service providers – be they special education units within schools (Algozzine, et al., 2001) or disability services (Powers, et al., 2002; Wehmeyer & Garner, 2003) – who determine which participants suit the prescribed selection criteria. Recruitment is then further refined by the researchers, who determine which participants best suit their project (Wehmeyer & Bolding, 2001).

The approach taken by self-determination researchers has generally relied heavily on a medicalised approach to impairment and the use of quantitative methods where self-determination indicators are measured. The results of measurement tools, such as the Arc’s Self-Determination Scale and the Supports Intensity Scale, are used to examine the relationship between self-determination and the factors which inhibit or promote it. They are a useful means of identifying personal strengths and weakness of those who undertake the assessments and can inform educational strategies to support people in building on strengths and working within the parameters of their weaknesses.

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27 “acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life, free from undue influence or interference” (Wehmeyer, 1999, p. 57).

28 The Arc’s Self-determination Scale was developed by The Arc of the United States in 1995, while the Support Intensity Scale was developed by the American Association on Intellectual and Developmental Disabilities in 2004 (Thompson, J. R., et al., 2004; Beach Center on Disability, 2010).
As helpful as such assessments may be, they nonetheless produce privileged knowledge for professionals and position participants as research objects. Furthermore, they cast people labelled with learning difficulties as the ones with a problem. I was uncomfortable with this approach. If self-determination was directly affected by the environment then it was not merely an individual’s problem but an environmental or social problem. I was interested in approaching self-determination from a social model of disability perspective. I wanted to create a research environment which supported those who thought their self-determination was constrained by social barriers, to name and explore those barriers for themselves. Building on work from the fields of behavioural science and special education, I have taken the construct of self-determination into a participatory and transformative region of critical Disability Studies (Rioux & Bach, 1994; Swain, 2004).

I proposed to undertake self-determination research with rather than on people with the label of learning difficulties. Informed by

i) the Convention’s Articles 3,4,29 and 30 which promote participation,

ii) critical pedagogy promoting consciousness raising (Freire, 1996), and

iii) feminist research (Smith, D., 1987; hooks, 1994) that relies on practice that promotes voice and narrative that builds understanding,

I wanted to develop a creative dialogic space wherein new voices in the field of self-determination - the voices of those whose self-determination was currently fettered - could be heard (Lather, 1991; hooks, 1994; Brooks, 2000; Tisdel, 2000). This called for an inclusive approach to self-determination, which appeared to offer decidedly more opportunities for self-determination than that which positions people as objects of research. It afforded opportunities for people to establish their own research agenda, to explore their own identified barriers to self-determination and name the world as they see it. It challenged the traditional power relations of self-determination research and was more aligned to the participatory research being called for from the international disability community (Finkelstein, 1999).

I was keen to provide a self-selection opportunity in an environment where the
decision to participate was not influenced by power relationships (for example teacher or service provider referrals) and people could choose whether or not they were interested in the project topic and if they wanted to participate. Exploring their own barriers, utilising their own strategy and actively implementing their own research plan was anticipated to have the potential of the project group members claiming their right to self-determination and being social change agents. A participatory approach also had the potential of making self-determination both the process and the product of the research. Although I had no intention of scaling and measuring people I did aim to utilise the research process to create a research environment that encouraged the exercising of self-determination in order to build skills and a flourishing of personal development (Horsfall & Titchen, 2009).

Self advocacy and leadership skills are two areas of personal development identified within self-determination research as important for people labelled with learning difficulties living on the margins of society (Wehmeyer, Agran, & Hughes, 1998).

"[In] order for people with disabilities to move into the mainstream of community life they must possess the skills to stand up for their rights, communicate effectively and assertively, learn to negotiate and compromise, and become effective leaders" (Wehmeyer, et al., 1998, p. xvi).

A participative and inclusive approach to research was seen as a means of facilitating opportunities that would assist in building such skills.

4.5 Conclusion

This chapter has argued the right to self-determination. It has considered the historical roots along with the theory of self-determination (Deci, E.L. & Ryan, 1985) and models that have been developed for application in the field of special education. Also discussed were methodological approaches to self-determination research. My interest in grounding the research in the assumptive right to self-determination, based upon my understanding of the Convention, was also explained.

I proposed to approach self-determination from a social rather than medical model
paradigm. I aimed to take the theory of self-determination, which had transitioned from philosophy to psychology to special education, into critical pedagogy and the field of Disability Studies through the path of Inclusive Research.

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The following chapter pursues the rights theme, outlining the right to inclusive research methodologies. Participatory Action Research is described and its application to Inclusive Research with liberatory expectations is considered.
Chapter 5 – The Right to Inclusive Methodologies

“It is absolutely essential that the oppressed participate in the revolutionary process with an increasingly critical awareness of their role as Subjects of the transformation.”

Paulo Freire (1996, p. 108)

5.1 Introduction

Collaborative research covers a number of research paradigms which facilitate the active participation of people in research concerning themselves. As a chief proponent of participatory research for personal liberation and social change Freire (1982, 1996) emphasised the right of all people to be actively involved as researchers in matters relevant to their own lives. Echoing these participatory principles, the Convention calls for the world to embrace the right of people with impairments to participate in all levels of society (Article 3c). Since, without question, this must include disability research, this chapter specifically presents the case for the right of people labelled with learning difficulties to be included in research concerning themselves. I discuss the methodologies I adopted in order to undertake inclusive, participatory and liberatory self-determination research.

To begin, I consider the questions that needed to be asked before the methodologies were identified. I then describe the two key methodologies chosen, Inclusive Research and Participatory Action Research, and how these were melded to form an accessible research strategy aimed at rendering the voices of the group members as central. Finally, the Liberatory Educational strategies woven into the methodological backdrop of this research are explained.

5.2 Finding an accessible methodology

Methodology, the generic term referring to the underlying logic and theoretical perspective of a research project, works through the How and Why questions of the research. To find the right logical and theoretical approach for my research I first needed to consider the Who and What questions: Who and what was the research essentially about? Who was it for and what did I hope to achieve? Who would be designing and conducting the research? What were the parameters and
Some of these questions pertain to motivation for the research rather than its focus and have been discussed previously in the rationale of Chapter 1.

Who and what was the research essentially about? Upon reflection, it became clear that the research was about more than my initial focus of simply confirming whether or not people labelled with learning difficulties experienced oppressive social barriers with regard to their self-determination. There was a distinct human rights issue closely tied to my own interests and concerns. Undeniably, a researcher’s values inform their choice of research topic, their motivation, the subject matter and the location of the research (Carspecken, 1996). The research I planned stemmed from my dissatisfaction with the Australian Government’s unemployment strategies and was informed by my Christian frame of reference and desire to uphold “the cause of the oppressed” (Psalm 146:7). Ten years of working as an educator in the disability industry, both in the United Kingdom and in Australia, had motivated me, as a citizen of the world, to respond to the international disability movement’s call for “nothing about us without us” (United Nations, 2004).

Recognising that this was value-driven and not value-free research I was aware that there would be numerous points during the research process where bias and the intrusion of values may occur (Bryman, 2001). It was important therefore that biases were declared and values challenged through a self-reflective process. This would require research methods that exercised and exhibited reflexivity.

Who was it for and what did I hope to achieve? From the outset I hoped that it would be mutually beneficial to those participating but also that it might benefit the wider community. Certainly, I hoped to achieve a doctorate at the end of it! However, it was also an intentional aim that the research would result in positive social change beyond the potential personal benefits for those involved.

Who would be designing and conducting the research? It was clear to me that the people with the right to name their own barriers should also contribute to the discussion of how those barriers would be investigated. A methodology that facilitated discussion on research design, inversion of roles and empowerment for
the participants to also become research architects and designers was vital. This
would be a pathway to consciousness raising and to what Freire (1996) calls the
humanising of oppressed people. It was also necessary for the scientific rigour of
the research, since a principal tenet of Action Research insists that research
conducted without collaboration with the relevant stakeholders is most likely to be
incompetent (Brydon-Miller, Greenwood, & Maguire, 2003). Therefore, for
authenticity, rigour and positive social change, the research needed a
collaborative methodology which actively involved people working as a team of
investigators rather than passive observers. Problems, such as disputes about
research focus or findings, that can arise when the researcher is viewed not as a
team-member but as an outsider may also be avoided (Titchen & Binnie, 1993).

The Universal Declaration and the Convention strongly influenced my decision to
use a collaborative methodology. Collaboration was a dynamic response to the
obligation to recognise the dignity of my research team and the value of their
experience. It was aligned to the Convention’s Article 8 - Awareness-raising, as it
was an opportunity to combat stereotypes and promote the capabilities of the team
along with the positive contribution they could make to social research. It was also
in accord with the Biwako Millennium Framework:

“It is imperative to recognize the right of persons with disabilities to self-
representation and to strengthen their capacity to participate in the decision-making
process. Persons with disabilities must articulate their own issues and advocate for
reforms that will bring about their development and independent living in their
communities and society at large” (UNESCAP, 2002, p. 1).

As a doctoral student, whose initial research proposal must be approved by a
university human research ethics committee before I could begin recruiting co-
research designers and architects, it was unavoidable that I would design the
basic framework for the research. However, with an explicitly evolutionary
research strategy, I could build in sufficient flexibility to allow for the sharing of
power, design development and the conduct of the research, once the project was
approved and underway.

It is inevitable that doctoral research has specific time and financial parameters.
On the other hand, collaborative research needs to accommodate participants’
schedules and methodology needs to match the skills and abilities of everyone
involved. When designing the research project and choosing the methodology I was cognisant of these factors. Despite a desire to address all social barriers to self-determination that might emerge, it was unlikely I was going to be able to change every barrier in just four years! However, working alongside a group of like-minded people, on an issue that was important to all of us, the possibilities of the research were numerous. They included positive social change, personal growth for everyone involved, enhanced quality of life for participants and others in the community, improved disability service practices and education of the broader community on issues directly affecting people labelled with learning difficulties.

How then should the research be undertaken? On human rights considerations I had already decided that the research should be collaborative, empowering those involved to explore issues they themselves identified. I had also determined that the methodology should be accessible for meaningful participation. This too was their right. Furthermore, disability literature emphasises that in order to gain an understanding of the participants’ subjective views on oppressive social barriers, the methodology should explicitly turn the research lens away from them and towards the oppressors (Morris, 1993).

Undertaking research from the participant’s perspective is not without its dangers. Smith has warned that much sociological research, though undertaken

"with the honest intention of doing research that was oriented towards people’s interests and from their viewpoint…led us into producing accounts which objectified them from a standpoint in the ruling relations" (Smith, D., 2004, p. 74).

Such research risked placing me in the shoes of the oppressor. I therefore needed a methodology that enabled the production of a sociology (an inquiry into the social world of people labelled with learning difficulties) from the standpoint of those labelled and which did not objectify them.

Inclusive Research and Participatory Action Research are both methodologies that accommodate non-expert researchers working collaboratively to produce knowledge through very practical means. Each of these research strategies facilitates access to the views of participant-researchers.

Inclusive Research and Participatory Action Research are not uncommon in the
Rights, Camera, Action!

field of Disability Studies. However, they do present challenges (as discussed below). As I explored Inclusive, Collaborative and Participatory Action Research options, a multi-methodological approach, rather than an either/or strategy, emerged as most suitable, with lines of attack flexibly drawn. Schalock and Felce (2004) affirm that such methodological pluralism is often undertaken in social-constructivist research (as outlined in Chapter 2). Thus my multi-methodological approach could be described as:

\[ \text{Inclusive} + \text{Participatory Action Research} = \text{IPAR}. \]

A synopsis of each of the methodological tactics adopted, with an historical overview, is provided below. The central reasons for their selection and how together they informed the principles and procedures of my study are explained.

5.3 Inclusive Research

As an emerging paradigm in the field of Disability Studies, Inclusive Research incorporates as co-researchers those who have traditionally been viewed as the object of research. The paradigmatic shift away from the privileged voice of the medical professional and towards those with impairments or learning difficulties, acknowledges them as the expert on what it is like to live with that impairment/difficulty. Such research welcomes the active involvement of people through a variety of means which include the following four different, but sometimes overlapping, approaches: “experiential” (Oliver, 2002, p. 2), “emancipatory” (Oliver, 1997, p. 15), “inclusive” (Walmsley, 2001) or “participatory” (Ramcharan, Grant, & Flynn, 2004, p. 91) research. I considered the relevance to my research of each of these methodological descriptions.

5.3.1 Methodological descriptions

Experiential Research in Disability Studies is a broad-brush label not specific to any one group of people with impairments. The term experiential can be applied to collaborative work, though it frequently refers to research on the experience of an individual. While Iwakuma (2002) claims the embodied experience of disability is a fundamental criterion for testing the validity of theoretical propositions associated with impairment, research focusing on the experiential alone has been criticised for prioritising and privileging individual experience, for assuming that
providing faithful accounts of individual experience is sufficient (Oliver, 2002). Oliver also criticises the standpoint epistemology of experiential research for frequently failing to connect itself to emancipatory theory or praxis. I was interested in the collective thoughts of the research group and hoped to incorporate a “praxis-oriented dimension” (McLaren, 1987, p. 136). I wanted to establish a research process that allowed for critical reflection of a situation: how we had affected it, the results of our actions, the new situation created and what further strategies would be required to pro-actively instigate change. I also felt that the term Experiential Research did not capture the essential inclusivity of the research that I wanted to conduct. Therefore, an experiential approach alone was deemed inadequate.

Emancipatory Research in Disability Studies has its own clearly defined criterion (for further information see Oliver, 1997; 2002). It expects that people with impairments initiate and control all aspects of the research process, including social and material relations (Barnes & Mercer, 1997). Given that I initiated the research, this seemed unachievable from the outset. My research clearly fell short of the initiation criteria and Val Williams warned that I would meet with semantic criticism if the Emancipatory label was attached (Field notes, 20/6/06). Another consideration was that at the commencement of the research the cognitive skills and research interests of the research group would be completely unknown to me.

Jan Walmsley and Kelley Johnson (2003) reminded me that I would be unaware of how much responsibility and control they wanted or were able to carry. Participants may not want the control required by an emancipatory methodology. Kiernan (1999) has highlighted the issue of impairment being a barrier for some to active participation in Emancipatory Research:

“Given that the research process relies heavily in intellectual skills, it is less easily accessible to people with learning difficulties than to groups of people with disabilities who do not experience intellectual impairments” (p. 46).

Emancipatory Research is also an ideal that is often difficult to realise (Oliver, 1997). So it appeared fruitless to set out with Emancipatory Research as a goal. Far more profitable for everyone would be a research strategy that accommodated difference and gave permission for support and shared control.

In Disability Studies, of the four research approaches mentioned above,
Participatory Research and Inclusive Research generally apply when specifically conducted with people labelled with learning difficulties. Participatory Research distinguishes itself from Emancipatory Research in a number of ways. Participation in does not necessarily mean ownership of the research and it is characterised by a relationship of support and cooperation with others (Ramcharan, et al., 2004). Gerry Zarb (1992, 1995) claims that the primary distinction between Participatory and Emancipatory Research is whether or not the research contributes to the empowerment of those who are, or perceive themselves to be, excluded from the processes which affect their daily lives. My aim was that the research process would contribute to a greater level of control and opportunity for self-determination (or empowerment) in the group members’ lives. This meant that, according to Zarb, my research might be described as emancipatory rather than participatory, except for the semantic issues mentioned above.

I also felt that the term Participatory Research might lead to confusion with the methodology known as Participatory Action Research (discussed below). Participatory Action Research does not necessarily include people with impairments. I chose to identify with the term Inclusive Research (Walmsley, 2001) as it is recognised within Disability Studies as that which specifically welcomes people labelled with learning difficulties as co-researchers and producers of knowledge (Walmsley & Johnson, 2003). In order to make plain my research objective, Inclusive Research was the methodological term I adopted.

5.3.2 Inclusive Research – historical background

Walmsley (2001) provides a comprehensive review of the social developments that have informed Inclusive Research. She notes the domination of disability research by psychology, eugenics, educational assessments and medical studies in which participants have been “tested, counted, observed, analysed, described and frequently pathologised, but never asked for their views” (p. 188). The concept of normalization, introduced in the 1960s by Nirje (1969; 1972) (developed by Wolfensberger (1972, 1983) into Social Role Valorization in the 1970s) also influenced Inclusive Research. Critics of normalization and Social Role Valorization claim that they value conformity over difference (Jenkinson,
They are concepts underpinned by ablest social value assumptions. They encourage people to behave as if they were normal (Shaddock & Zilber, 1991; Williams, L. & Nind, 1999), wearing what Edgerton terms a “cloak of competence” (1967, p. v). Jenny Morris criticises such disablist attitudes:

“one of the most offensive features of prejudice which disabled people experience is the assumption that we want to be other than we are; that is, we want to be normal” (1991, p. 34).

Normalization and Social Role Valorization are assimilationist rather than inclusive strategies. Culham and Nind (2003) note that the concept of inclusion encompasses ideas of respect, equality and collective belonging in addition to increased access and participation with decreased exclusion from mainstream settings. Inclusion transcends “the concept of normalisation… by using language that emphasises participation over normalcy” (Florian, 1998, p. 16).

However, normalization did serve as a motivating force for the disability rights movement across the western world, raising the profile of those with impairments as being first and foremost people with the right to speak for themselves and to be heard (Wehmeyer & Schwartz, 1998a). Normalization has thus served as an impetus for more inclusive social strategies, which have also grown since the signing of the Salamanca Agreement (UNESCO, 1994), the Biwako Millennium Framework (UNESCAP, 2002) and the Convention.

Other major influences on Inclusive Research include the promotion of a social model of disability and the call for emancipatory research from people within the disability rights movement. Self-advocate critiques of traditional research have stimulated an increased interest in Inclusive Research (Aspis, 1997, 2000; Walmsley, 2001). Criticising the traditional research paradigm as serving the interests of professionals and academic researchers, some have called for people with impairments to become the authors of research and not merely treated as research subjects (Ramcharan, et al., 2004). Dowson (1997) goes so far as to

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29 In the Scandinavian models of normalization Nirje (1985) highlights undesirable social behaviours while the earlier work of Nirje (1969) and that of Bank-Mikkelson (1980) assume valued social routines and practices. Social Role Valorization is based upon assumptions of socially valued roles (Wolfensberger, 1972; Wilson & Bartak, 1997).

30 Signatory nations committed to a philosophy in which inclusion and social participation were recognised as essential to human dignity and the exercise of human rights (Culham & Nind, 2003).

claim that it is a “comfortable delusion” (p. 101) to expect that positive social change will ever occur in the lives of people with impairments through traditional (medical model based) research.

The feminist movement has also influenced the development of Inclusive Research. It has raised awareness of the need to interrogate the objectification and marginalisation of the ‘other’, of which, clearly, people labelled with learning difficulties are an example (Lengel, 1998). Feminist research has assisted in calling for more qualitative research methods to prioritise the validity of personal experiences. By utilising feminist methods, such as personal narratives, Inclusive Research has facilitated people labelled with learning difficulties in taking on the roles of life historians and autobiographers (Atkinson, Jackson, & Walmsley, 1997; Roets & Goedgeluck, 2007; Björnsdóttir & Svensdóttir, 2008).

5.3.3 Key features of Inclusive Research

Inclusive Research aims to be accessible to the participants throughout the research process. It permits participants to engage with and exert control over the process and outcomes of the research without objectifying them as research subjects (Abberley, 1987). Inclusive Research has been successfully used to clearly articulate the voices of people labelled with learning difficulties as valid (Atkinson & Williams, 1990; Smith, P., 1999b; Williams, V. & Heslop, 2005; Roets & Goedgeluck, 2007; Williams, V., Ponting, Ford, & Rudge, 2009). Inclusive Research promotes a democratic interaction and transfer of power, thereby reducing the likelihood of exploitation (Chambers, 1986, noted in French, S., 1994a, p. 142).

Including the word inclusive in the methodological description calls attention to the inclusion of people who are usually excluded from the process or merely used as research subjects, informants or consultants. Inclusive Research involves people as co-researchers, collaboratively and intrinsically, providing a balance between grassroots and macro analyses in disability research (French, S., 1994a) In this capacity, co-researchers are involved in a range of research activities, based on their skill levels, including research design, interviewing, data collecting, ideas generation, analysis, writing, presenting and using research findings. Inclusive Research may require the principal researcher or support workers to adapt
research strategies to suit the competence of the group members. However, Radermacher’s (2006) concern is that an absence of skill in those participating in research may reduce the activity to tokenism or “an empty gesture” (Heller, 1991, p. 278, quoted in Radermacher, 2006, p. 13), while Riddell, Wilkinson and Baron warn of the temptation to “trivialise” or “stage manage” (1998, pp. 81-82).

Inclusive Research permits non-disabled researchers to identify the research problem and then bring it to the community of people labelled with learning difficulties (Chappell, 1998). This gives the community authority to decide if the issue is of interest to them and warrants investigation. The research topic is therefore owned (though not necessarily initiated) by the participants (Walmsley & Johnson, 2003). The aim of Inclusive Research is to further the interests of the participants, providing a means by which people can analyse their situation and take action within a supportive environment (French, S., 1994b). The research team would explore areas of interest to everyone, not just the outsider facilitator (Titchen & Binnie, 1993). This has an educative benefit in breaking down the mystique of research and demonstrating that it can be accessible and practical in the every-day (Chambers, 1986, noted in French, S., 1994a, p. 142).

One of the dominant principles of critical pedagogy is that all students (such a powerfully inclusive term) can become critical and engaged learners committed to transforming social inequalities and social injustices (Horton & Freire, 1990; Shadduck-Hernandez, 2006). As an adult educator with extensive experience as a vocational trainer within the disability industry I believed I had the professional skills to collaboratively embark upon an Inclusive Research project, adapting research methods and processes to make them accessible to group members. I could support the participants in becoming critical citizen-researchers.

Brisendon (1998) highlights the broader implications of Inclusive Research on the consciousness of mainstream society. Information presentation influences the way it is received. Therefore, Brisendon claims that if the experience of people with impairments is expressed by the people in their own words, they are acknowledged as, and afforded the respect of, being an expert on what that experience is. This aligns with the Convention’s Article 8- Awareness-raising, and educates the community about the people’s experiences and dismantles stereotypes. Freire also stressed, as a fundamental principle of emancipation, the
importance of permitting people to speak about their world in their own language (Freire & Macedo, 1987). The experience of living with an impairment is generally presented by medical and rehabilitation experts, using their terminology and in the context of the medical implications of the impairment. The experience is generally seen as a matter of physical or intellectual dysfunctions and little else (Brisendon, 1998). Rapley, (2004) claims that the generally accepted and psychologised view of people labelled with learning difficulties is of people with “defective ‘intelligence’ and an impoverishment of ‘competence’” (p. 48). These are ableist assumptions that dismiss the status people have as knowers and namers of their world. Adopting an Inclusive Research approach was a way of giving people an opportunity to articulate their knowing into the consciousness of the broader community.

Involvement in research by people labelled with learning difficulties has also been seen as offering a valued social role, in line with Wolfensberger’s (1983) ideas of Social Role Valorization (Walsmsley, 2001). This includes gaining the status of co-researcher, co-author, report writer/editor and conference presenter (Williams, V., Ford, & Ponting, 2006).

An important aspect of Inclusive Research is to present the results in a meaningful way to those involved and their community. In order to make that information accessible researchers stress the importance of the partnership from the outset, testing rough drafts, involving people in information production and testing the final draft before it goes public (Ward, L & Townsley, 2005). As anticipated, the inclusive nature of the project provided many opportunities for researchers to do this.

Inclusive Research is collaborative research. It requires researchers to co-operate with each other and to be flexible, adapting research methods to suit the situation and people involved (Walsmsley, 1994). The practical implications of how this worked out in our research project are elaborated below (5.5) and in the Part 3 – Action! section of this thesis.

An inclusive approach to the research provided me with an opportunity to establish a research environment where I could support my colleagues in exercising their right to identify and name their social barriers to self-determination while being
immersed in the group as both facilitator and co-researcher and, eventually, as a research-advisor. Flexibility in control and accountability of the research permitted me to relinquish more and more control to the group as they became better able to direct the research activities on their own.

Inherent in the Inclusive Research design were collaborative strategies of inquiry that not only identified but provided opportunities for overcoming oppressive barriers. The utilisation of an Inclusive Research methodology was also used as a tool for personal development in self-determination. It provided an educational opportunity for participants to increase their skills, self-reliance, self-confidence and to exercise their skills of self-determination, “leading to social action which they perceive to be relevant and important” (French, S., 1994a, p. 142).

Although highly participative, Inclusive Research differs from the methodology known as Participatory Action Research. In the following section I explain these differences and provide an overview of Participatory Action Research.

### 5.4 Participatory Action Research

Participatory Action Research is a process enabling participants to move from the way things are to the way things could be. There is an overt aim to change the status quo. It is about transformation on both personal and social levels and falls under the research genre called “Empowerment Research” (Smith, S., Willms, & Johnson, 1997; Gergen, M. & Gergen, 2000, p. 1034). As reflected in the genre’s title it is underpinned by values which conclude that the research process must be democratic, equitable, liberating and life enhancing for those involved (Stringer, 1996). The following section outlines the purpose of the methodology.

#### 5.4.1 Definition and purpose

Gaventa (1988) defines Participatory Action Research as a process that “attempts to break down the distinction between the researchers and the researched, the subjects and the objects of knowledge production by the participation of the people-for-them-selves in the process of gaining and creating knowledge. In the process, research is seen not only as a process of creating knowledge, but simultaneously, as education and development of consciousness and of mobilization for action” (p. 19).
Participatory Action Research, therefore, has three core activities: research, education and action (Small, 1995). The educational aspect of Participatory Action Research is discussed in greater detail below (5.6) as I sought to incorporate Liberatory Educational outcomes into the research.

A requirement of Participatory Action Research is that knowledge must be practical and implementable for those involved (Shotter, 2004; Reason & Bradbury, 2006). According to Dewulf, Craps, Bouwen, Abril and Zhingri, “it is a kind of knowledge related to the course of our particular actions, giving us a sense of where we might move next” (2005, p. 177). It is about learning, growing and taking risks (Smith, S., et al., 1997).

5.4.2 Participatory Action Research – historical background

Participatory Action Research has its roots in the work of Kurt Lewin during the early 1940s, who tied the systematic and experimental approach to a social problem with social action as a means of resolving it (Smith, S., et al., 1997; Schalock, R. & Felce, 2004; Fox, Martin, & Green, 2007). Lewin’s Action Research came under strong criticism for being unscientific and methodologically poor. It was argued that practitioners did not have the basic research skills and that “research is no place for an amateur” (Hodgkinson, 1957, p.142 quoted in Oja & Smulyan, 1989, p. 5). However, the model of Action Research was enthusiastically taken up during the 1970s, particularly by educators, as it challenged the distinction between researchers and practitioners and between theory and practice (Fox, et al., 2007). Kemmis and McTaggart (1988) argued that solutions to problems were to be found with practitioners critically reflecting on and researching their own practice rather than this being done by distant, expert academic researchers. Participatory Action Research has developed from Action Research and highlights the importance of being both a practitioner and researcher. It recognises the skills and rights of practitioners as professionals and it encourages their involvement in the self-reflective interrogation of practice and clarification of theory (Oja & Smulyan, 1989).

Phenomenology also contributed to the development of Participatory Action Research, legitimising “experience as a basis of knowing” (Corbett, Francis, & Chapman, 2007, p. 83). The recording of human emotions and feelings through
narrative recognises these experiences as ways of knowing in addition to experiential learning as a legitimate form of knowledge that could be used to inform practice.

Participatory Action Research can also be traced back to Latin American adult educators and social scientists, such as Freire (1996) and Fals Borda (1988) engaged in collaborative processes of investigation, education and action with poor and oppressed groups. Their goal was to transform community and societal structures to improve the lives of the oppressed (Gaventa & Cornwall, 2001). It remains the stated goal of Participatory Action Research to bring about a more just society by transformative social change (Small, 1995). Such explicit aims closely link Participatory Action Research with critical theory as Habermas claims “in the process of enlightenment [and empowerment] there can be only participants” (1974, p.40, Kemmis, 2001). Practitioners of Participatory Action Research draw from a variety of perspectives, including Marxism, Freire’s theory of conscientization, Gramsci’s identification of workers as organic intellectuals, critical and feminist theories (Park, 2001; McIntyre, 2003). It was developed primarily as praxis, that is, another form of dialectic. Rather than considering a problem in a linear fashion which often restricts critical analysis, a dialectic approach considers forces acting in relation to each other. Dialectic thinking recognises the ongoing shaping and reshaping that takes place between forces (Smith, S., et al., 1997).

The tenets of Participatory Action Research have been applied to a wide field of research including Feminist Research (Olesen, 2000), Participatory Research – typically concerned with social, economic and political development in developing countries (Denzin & Lincon, 2000), Critical Social Research (Reason & Bradbury, 2006), Education (Stringer, 2004), Cultural Studies (Pyrch, 2007), Healthcare (Hughes, I. & Seymour-Rolls, 2010), Business and Economics (Breu & Hemingway, 2005), Rural Science (Bush, 2000) and international development problem-solving (World Health Organization, 1978). Furthermore “collaboration is currently seen as the direction in which practitioner research should develop” (Fox, et al., 2007, p. 116). As someone working within the disability service industry I was well positioned to undertake practitioner researcher in collaboration with disability service users.
5.4.3 Key features of Participatory Action Research

The key feature of Participatory Action Research is the collaboration of people (Fox, et al., 2007). It incorporates those affected by the issue under investigation as the primary investigators and change agents (McTaggart, 1994). It is not “simply an exotic variant of consultation” (Wadsworth, 1998, p. 1). Stringer (1996) emphasises the democratic and equitable nature of Participatory Action Research, enabling the stakeholder contribution and acknowledging equality of worth. Participatory Action Research is an intentional interplay between reflection and making sense on the one hand, and experience and action on the other (Heron, 1996). It actively seeks to synthesise action and reflection, theory and practice in participation with others “in pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and communities” (Reason & Bradbury, 2006, p. 1). This requires critically reflecting on those historical, cultural, economic, political, geographic and other contexts which make sense of the issue under investigation. Participatory Action Research is a political process because it seeks to improve social practices by changing them (McTaggart, 1991, 1997).

Participatory Action Research privileges the production of responsible knowledge so that the common people, including those who are the victims of oppression and exploitation, become the beneficiaries of the research (Fals Borda, O., 2001). The principle of beneficence for those participating is intrinsic to the research. Without specific benefit to participants Goodley (1999) warns that collaborative disability research is, despite appearances or intentions, reduced to research “on” rather than “with” participants (p. 43). Participatory Action Research can be a tool for liberation and humanisation (or life enhancement, enabling the expression of people’s full human potential) (Freire & Freire, 1994; Stringer, 1996; Freire, 1998). An explicit intention of Participatory Action Research is also to enhance a system’s capacity for self understanding (Reason & Lincoln, 1996). It is not, therefore, a method or procedure but more a commitment to look at and then problematise what is happening in each stage of the research process (McTaggart, 1994).

Participatory Action Research is contingent on authentic participation allowing people to gain and experiment with knowledge. Part of this experimentation is the call to test practices, ideas, and assumptions about institutions. Participants must
be reflective and are required to theorise about their practices. Participatory Action Research has therefore been described as “critical reflexive, sceptical and imaginative inquiry” (Wadsworth, 1998, p. 1). The research must provide opportunity and freedom for the collaborators to assert their perspectives. This ensures that voice, reflexivity and textual representation are embodied in the writing.

Participatory Action Research is a systematic methodology which keeps records to assist in the reflective process and analysis, tracking developments and monitoring results (Kemmis & McTaggart, 1988). Researchers claim that successful Participatory Action Research requires a balance of co-generative dialogue and decision-making control against the need for efficiency (Fear & Edwards, 1995). It is a methodology that therefore benefits from a structure with defined parameters such as timeframes, responsibilities and rules (Stoecker, 1999). These are democratically determined as the research group works to function in a cooperative and egalitarian manner (Lundy & McGovern, 2006). Proponents of Participatory Action Research stress that the research must be person-centred and be carried out with people, not on them or about them or for them (Heron, 1996, p. 19; Goodley, 1999, p. 27).

Participatory Action Research requires time and patience. The pace of the journey will vary throughout. Usually, people need time to talk through the issues in a critical dialogue of “authentic listening and speaking” (Smith, S., et al., 1997, p. 8). The research groups develop strategies to remove or avoid barriers in their path and in doing so develop a sense of community. The strength of Participatory Action Research lies in its unified approach.

In Participatory Action Research the primary researcher moves from the role of expert in research into the role of “process facilitator” (Fox, et al., 2007, p. 53). Their task is to support participants with the research process as co-researchers or collaborators. Goodley (1999), notes that in participative disability research participants are regarded as novice researchers but disability experts.

While participants are included as full and equal partners “in all phases of the research”(Beach Center on Disability, 2006), it is the job of the research facilitator to establish trust within the research group. Heron (1996) argues for participatory
research based on grounds of validity, claiming the conclusions reached by researchers considering the human experience of the subjects who were not actually the researcher themselves, are not properly grounded. Furthermore, he makes the serious accusation that to generate knowledge about people, without their full involvement in deciding how to generate it “is to misrepresent their personhood and to abuse by neglect their capacity for autonomous intentionality” (1996, p. 22), so rejecting the practice as unethical. If subjects are required to produce behaviours according to a research protocol over which they had no say Heron argues that the subjects are acting as conformists and other-directed subpeople rather than as self-directed people. They are, in fact, being asked to acquiesce to the imposition of values and norms that are not their own, to be disempowered and oppressed. Heron, along with many in the Disability Studies academy, claims that research must provide opportunity for subjects to exercise their right to self-determination with respect to research decision-making (Hunt, 1966; Oliver, 1992; Finkelstein, 2002).

Participatory Action Research typically involves a spiral of the self-reflective active cycles. Kemmis and McTaggart (1988) describe the cycle as: plan, act and observe the processes involved and their consequences; reflect upon the processes and their consequences; then, in the light of this, repeat the cycle as necessary. As researchers repeatedly plan, act, observe and reflect, the aim is that the process spirals towards appropriate action and achievement of the research aims (Dick, 2000).

5.4.4 Types of knowing

Participatory Action Research engages in what Heron and Reason call “an ‘extended epistemology’ of experiential, presentational, propositional and practical ways of knowing” (2008, p. 366). Experiential knowing is gained through the immediacy of being with and perceiving a person, place or thing. They claim that any form of inquiry that fails to honour experiential presence ignores the foundational bedrock of all knowing. Presentational knowing articulates the significance of experiential knowing. It manifests the vague and inchoate through creative expression – images, dance, sound, music, drawing, painting, sculpture, poetry, story, drama – that non-discursively reveal knowledge. Propositional knowing is intellectual knowing about something and produces spoken or written
information. Practical knowing is knowing how to do something and is demonstrated through skill or competence in a particular area.

Being part of the Photo-voice research project was intended to heighten the team members’ experiential knowledge by drawing their attention to new dimensions of their world. Charged with the task of making explicit their participation in the world, they would look for and name their social barriers. This would exercise the foundational skill of being present and mindful of the world around them, of becoming intentional with their actions and their responses to the situations they encountered. I would seek to honour experiential presence in this inquiry/research by taking the group members’ standpoint and encourage all four forms of knowing by utilising a range of inclusive and accessible methods.

Developing an interpretive framework – by which meaning is made (Newman, 2000) – for Participatory Action Research is challenging. The facilitator must discover ways of balancing individual interpretations with the interpretive community. As all meaning making is rooted in our own cultural histories and tacitly absorbed both from our immediate and wider communities, much is unquestioned. Newman points out that all our understandings are mediated, to a large extent, by the culture in which we live, by the media and by our everyday conversations. And yet, in spite of the social influences and our interpretive communities, we still make sense as individuals. This theoretical perspective is an imperative basis for Participatory Action Research as it centres attention on interpretation. It highlights the need for reflection and points towards our method of analysis. It prompted me to think about contexts and how they might affect research judgments and the interpretations upon which those judgments were based. Utilising conscientization strategies of critical pedagogy, Participatory Action Researchers can reflectively and collectively question their tacit theories, values and beliefs upon which their judgments are largely based (Freire, 1996). A collaborative dialogue enables a narrative to be created (Newman, 2000). Through the narrative researchers can distance themselves from their judgments. This distance turns the subjective (judgment) into the objective. This provides an opportunity for reflection and provides clues for people to determine the kinds of cultural values that are affecting their judgments. Plans are made, actions evaluated and research findings discovered based on the group’s interpretive
Rights, Camera, Action!

framework. Smith warns that reflection alone can lead to “informed passivity” while action alone can lead to sporadic results with the “potential for authoritarian controls over decision-making” (Smith, S., et al., 1997, p. 187). Participatory Action Research group members systematise their experience through their interpretive framework, organise their data and do analyses while identifying gaps and relationships. In doing so, they build new levels of understanding and make meaning collaboratively. The content that was subjective (their personally held belief or individual opinion) gains objectivity by being conceptualised in a different way. The personal is transformed into the corporate, something that is held by the rest of the group (Smith, S., et al., 1997).

Launching a research project is a challenging task. Issues regarding project goals, control and leadership need to be clarified from the outset (Oja & Smulyan, 1989). The facilitator must create a community of shared values without compromising those values or colonising the values of others. Facilitators have a responsibility to educate without indoctrinating the co-researchers (Heron, 1996). Recognising this responsibility, and the inherently political nature of Participatory Action Research, critical pedagogical principles urge “teachers to disclose, but not impose, their political views in seeking, with students, to understand more deeply a given object of study” (Roberts, 1996, p. 335, emphasis in original). This political intent of Participatory Action Research has been criticised as potentially manipulative (Sharma, 2006). This was an area on which I needed to keep a close eye as I was aware of my own assumptions of social oppression and political biases. I sought to assist the research group to develop their own critical consciousness without manipulating them.

Building trust and a sense of safety within the research group is imperative if the group is to operate democratically. Costello reminds those embarking on Participatory Action Research, “we need to embody an ongoing flexibility, openness and willingness to listen to all the points of view of all the participants” (2004, p. 1). While Participatory Action Research’s primary aims are to improve practice, contribute to theoretical understanding of that practice and provide professional or personal development experience for the participant, it has been criticised for rarely achieving all three goals and for emphasising one at the expense of the others (Oja & Smulyan, 1989).
Participatory Action Research has also been criticised for lacking scientific rigour and confusing social activism and community development with social research (Denzin & Lincon, 2000). Bogdan and Biklen (2007) note that Participatory Action Research is also critiqued for lacking objectivity. They refute this, stating that researchers objectively study the subjective state and, while they might not be able to transcend their own biases, they implement methods to assist the procedure. Bogdan and Biklen claim “objectivity means being honest, going to the source of the data and eliciting the views of those involved in the issue” (2007, p. 239). In contemplating the risk of bias from subjective, value-driven, Participatory Action Research, Wadsworth claims “the strength of the values we hold will determine the power and direction of our research efforts” (1998, p. 1).

Smith warns that Participatory Action Research has the potential for consensus or even worse, group tyranny, which can overshadow consideration of individual welfare (Smith, S., et al., 1997). One strategy is to attend to the group as a unit and to individuals as separate beings in order to move forward. However, the progressive momentum can become difficult when varying and often competing, motivations and interests are involved.

5.5 Inclusive Participatory Action Research

5.5.1 Introducing IPAR

The term Participatory Action Research has been allocated specific standards by some research groups that were expected to be unattainable in the context of my research. In particular it was anticipated that my co-researchers would be unable to participate as full research partners “in all phases of the research” (Beach Center on Disability, 2006, p. 1) due to the nature of their impairments and the parameters of a doctoral dissertation. It was likely that some may lack the literacy and investigative skills required for an intensive literature review. They may have limited complex cognitive abilities preventing equal participation in research design and analysis. They may have lacked the social skills required to negotiate meetings with stakeholders, book rooms or attend to clerical tasks required for managing data collection and recording. Furthermore, since thesis writing was specifically my responsibility in the doctoral program, this was not something that the participants needed to be involved in. On the other hand, Inclusive Research
was an approach to investigative study with people labelled with learning difficulties not unlike Participatory Action Research and it allowed for disparate responsibilities. I felt that the two methodologies could meld effectively. For the purpose of this research I have coined the term Inclusive Participatory Action Research (IPAR). IPAR is a methodology that strives to combine the tenets of Participatory Action Research as much as possible with Inclusive Research. IPAR embraces people’s contributions to a project explicitly focused on improving their situation without excluding them because of their limitations. Similar research approaches have been undertaken utilising institutional ethnography, though these have been called “collaborative” (Campbell, M. L., Copeland, & Tate, 1998) rather than participatory as they fell short of the Participatory Action Research ideals.

The collaborative nature of IPAR goes some way to addressing the criticisms of objective structures of oppression within traditional disability research which positions disabled people as inferior because of their lack of control over research resources and the research agenda (Oliver, 1990; Zarb, 1992; Stone & Priestley, 1996). The term IPAR suited the research because, while my approach was inclusive and collaborative, the initial Stages (1 and 2) differed from Participatory Action Research in that I facilitated the research and necessarily maintained significant control of the process (Brookfield, 1986). Therefore, while an unequal power structure was inevitable, an awareness of this enabled me to make it visible and work to minimise it. Discussion and shared decision making on how the research resources should be utilised was one way of distributing power. Establishing a set of social and material relations of research production bent on collaboration and shared responsibilities within the research group devolved a measure of control to the group members. Democratic allocation of research responsibilities also provided self-determination opportunities. The research team were given the responsibility of identifying the social barriers to be explored. They were acutely involved in the decision-making processes about how exploration would be pursued and data collected. Critical research team discussions evaluated actions taken and analysed data. The group also contributed to the decisions on how the research findings would be disseminated. Furthermore they have all been actively part of the dissemination process through co-presenting at conferences and information sessions (discussed in more detail in Chapter 12). These actions were all practical strategies to counteract the inherently unequal
power relations between my co-researchers and me, and to share control.

Campbell, Copeland, and Tate, (1998) have noted a number of contradictions within their collaborative methodology. Unequal division of responsibility and labour, inequity between paid and voluntary research team members, unequal division of power over research funds were all issues with which I could relate. As the funded research student, the initiator and facilitator of the project, I necessarily held the role of chief investigator responsible for managing the student project funding, the scholarly rigour and ensuring that the thesis was eventually written. While I was a scholarship-funded student, my research team were recruited as volunteers and were therefore unpaid. In order for the project to be completed within the limited timeframe I was ultimately responsible for ensuring deadlines were met. This involved completing tasks that were tedious though necessary, many of which were negotiated without the participation of the co-researchers (such as choosing the project venue, setting up email accounts for correspondence, initiating correspondence to which the research team could reply, purchasing equipment, liaising with community agencies and the funding body). While partnership with participants was inherent in the research design, it was inevitable that the power relationship would be imbalanced.

One of my primary roles within the IPAR group was also to facilitate and adopt a “catalytic and supportive role” (Rahman quoted in Lundy & McGovern, 2006, p. 73). As a facilitator and supporter of the IPAR I needed to discover from the co-researchers their skills and experiences in order for the group to work out roles. Inclusive Research literature provides a number of examples where people living with impairments have successfully worked as interviewers, analysts and transcriptionists (Grundy, McGinn, & Pollon, 2005; Williams, V., et al., 2006). The project therefore needed to provide opportunity for getting to know the group and brainstorming what abilities we each brought to the project.

Undertaking IPAR was always going to be challenging. Rogers (1999) admitted

“I found it hard to contemplate how the methodological considerations that I found challenging could be made more accessible to people with learning difficulties” (p. 431).

Following Rogers’ strategy, my aim was to keep all communication and concepts
straightforward and accessible to everyone. After all,

“if ideas are too sophisticated for people with intellectual disabilities to understand,…such ideas cannot be used meaningfully by people with intellectual disabilities themselves in seeking to change their lives” (Ramcharan, et al., 2004, p. 86).

Incomprehensible ideas would thus be also inappropriate for IPAR research. I endeavoured to include the participants in the analysis tasks wherever possible. Where transcriptions might prove too densely informative, I planned to find the emerging themes within the data and bring these to the group for validation or debate. This approach has been questioned by Booth with regards to the “ethics of representation” (quoted in Ramcharan, et al., 2004, p. 95). When dealing with people labelled with learning difficulties, the issue of the ethics of representation has to do with acquiescence and learned helplessness. Many people so-labelled lack confidence in their abilities, “causing them to over-rely on the leadership and skills of others” (Langone, 1992, p. 10). Therefore, when seeking discussion on, or validation of, research analysis or how information is to be conveyed, this issue must be closely considered. Booth (1996) has questioned whether it is ethical to bring an academic analysis of themes to a group of people labelled with learning difficulties. Yet Inclusive Researchers have reported how issues such as these have generated discussion and differing opinions between non-disabled researchers and their participant-researchers, resulting in compromise in which the viewpoint of the participant-researchers ultimately prevailed (Walmsley, 2001). It was encouraging that such issues are not insurmountable but need to be tackled transparently and collaboratively. Thematic analysis has been suggested as possibly the best fit for a participatory approach to disability research (Ramcharan, et al., 2004). Rather than employing theoretical or epistemological grounds for choosing particular analytical methods, researchers pragmatically utilise analytic tools suited to the research team’s skill level and which enable them to accomplish their task.

Another consideration was the problem of “collectivising analysis within a social model where that model was not necessarily part of the participants' own understanding of disability” (Priestley, 1997, p. 92). Addressing this issue meant that the group was engaged in numerous discussions, with the intention of conscientization, on issues of social barriers which were clearly not their fault and
had nothing to do with their cognitive skills but were social structures (Freire, 1996).

Although supporting inclusive collaborative research is challenging, the difficulties are frequently outweighed by the benefits gained (Campbell, M. L., et al., 1998). The working relationship between the facilitator and the IPAR research team provides opportunity for open discussion about power and authority. Such discussions encourage debate and multiple perspectives to be shared. They also provide opportunity to correct misrepresentation. In my research I also utilised the notion from institutional ethnography that "a knower's location in the world provides the basis for what can be seen and understood" (Campbell, M. L. & Gregor, 2004, p. 119), so I was able to sort out and better understand the differences in the team members’ perspectives.

My experience as an adult educator of people labelled with learning difficulties prepared me with skills to undertake such a mixed methodology. It must not be assumed that supporting inclusive research is an easy undertaking: to do so would be to negate the skills I bring to the research project and would in itself be “like a reflection of the devaluing of people with learning difficulties” (Walmsley & Johnson, 2003, p. 195). Ten years as a vocational educator and training designer have been solid and important preparation for the task.

IPAR is a methodology which provides recognition for the research group (and the academic community) that they are the experts regarding their own perceptions of social barriers to self-determination, that their opinions are valid and that their contribution is integral to the research process. It is an opportunity for the powerless to recognise a problem and be afforded the liberty and support to address the problem for positive change. Nelson and Prilleltensky (2005) claim that research on the process of empowerment has demonstrated that individuals will rarely engage in emancipatory actions until they have acquired an appreciation of their own oppression and have enjoyed support from other community members. IPAR provides such support. Furthermore, Zarb (1992) has identified participation in research as a “pre-requisite to emancipatory research” (p. 128). IPAR therefore is also a journey. It is perhaps the first positive step through which researchers and people labelled with learning difficulties can come to understand that each can learn from the other. It affirms the co-researchers as knowers,
provides opportunity for personal growth and self-determination, welcomes their involvement and contributions and is a constructive move toward a more inclusive society.

5.5.2 Reflections on IPAR

One of the difficulties with Action Research is that although it may have a strong knowledge component, it is not always successful in delivering or creating knowledge that is implementable for those involved (Argyris, C., 2004). An element of the issue may be found in the question “for whom is that knowledge actionable, implementable or practical?” In the case of my Inclusive Participatory Action Research, my desire was that the research outcomes might be accessible. Furthermore I hoped to support the development of self-determination skills within the research team through the research process, producing practical knowledge that was implementable for them.

Horsfall and Titchen (2009) similarly aimed for human flourishing to be the process and product of their research and have also pointed out that research can be equitable and accessible, creative and fun while maintaining integrity and rigour. Human flourishing occurs when people experience growth that pushes their boundaries in various directions (Horsfall & Titchen, 2009).

5.6 Liberatory Education

Building on the theoretical position outlined in Chapter 2 which claimed ableist structures and attitudes of society oppress and disable people labelled with learning difficulties, a Liberatory Education approach could be incorporated into IPAR. This would provide a means by which people might emancipate themselves from disabling social barriers and from internalised ableism. The importance of dialogue and developing critical consciousness for the purposes of liberation and positive social change are key Freirean Liberatory Education methods that fit well with the educative purpose of IPAR and the reflective cycles of Participatory Action Research. These are discussed below.

5.6.1 Critical reflection

Critical pedagogues recognise the importance of critical reflection in learning, see
for example Paulo Freire (1985), bell hooks (1994), Chris Argyris (2000), Victoria Marsick and Karen Watkins (1990), Stephen Brookfield (1986), Patti Lather (1991), Jack Mezirow (1990, 2000), Ivan Illich (1973) and Donald Schön (1987). Education which is liberatory is reflective. It encourages learners to challenge and change the world, rather than uncritically adapt themselves to it. Hearney (2005) explains that education for liberation challenges the givenness of the world and enables students to reflect on their experience historically. This gives their “immediate reality a beginning, a present, and, most importantly, a future” (Hearney, 2005, p. 1). The aim is to awaken an expectation of change within the learner. Once awakened this seeks expression in collective action for social change.

The content and purpose of Liberatory Education is the collective responsibility of learners, teachers, and the community alike who, through dialogue, seek political, as well as economic and personal empowerment. Programs of Liberatory Education support and complement larger social struggles for liberation.

Liberatory Education focuses on raising the consciousness of those who are oppressed (Freire, 1996). It has significantly affected many disciplines including Political Science (McLaren & Leonard, 1993), Rehabilitation (Sharma, 2006), Nursing (Burnard, 1989), Social Work (Breton, 1994), Feminism (hooks, 1994), Sociology (Sweet, 1998), Psychology (Campbell, C. & Murray, 2004), Linguistics (Gee, 2000b), Disability Studies (Ware, 2001) and Adult Education (Horton & Freire, 1990). Liberatory Education recognises that students can participate in personal transformation and social liberation. I sought to utilise Freirean strategies in my research and support my research team to also envisage a new world.

### 5.6.2 Political intent

Freire repeatedly stated “there is no such thing as neutral educational processes” (Freire & Freire, 1994; Freire, 1996, p. 34; 2004). All education is political. It is either for the liberation (humanisation) or the domestication (domination) of people (Freire, 1996). Therefore the deliberate educational methodology within IPAR would also be political. The notion of education for liberation can be applied to Disability Studies where disability is frequently analysed as a distinct form of social oppression (Barnes & Mercer, 2003). Echoing Freire, Barnes highlighted the
political nature of disability research, claiming

“There is no independent haven or middle ground when researching oppression: academics and researchers can only be with the oppressors or with the oppressed” (1996, p. 110).

The assumption underpinning Liberatory Education, and particularly that of Freire, is the belief that a “critical, multicultural democracy should be the driving force in the struggle for freedom” (Leistyna, 2004, p. 17) against dehumanisation. Freire claimed that the ontological vocation of each person was to humanise themself by transforming the oppressive structures of the world that have dehumanised people through injustices, exploitation and acts of oppression (Connolly, 1980; Davis, R., 1980; Freire, 1996). From my position as a practitioner within a disability service, I recognised the treatment of people labelled with learning difficulties as dehumanising. I saw my own role in the dehumanising process – as an oppressor I too was dehumanised (Freire, 1996). I had a personal need for liberation just as much as I believed my research colleagues had. Dialectically the two are inseparable.

Taking a Freirean Liberatory Education approach to research provided a path by which I could engage in the struggle for freedom for both the oppressed and the oppressor. This is explicitly political.

Developing political knowledge of the world around them through IPAR would provide people with an increased sense of their own ability to change and shape the context in which they live and, hopefully, an increased willingness to do so (Roberts, 2005).

“Awareness of the world and awareness of myself make me not only a being in the world, but one with the world and with others. It makes me a being capable of intervening in the world and not only of adapting to it. That is why not only do we have a history but we make our history, which equally makes us and thus makes us historic” (Freire, 2004, p. 15).

Liberatory Education calls upon students to reflect upon their own experiences of oppression through personal devaluation, poverty, poor education systems, displacement and injustice (Horton & Freire, 1990; Freire, 1996). Critical reflections are used as theoretical tools with which to more clearly interpret the world in order to actively respond to it (Matthews, 1980; Horton & Freire, 1990).
This is praxis, the heart of Action Research. I endeavoured to build praxis, as an integral process, into the research methodology through an ongoing cyclic process of dialogue $\leftrightarrow$ action.

### 5.6.3 Dialogue

Dialogue, a two way means of communication contained in a respectful relationship, is the most significant feature of Liberatory Education. The emphasis on respect is vital. Dialogue is understood as two people working together rather than the traditional educational approach which involves one person (the teacher) acting on another (the student)\(^{32}\) (Sleeter & McLaren, 1995).

The conditions I aimed to establish within the IPAR group were loosely modelled on the principles of Habermas’ (1984) Ideal Speech Situation wherein no voice is privileged and everyone has the right to participate freely. This requires that those participating in the dialogue recognise the need to ensure it is based on the three central criteria for an Ideal Speech Situation. These are:

- **Equal rights of discourse** – presumes that all participants have the right and opportunity to initiate and continue discourse on any issue;

- **Absence of role privileges** – rejects status, for example of the group facilitator or chief research investigator. All special knowledge needs to be shared with the team as part of the process of communication;

- **Freedom from coercion and constraint** – insists that all forms of coercion and constraint which might in some way engender less than full discursive reciprocity be eliminated. Any suggestion that the facilitator knows best is discouraged.

Dialogue based on equality and respect is crucial to Freirean pedagogy. Paulo Freire warns that respect

> “is violated, or prevented from materializing, by authoritarianism. Permissiveness does the same thing, in a different, but equally deleterious way” (Freire & Freire, 1994, p. 101).

Dialogue is a cooperative activity of discovery, capable of building community and

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\(^{32}\) Freire was highly critical of this “banking method” (Freire, 1996, p. 73) of teaching which sees teachers depositing information into supposedly empty headed students.
social capital. Dialogue is therefore not a research method but a methodological approach informing how the research is undertaken. The voice of the oppressed is often silenced. Certainly, the voice of people with the label of learning difficulties is largely absent in the literature of Disability Studies. I anticipated that research grounded in a dialogical methodology, which encourages people to engage in dialogic processes, to question societal relations with which they interact and practices with which they must conform, and to contribute their own knowledge to that dialogue, could be liberatory (Sigamoney, 2005).

The essence of Freire’s liberatory pedagogy is a process called conscientização, translated as conscientization. Dialogue is crucial to conscientization, which is described further in 6.3.2.

5.6.4 Freirean starting point: experience

Liberatory Education begins with the lived experience of the student, which are integral to the exploration of the social world (Darder, 1995). Through dialogue, students problematise (or pose questions about) the objective realities of their lives in order to develop a critical awareness of their own history and social positioning (Freire, 2004). This enables them to accurately read their world, to explain the way life is for them, rather than unquestioningly accepting the taken-for-granted truths that they have been told by others. Problem-posing occurs not only around the reality explored through the dialogue but also around language used in the discussion. Freire carefully deconstructs language as a powerful tool capable of cultivating either dominance or freedom. Working with a group who have been labelled all their lives, I anticipated that deconstructing the language they used and the language of labels might be a politically powerful experience for the group. Reading the world, including the purpose of labels such as learning difficulties or intellectual disability, is a way of apprehending reality, taking hold of it and claiming it or denouncing it.

Freire (1996) stresses that the world does not exist separate from people that are in the world, as a static reality, but as a reality in process. We are in the world and part of the history-making process. As subjects of history, history is not pre-determined but full of possibilities of our making. With the notion of possibilities, hope is situated as an integral component of progressive education – not a
passive cross-your-fingers kind of hope, but an active force which is imperative to the success of problem-posing education and the process of conscientization (Hendriks, 2009). The critical awareness of oppression is not sufficient for liberation. It is, however, "indispensable" (Freire & Freire, 1994, p. 31) to a new visualisation of the world based on justice and freedom. Equally important is hope for the envisioning of how the world might be otherwise. On the other hand, hopelessness is a "concrete entity" (Freire & Freire, 1994, p. 8) created by economic, historical and social forces of oppression, and intensified in the absence of a "critical knowledge of reality" (p. 30).

Praxis is an intrinsic characteristic of Liberatory Education and Participatory Action Research. Praxis is action which is informed by awareness gained from critical reflection. Dialogue is not merely for a deeper understanding of life, but for action, for liberation, for making a difference in the world. Following a naming of the world – apprehending the situation in which people find themselves – comes a denouncing of that situation and “announcing its overcoming” (Freire, 2004, p. 17), envisioning hope. Through further dialogue and what Freire describes as methodical curiosity, people discover how they can create a new vision of the world for themselves, rewriting their world through transformation or social action (Rossatto, 2000). By encouraging students to verbally express themselves and name their world Freire created a dialectical solidarity between reading the world and reading the word (Butterwick, 2001). Freire speaks of two kinds of praxis. One is a reflection that causes action. The second, theoretical praxis, is “action and reflection” (Freire, 1984, p. 527). These are explicitly Action Research strategies (Kemmis & McTaggart, 1988). Theoretic praxis is only authentic “when it maintains the dialectical movement between itself and that praxis which will be carried out in a particular context” (Freire, 1984, p. 527). The two are inseparable. Real reflection can only occur when it sends us back to a specific situation in which we act. The iterative cycles of Participatory Action Research are grounded upon this principle. I hoped to bring this visionary methodology to my research so that the group members might not think their situation was inevitable but that change, through them, was indeed possible and that they could be change agents and history-makers.

33 “Reading the World” became an axiom for Freire’s epistemological approach to critical pedagogy (Freire & Macedo, 1987; Gee, 1989).
5.6.5 Criticisms of Freirean Liberatory Education

Freire’s explicitly political and social purposes have been criticised for having the ability to be used for political manipulation, to indoctrinate and domesticate rather than to liberate people. Freire (1996) clearly articulated the differences between true dialogue and anti-dialogue (which is used to domesticate and oppress). Freire recognised the need to scrutinise the motives and actions of those claiming they are pursuing “dialogue” when, in fact, they were employing communication as “a technique for manipulation” (Freire & Shor, 1987, p. 98).

Freire is also criticised for “excessive idealism” (Sharma, 2006, p. 48), in his descriptions of learners and educators participating as equals, which Sharma claims is “seldom achieved in real world settings” (p. 48). While this statement may be, to some extent, accurate it does not negate the need for the struggle. Doing nothing is not an option, as inaction is to side with the oppressor (Freire, 1996). Furthermore, such criticism does not exclude the merit in Freire’s explicit goal of mutual respect between teacher and student, the imperative for highly ethical practice and attempts to address inequality. Freire clearly articulated the differences between student and teacher, particularly in his later writings (see for example (Freire & Shor, 1987; Horton & Freire, 1990; Freire, 1998) yet also stressed the willingness required of teachers to submit to be learners also in an educational setting. As I approached this research I endeavoured to position myself as a willing learner alongside my co-researchers, but I was necessarily different from my colleagues. I had to know the literature in my field (Disability Studies), prepare the research and ethics proposals and facilitate the research, including consciously facilitating critical dialogue. I also needed to relearn material and extend my own pedagogical knowledge throughout the research. I recognised also, that I was not the expert in knowing what it was like to be labelled with learning difficulties. In Freire’s footsteps the research needed to permit that expertise to be articulated so that their world could be named and reclaimed.

Freirean methods have been criticised (Berger, 1974), for arrogance and intellectual elitism which promote an anti-dialogical and paternalistic relationship between a knowledgeable group of higher-class intellectuals and an ignorant, lower-class group of educational participants. Bowers (1983), in a similar line of argument, maintains that a Liberatory Educational commitment to intellectual
qualities such as critical reflection, questioning and problematisation, would in some contexts become culturally invasive. Margonis (2003), similarly, identifies elements of colonialist thought in Freire’s work. Freire’s appeal to universal propositions in discussing issues of oppression and liberation has also attracted critical comment from feminists (Ellsworth, 1989; Weiler, 1994).

Freire (2004) notes that some have criticised his language as pompous and unintelligible. However, Freire’s work has significant theoretical depth. In order to make his work more accessible Freire modified his complex language in his later works following Pedagogy of the Oppressed to a more conversational style (see for example Freire & Shor, 1987).

5.7 Conclusion

IPAR positions people labelled with learning difficulties not as disability service users (though they have that knowledge and experience), but also as activists, learners, self-advocates, social researchers, colleagues, and social commentators on disability services and public facilities. This chapter specifically presented the case that people labelled with learning difficulties have the right to be included in all those kinds of activities. They have the right to be involved in and contribute to research concerning themselves. By synthesising inclusive and participatory research methodologies, and intentionally seeking Liberatory Education, a suitable research approach was created. However, inclusive research methodologies require accessible research methods – this too is a right – in order to facilitate meaningful research participation.

* This concludes Part 1- Rights, but by no means sets rights aside as an area of interest. The discussion thus far underpins all that is to come. My primary research questions are now: What do people labelled with learning difficulties consider to be social barriers to their self-determination? What suitable research methods can be found or adapted to facilitate their access to the research process? In what ways does IPAR lead to social action?

In Part 2 – Camera I introduce a range of accessible research methods and describe how the research team embraced them in order to explore, discover and claim their rights. The camera was integral to that process.
Part 2 – Camera

The theme of Part 2 is the camera. Through the narrative of this section I create a picture of the research process by focusing the thesis on the following areas: accessible research methods (Chapter 6), preparations and recruitment process (Chapter 7) and Stages 1 and 2 of the Photo-voice project leading to the identification of our research problematic (Chapter 8). We will now look inside the camera bag to discover the range and reasons for the research methods used.
Chapter 6 – Opening the Camera Bag: accessible methods

6.1 Introduction

This thesis has so far established that people with the label of learning difficulties have a right to both self-determination and to participate in research concerning them through inclusive research methodologies. Inclusive research methodologies require accessible research tools. In this chapter I consider what was in my metaphorical research camera bag, the tools or research methods utilised during the research. In particular I consider how photography was integral to the research process. I begin with a brief introduction to photography and its utilisation in qualitative research, followed by an introduction to the research method known as Photo-voice. The theoretical foundations are presented along with a discussion of Photo-voice’s accessibility merits. Photography is a highly versatile medium yet one which is accompanied by a range of ethical considerations. These are explored, focusing particularly on Photo-voice ethics, the risks associated with Inclusive Participatory Action Research and the strategies developed to meet the ethical demands.
Other research methods discussed in this chapter include the use of metaphor, institutional ethnography, meeting minutes, conversational transcripts, field notes and journal writing. Research analytical methods are also explained. A variety of creative means were used to analyse both the data and the research process. These included critical conversations, creative writing and patchwork- analyses.

### 6.2 Photography in qualitative research

The word photography has its roots in the Greek words photos and graphos meaning light writing or writing with light. It is a craft that mixes science and art to create images on a light sensitive surface (Nikonians.org, 2008). People have been photographing for almost 180 years. Interest in photography as a social science tool has fluctuated during the past one hundred years (Hurworth, 2003). However, during the last twenty years it has gained renewed popularity as a versatile and significant device for qualitative research. Sarah Pink (2004) has praised photography for bringing about new ways of working as well as new forms of reflexivity and consciousness to the researchers. Curry and Strauss (1994) used documentary photography as both a research tool and a means of disseminating research findings. Booth and Booth (2003) recognised the benefits of photography as an inclusive research tool for its emphasis on action over cognition. It is a means by which abstract concepts can be captured on film and made concrete (Curry & Strauss, 1994).

Adapting photography as an instrument for interviewing has been variously known as “photo-elicitation”, “autodriving”, “reflexive photography”, “photo novella” and “photovoice” (Hurworth, 2003, p.1-3). Photo-elicitation entails providing informants with photographs in order to gain information from them about the photograph or its theme, sometimes to record their memories associated with the photograph and to verify existing data. It is generally undertaken one-to-one rather than in groups. John and Malcolm Collier (1986) are credited with developing photo-elicitation as a research method.

Autodriving is a term used by Heisley and Levy (1991) in market research to indicate that the interview is driven by the informant who reviews their own behaviour in photographs which they have taken and upon which they reflect.
Reflexive photography and photo novella are both techniques that entrust a camera to research participants and asks them to capture day-to-day experiences on film in order to generate picture stories that are later explored through discussions. This method is now commonly referred to as “Photovoice” (Hurworth, 2003, p. 3).

### 6.3 Photo-voice

“Photovoice is accessible to anyone who can learn to handle an instamatic camera; and, what is more, it does not presume the ability to read or write.”

(Wang & Burris, 1997, p. 372)

#### 6.3.1 Overview

Photovoice is a photography-based research technique developed by Caroline Wang during the 1990s. For the purposes of this thesis I have chosen to hyphenate the word Photo-voice. Linking the two concepts of photo and voice with a hyphen provides a visual break in the word which I feel emphasises its dual purpose and clarified its meaning for the team.

Originally designed as a community development research tool, Photo-voice involves “giving people cameras and using the pictures they take to amplify their place in and experience of the world” (Booth, T. & Booth, 2003, p. 432). This elevates the participant to the status of expert in the analysis of their own lives instead of merely making their lives available for analysis by others (Wang, 2005a). In this regard it shares a common principle with IPAR, making it an excellent inclusive tool. It enables people to “record and catalyse change in their communities, rather than stand as passive subjects of other people's intentions and images” (Wang, 2005b, p. 1). It can also focus discussions with direct stakeholders on issues that concern them.

Photo-voice can be an empowering tool as participants have control over how they represent themselves and their communities. It affords opportunities to be self-determining as the Photo-voice participants decide how, when, why and what they will photograph. Participants select from their photos only those that best suit their purposes and determine the order of the photographic sequence through which to describe what it is they want to say through their photo-voices. Through reflective
discussions on the photos the photographer also develops the script or text that accompanies the photograph, using their own words rather than the interpretation of another. Photo-voice has been commended for its ability to access information that would not be accessible through traditional research means (Graziano & Litton, 2007).

6.3.2 Theoretical foundations

As a research method, Wang and Redwood-Jones (2001) claim Photo-voice is informed by three theoretical understandings: Freirean pedagogy, Feminism and Community-based Photography. Each of these theoretical approaches is informed by social constructionism. As Liberatory Education formed a deliberate methodological strategy for this research I pay particular attention in the following section to how Freirean methods were applied to the research. Feminism and Community-based Photography are also discussed, though in less detail. It is my purpose here to explain the methods I used, not the theories behind Caroline Wang’s research method.

Freirean pedagogy

It was Freire’s conviction that every person,

“no matter how ‘ignorant’ or submerged in the ‘culture of silence’ he or she may be, is capable of looking critically at the world in a dialogical encounter with others” (Richard Shaull in Freire, 1996, p. 14).

Given the proper tools and support, Freire (1996) claimed that anyone could gradually perceive his or her personal and social reality in addition to the contradictions in it. Applying an explicitly dialogical approach to the research the pedagogical strategy of conscientization is used. Problematisation (problem-posing) is a key process in conscientization.

Conscientization – This is the essence of Freirean pedagogy. Conscientization is an ongoing process by which a critical consciousness is aroused and people are moved to act to change the way things are. It begins with consciousness-raising, a term that has a distinct association with Marxist thought (Stromquist, 2002). Kenway and Modra (1992) note the difference between consciousness-raising and conscientization, and Hughes (1998) has noted that consciousness-raising is
looked upon as “the sad little sister of the more theorised conscientization” (p. 140). Nevertheless, consciousness-raising is the starting point. Through critically reflective dialogue people can begin to become aware of their situation in the world. They are encouraged to challenge their inherited beliefs, values and assumptions. Through interrogative, dialogic exploration, what Freire refers to as “critical curiosity” (1987, p. 5), people can achieve a deeper level of awareness of social realities which have shaped their lives (Mackie, 1980; Darder, 1995; Freire & Macedo, 1996). They become critically conscious.

Raising critical consciousness can, for example, lead people to become critically conscious that hunger is not merely the result of not eating food but may be the manifestation of political, economic and social inequity (Freire & Macedo, 1996). An example, from our research, of critical consciousness was seen when the group became aware of exclusive signage on the public transport system. Through critical dialogue which interrogated transport signage – where it was placed, the language it used or the size of the printing – our group was able to recognise that some signs were not intended for all commuters, but only those who could read. Such a critical consciousness provided an insight for the group to injustices in the world. It opened the way for historical discussions about why things are like this, who benefits and what action is required for change. Using conscientization people can reflect upon how they actively perpetuate inequalities and devise ways of redressing the situation.

It has been argued that people who are labelled disabled can internalise ableist values (Campbell, F. K., 2008a). Much like internalised racism (Jones, C. P., 2000), this can lead to self-loathing. Freire would view this as internalised oppression (Freire, 1996). Through conscientization people can come to critically understand the ideologies that oppress them, from within and without their own bodies, and also discover their own capacity to transform them in a process of recreation.

Problematisation - To problematise involves engaging a group in the task of codifying reality into symbols (McLaren, 1995). It incorporates visual imagery with discussion in a process Freire refers to as “codification” (Freire, 1985, p. 91). In Photo-voice this is done using photography. Concrete situations are reduced to photographic text, forming a discussion topic through which the group de-codifies
or analyses a photo. This process can generate critical consciousness by exposing unquestioned injustices, developing a theoretical context for the reason that they live this way. It can empower people to alter their relations with nature and oppressive social forces. Problematising is a logical task which allows all previously taken-for-granted notions regarding a problem to be questioned. Problematising occurs not only around the reality explored through dialogue but also around language used in the discussion.

Feminist theory

Feminist and Freirean pedagogies have much in common in their desire for social transformation and liberation from oppression. However, while Freire’s major concern was the oppression of people, his conscientization tools have been criticised for ignoring domination of women by men (Weiler, 1994). Moving on from Freire, feminist theory proposes that power accrues to those who have voice, who set language, make history and participate in decisions (Smith, D., 1987; hooks, 1989; Kramarae & Spender, 1992; hooks, 2000). It claims that a process of empowerment occurs when knowledge creation is moved out of the hands of the “institutionalized expert to women and other marginalized actors” (Naples, 2002, p. 13). People labelled with learning difficulties are such actors. Photo-voice tests these theories in practice bringing “new or seldom-heard ideas, images, conversations, and voices into the public forum” (Wang & Redwood-Jones, 2001, p. 561). In line with Feminism’s recognition of the importance of grounding theory in lived experience and of making plain the way the world is constituted through subjective experiences (Butler, 1988; Jones, A., 2003) and participatory methodologies (Campbell, M. L., et al., 1998), Photo-voice allows participants to tell their story as they see it, through the camera lens (Booth, T. & Booth, 2003).

Community-based photography

Community-based photography creates the opportunity for ordinary people to use the camera to discover how to relate to themselves and to others more positively through images of themselves. In turn, these images can be used for social change to counteract stereotypes usually seen in the mass media. (Spence, 1995; Wang & Redwood-Jones, 2001; Wang, Morrel-Samuels, Hutchison, Bell, &
6.3.3 Accessibility

The Photo-voice technique is particularly potent in assisting those who have difficulty articulating their thoughts (Woolrych, 2004). The camera enables participants to tell visual stories about themselves, creating opportunities of expression through images, words and reflections. In turn, these images become points of entry into unexplored areas of life (McIntyre, 2003). The control maintained by the participant over the images fortifies inclusive research against the tendency of primary researchers in participatory research projects to negotiate participants’ realities according to their own frames of reference (Manias & Street, 2001).

An easily adaptable tool, Photo-voice accommodates people from various backgrounds and skill levels and has been successfully used as an inclusive research tool by people labelled with learning difficulties (Booth, T. & Booth, 2003; Colchester Borough Council, 2007). Woolrych claims it is “particularly attractive to people who have difficulty with written and verbal communication” (2004, p. 31).

For those with limited literacy skills photography is a medium through which they can write without using words. Participants develop a visual text using the camera. Combining a visual text (photo) with group and individual discussions (voice) makes Photo-voice a more effective means of expression for people labelled with learning difficulties, rather than relying on speech alone. The visual text and the discussion text data are analysed together. In this way the Photo-voice technique assists in establishing different engagements from those accessed through traditional research (Radley, Hodgetts, & Cullen, 2005).

Photo-voice uses photography to gain access into areas of people’s lives that have previously been unexplored, hidden and inaccessible. The extent of the exploration is completely within the control of those who hold the camera. In this manner it goes some way towards fulfilling the emancipatory research ideals of the social model of disability.
6.3.4 Ethical considerations – the risk of risk-taking

This thesis opened with the poem The Dignity of Risk. It expressed life devoid of risk with restrictions that most people simply would not tolerate. However, this is not an uncommon experience for many people labelled with learning difficulties. One of the great attractions of Photo-voice for me was its promise of considerable freedom for the Photo-voice participants/co-researchers. Freedom opens opportunity for trust, respect and risk taking (Texas Centre for Disability Studies, 2010). This section is a brief discussion on my approach to risks during the research.

Every activity in life involves some measure of risk. It is generally accepted that “we all have the right to take risks in our lives, risk taking is a part of normal life” (Mental Welfare Commission for Scotland, 2006, p. 2). Paulo Freire (2004) speaks of the necessity of risk for those who would be a presence in the world. Rather than deny risk or avoid risk Freire claims risk must be prepared for and embraced, for “there is no human existence without risk” (2004, p. 5).

Coming from a human services background, I know that client freedom and the notion of respect are things that are often illusory or rhetorical. We talk of client freedom, respect and dignity of risk,(Department of Employment Education and Workplace Relations, 2009) but in reality, program targets and policy often constrain choices so that freedom is more an illusion created by the lip-service given to concepts such as dignity and respect, than a reality. I concur with those who claim that disability services’ discussions about risk often concern health and safety issues, with an unspoken assumption that service users are predisposed to gravitate towards danger (Texas Centre for Disability Studies, 2010).

I understood that in the research project there would be a need to maintain an appropriate balance between my ethical responsibility of duty of care to the Photo-voice project members and of providing an environment of trust where people were afforded the freedom and dignity to take risks. Of course, this raises the question of what is appropriate and who makes that decision? This was something that the Photo-voice team endeavoured to thrash out collaboratively on many occasions. One such incident concerning privacy and confidentiality is discussed below. However, throughout the project I was frequently challenged by
these questions and also sought advice from more experienced researchers within University of Western Sydney (UWS)\textsuperscript{34}. As Robin Morgan has suggested, “Transformation requires that we enter history on our own terms and audaciously place ourselves at the centre of it” (2001, p. 38). Convinced that the research group members had the right to self-determination I wanted to encourage them to be audacious. Reflecting on the comments of Shapiro (2001) given previously, I hoped that the research team would have an opportunity to live life on their own terms and, in a Freirean sense, claim their presence in the world. In this context beneficence was regularly weighed against risk, yet risk was also viewed as beneficial and a mark of humanity. The tension between providing dignity of risk (an important consideration in self-determination) and maintaining duty of care has been addressed below. Some of the strategies were planned independently by me in order to obtain ethics approval from UWS.

Risk minimisation strategies

Forewarned is forearmed. Freire (2004) links the preparedness to take risks with the agency of those who apprehend and name their surroundings – making sense of their world in order to transform it. This section looks at anticipated risks and strategies to avert or minimise them (Wang & Redwood-Jones, 2001). Also discussed is how some of these strategies were negotiated with the group in order to share the implementation responsibilities and devolve power with research group members.

Risk of coercion – Discussed further in section 7.3, this risk was overcome in the recruitment stage by providing self-selection opportunities free from undue influence of service providers or by me. Modelling our discussion group on Freire’s notion of dialogue, grounded in love, respect and collegiality, we explicitly aimed to reduce this risk by establishing ground rules to promote equality. A code of conduct (see 8.2.5) was drafted by the group to make clear behavioural expectations. Coercion was also avoided by reiterating on occasions the participants’ freedom to withdraw from the research at any stage.

Risk of participant acquiescence (saying what they think others want to hear) –

\textsuperscript{34} 10.2.2 discusses difficulties experienced when the research group encountered unexpected reprisals resulting from risk-taking.
This was something I sought to minimise with “consistency checks” (Ramcharan & Grant, 2001, p. 356) against other data and by rephrasing questions.

Risk of misrepresentation - This is important in Inclusive Research as the participants have traditionally been categorised and labelled by others. Photo-voice provides an opportunity to challenge labels and avoid or even address misrepresentation through self-representation. Through the self-advocacy movement Monroe has noted

“We have a lot of troubles with labels. Labels are for jars, not people...” (Monroe, quoted in Smith, P., 1999a, p. 130).

Misrepresentation of participants is a risk in qualitative research and I was aware that “people with learning difficulties have less power of redress than non-disabled people” (Stalker, 1998, p. 12). Photo-voice addressed this risk by putting people in charge of how they documented their own lives (Booth, T. & Booth, 2003). The photographer chooses which stories to tell. I recognised the responsibility I had as the IPAR facilitator to clearly identify whose voice was speaking (mine or the group’s) when documenting the research (Stalker, 1998).

When research participants are elevated to the position of co-researchers, with the authority to name their barriers, there is also the risk of misrepresentation of others outside the research team and of inadvertently causing embarrassment. This was an issue for considerable discussion (see 8.4.1 discussion on the Government barrier) after some co-researchers took photos of one thing (for example, an electoral campaign poster of a local State Member of Parliament (MP)) to symbolise something else. In that instance, a picture of the MP symbolised the Government. Discussion over the responsibility of the representation of others in our photos saw the group realise that hurt can occur unintentionally. Photos and their accompanying stories had the power to misrepresent, to mislead viewers and to confuse the message intended by the photo. Their order and display required deliberation and care.

Risk of participants’ misunderstanding concepts – This risk was minimised by using Photo-voice as a means of concretising abstract concepts into images (Booth, T. & Booth, 2003). Discussion around photos also provided an additional way to talk through concepts and assist those who were visual or auditory
learners. Seeking clarification from participants of what was being discussed or by rephrasing questions was another means of checking understandings (Ramcharan & Grant, 2001).

Risk to safety while photographing - This was addressed by providing training during a photographic workshop that specifically dealt with this issue (see 8.2.6).

Risk to anonymity due to identification through photos – It was thought that this may have been a concern for some participants. If this was so, I intended to recommend only the use of photos without identifiable links back to the participants. Booth and Booth (2003) have also suggested laying false trails where necessary, to disguise settings.

Risk to anonymity/privacy through the identification of names and incidents recorded in the research report, subsequent journal articles and the thesis – This issue was discussed at length by the research group. Each member chose their own pseudonym for use in this thesis, journal articles that have been drafted, conference presentations and our project website. As previously described, I further encoded participants where necessary to completely de-identified my colleagues when discussing sensitive information. However, it should be noted that in the funding application and report submitted to Break Thru People Solutions35 (Break Thru) (see 12.5.7 for further details) the group members self-determined to use their real names.

Risk of breaching the privacy of others while photographing – In order to avoid intentional and unintentional breaches of privacy a workshop in photography ethics (see 8.2.7) was conducted utilising the expertise of a trained photographer and an experienced Photo-voice practitioner. During the workshop a photographic participant consent form was composed by the research group in the language of the group members (Appendix 1). Everyone contributed to its composition and understood its purpose, content and usage.

Risk of distress – It was recognised that discussions, interviews, workshops or critical reflection may trigger emotional responses or cause distress to the co-researchers. These were anticipated and prepared for by compiling a Disability

35 A NSW and Australian government funded employment service.
Rights, Camera, Action!

Services resource booklet containing an extensive list of support services. All participants were given a copy of this document. The NSW Council for Intellectual Disability supported the research and their Project Officer, Amy McGowen, agreed to be a direct referral contact for participants requiring counselling so that their specific situation could be catered for. Furthermore, all co-researchers were asked to provide the name and contact details of someone who would be available in case of illness, accident or distress during the research process. These details were stored on my password-protected computer. It was important that co-researchers had a support person with whom they could speak about matters that may have arisen out of the study if they wished. Any research team members who became distressed was invited to withdraw from the discussion if they preferred or have the discussion suspended. All research group members were reminded of referral service details throughout the project and asked at various times if they wished to continue participating in the IPAR (See 10.2.2 Dealing with disclosure and 10.2.3 Opening wounds, for specific examples of how participant distress was dealt with).

Risk to my privacy – In order to preserve my own privacy, contact with the group was restricted to a project email account, a mobile phone number (purchased specifically for the research), and the UWS address. This protected me from unsolicited phone contact at home or via email. As one co-researcher frequently phoned numerous times a day, the mobile phone proved to be a good strategy for securing privacy as it could be turned off.

Risk of group members’ expectations of an extended friendship – Throughout the project the limited timeframe was reiterated. The group was aware that the project was expected to only last 8 months (from April 2007 – December 2007). In December 2007 there were still unresolved issues which we expected to be finalised by January 2008. We therefore agreed to meet in January 2008 and consolidate our findings and action results. At this meeting the research group decided to become a self-determined group rather than relying on me for organisation, and to remain functioning. My involvement was decreased throughout 2008 and 2009, although as of August 2010 I still provided a measure of support (discussed further in Chapter 12). Throughout the research project I endeavoured to make very clear my professional position as project facilitator and,
from 2008, support resource, in accordance with the 2007 National Statement on Ethical Conduct in Human Research guidelines (National Health and Medical Research Council, Australian Research Council, & Australian Vice-Chancellor’s Committee, 2007). When invited to socialise with group members, for example at birthday parties, these offers were politely declined with the reminder that when not undertaking the Photo-voice project I had family and other responsibilities to attend to. Nonetheless, over the past three years I have developed a close bond and a strong commitment with each of my colleagues to support them in their desire to set up their own group.

Other ethical issues

Ethical dilemmas of disclosure for the researcher – The principle of confidentiality came into conflict with wider moral and legal responsibilities during the project when a co-researcher disclosed ongoing incidents of sexual harassment and intimidation (discussed further in 10.2.2). Although the position that this research adopted was that confidentiality must be upheld, in cases where I perceived that a co-researcher was at risk of harm I sought advice from my supervisor. On one occasion, when concerned about my colleague returning home to an environment of ongoing harassment and intimidation, I sought advice from a senior research staff member within UWS. Another incident occurred when I was contacted by a co-researcher’s parent (who resided 200km away) requesting my assistance as my colleague was home alone and threatening suicide. On this occasion, after contacting my colleague to check on his safety, I notified the Government agency under whose care he lived, warning them of this incident and urging immediate attention. I also contacted my supervisor to advise of this incident and check that I had done everything required to fulfil my duty of care to the research colleague.

Incidents like these could not have been foreseen because specific social barriers were unknown prior to the commencement of the project. However, they did arise – in part from the general risk that research “may lead to unfair discrimination or have effects on social cohesion” (National Health and Medical Research Council, et al., 2007, p. 16). Empowering the research group to speak out with their photo-voices disrupted an already dysfunctional environment. Doing so led to unanticipated discriminatory recriminations for one of my research colleagues. Upon reflection, however, silence was not an option. As a result of the research
actions, the benefit to the colleague and the social community from which he came outweighed the harm generated by the recriminations – in my judgment at least, based on comments made by both the colleague and his family (see 12.8 for example).

Ethical issues in advocacy - The Photo-voice exhibition presented its concerns over a range of issues to community leaders, service providers, academics and Governmental policy makers. These were people of influence with the power to bring about change. Meredith Minkler (1978) and Julia Ballerini (1997) raised ethical concerns regarding bringing up issues with policy makers arguing that it reinforces the status quo rather than challenges power structures or shifts power from one group to another. Our purpose, at that stage of the project, was to bring our issues before those who had the ability to instigate social change. This action challenged the power of those in authority to voice how things are in society, to name the world on behalf of others. It challenged the elected representatives to hear the people’s call for change and to respond. It also challenged stereotypes of people labelled with learning difficulties by demonstrating crucial skills of social awareness, citizenship and activism. Furthermore, it raised the awareness of the public to issues that were of concern to the Photo-voice group members. In doing so the Photo-voice group became self-advocates in their own lives and in their community (Wang & Redwood-Jones, 2001).

The ethics of not paying someone to do research – It has been proposed that if people labelled with learning difficulties are to be researchers then they should be financially reimbursed for their efforts (Williams, V., 1999). However, Walmsley & Johnson (2003) have noted that there is rarely sufficient financial resources in Inclusive Research to do this and also that payment to participants can negatively affect disability pension payments. As a student researcher with limited research funding financial remuneration was not possible. The voluntarily (unpaid) aspect of the research was therefore an issue discussed at the project information session. Interestingly, not only was the voluntary nature of the project not an issue, but the group appreciated being able to participate in the project for free. Several participants inquired about registration costs, assuming that the use of tools and gaining of skills would come at some financial expense. Comments such as “Free? Cool!” (Kathy, 23/5/07) demonstrated that they were pleased to
hear that there was no charge.

The length of the project was discussed, initially seeking a commitment of six to eight months from participants. However, in January 2008, nine months after starting the project, the group decided to become self-directed, envisaging that the project would continue for at least another 14 months, and committed to this with no expectation of remuneration.

UWS Human Research Ethics Committee approval for this study was granted.

6.5 Metaphor

In this section I discuss another research method that the research project incorporated with its use of Photo-voice, the tool of metaphor.

Photo-voice can also incorporate the adult educational method of metaphor as a means of assisting adult learners to express themselves. Adult educators utilise metaphor’s powerful ability to illuminate the subject. This enables us to imagine and better understand the experience of others (Goss, 2001). Metaphors have been used as a means by which learners can name aspects of their world and
thus, they represent “an act of power” (Deshler, 1990, p. 311). Building on Freirean concepts, researchers (Deshler, 1990; Cooper, 1991) have used metaphor as a reflective tool assisting learners to examine themselves and to “recognize major unexamined influences over their lives” (Deshler, 1990, p. 296).

Coming to the project with my own stereotypes regarding prospective participants, I oscillated between whether or not metaphor would be too abstract for the group or if it would complement the naming power of Photo-voice. Metaphors are praised for their accessibility as they are grounded in the familiar and for some learners can “facilitate rapid comprehension” (Union of International Associations, 1995). I was encouraged that metaphor had been successfully used as a teaching tool for adults with “diagnosed learning disabilities, including language-based learning disabilities, non-verbal learning disabilities and attention deficits” (Goss, 2001, p. 8).

Metaphor was a tool some group members embraced36. William’s photo, shown in Figure 2, was adopted by our group to represent all social barriers and advertise our Photo-voice exhibition.

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36 The group, to be introduced more formally in Chapter 8, would eventually consist of five people aged 18 to 24. In this thesis they have taken the pseudonyms Bart, William, Andrew, James and Anne, the first three of these being further encoded as Alex, Brendan and Chris as necessary.
Metaphor permits people to express ideas not fully understood yet grasped intuitively or on a gut level (Goss, 2001). Reflective deconstruction of metaphors through discussion can provide new perspectives on the experience. I reckoned if metaphor had been used to assist adults with learning disabilities to express ideas and feelings, then perhaps photography could be used to more fully articulate the intent of the metaphor.

Very early in the Photo-voice project my apprehensions regarding the use of metaphors were allayed and my stereotypes radically dismantled as the group raised all manner of simile and metaphorical suggestions for social barriers.

“We could take a photo of the grass. It is like the pathway we are on in life. And it is growing where there could be a tree instead” (William, 31/5/07).

Discussion around this graphic image revealed that the pathway represented limited options for people labelled with learning difficulties. William referred to grass and a lack of trees (because they had been cut down) as symbolising a cutting down of opportunities, leaving a path made by others, a pre-determined future. This poetic and complex thought from a young man educated through the special school system surprised me. It challenged my preconceived ideas about the research group members and exposed my own disablist assumptions.

The social barriers limiting self-determination are all those things that get in a person’s way, like the trolley, hampering their development. Figure 3, also taken by William, represents what he believes we, as seedlings, can become if social barriers are removed.
The ability to use metaphor encouraged me to adapt other research methods, including institutional ethnography, so that it would be more accessible. In the following section I discuss how Photo-voice was incorporated into institutional ethnography.

### 6.6 Accessible institutional ethnography

#### 6.6.1 Overview

Institutional ethnography is a particular way of looking at things and is distinctive in what it looks for (Campbell, M. L. & Gregor, 2004). It has been successfully used to explore the disjuncture between human services’ rhetoric of empowerment and client-centred service delivery and what actually happens in practice (Cohn & Lyons, 2003; Townsend, Langille, & Ripley, 2003). It is well suited to research into the human services because of the enormous power held by professionals and institutions to control people’s lives (Bogdan, R. C. & Biklen, 2007). It is however, a highly complex research strategy and this characteristic could make it inaccessible to people who have difficulty grasping abstract concepts.
Institutional ethnography is grounded on the assumption that we live in a textually-mediated world (Smith, D., 1987). Campbell and Gregor have noted that texts form part of the “ubiquitous feature of social organization and they are accessible to research” (2004, p. 29). However, it was precisely the inaccessibility of printed text and text-based technology that was identified as a social barrier for non-readers by the research group. Therefore, if I was to utilise the benefits of institutional ethnography’s systematic and innovative approach to research then its explication strategies needed to be adapted to the skill level of the group in order for it to be accessible to them.

Institutional ethnography has been successfully used in Participatory Action Research undertaken with people described broadly as having impairments (Campbell, M. L., et al., 1998), but I am so far unaware of any institutional ethnography research undertaken collaboratively with people labelled as having learning difficulties. Dorothy Smith’s (1990) theory of social organisation played a key role in the investigation of the social barrier of Public Transport (discussed further in 9.3.2). Using institutional ethnography we explored the research team’s positions as actors and knowers, and non-readers, in a text-mediated world. In order to investigate the social organisation of public transport the group needed to gain an understanding of not only how they interacted face-to-face with the barrier in their daily lives but also how they unconsciously interacted with the barrier trans-locally, that is, outside the experience of their daily lives. This moved the research into the field of the abstract. Photography was therefore utilised as a means by which the potentially exclusive written text and abstract concepts were transformed into concrete subjects (visual texts) of analytical dialogues.

6.6.2 Institutional ethnography textual analysis

Instead of reading printed texts, institutional ethnography strategies were applied by the research group to photos taken of printed text (such as signs) in order to analyse the visual text created. Using Lois Andre-Bechley’s (2007) strategy for explicating power structures and meaning behind institutional text, the group conducted textual analyses considering the following points:

- The design: size of signage, size and type of font used, colour of printing and background, layout, density of information. Was it eye catching and
attractive? Was there too much information?

- The intended readership: was it for staff or commuters? Was it meant to be read at all?
- The author: Local railway staff, Department of Transport, federal police?
- The initiator: Who ordered the text? Health Department? Federal police? Legal advisors?
- The purpose: propaganda, public safety, compliance obligation, helpful public information, recruiting informants, sharing (or devolving) the responsibility of national security with the public.
- The placement: conspicuous, unobtrusive, hidden, overshadowed by other signs.

Through critical discussions and probing questions the group was able to think about and discover the trans-local interactions that they unconsciously engaged with. This had a consciousness-raising effect and generated a greater awareness within the group of the complex social web within which we live. Through adapting Photo-voice to institutional ethnography techniques this group gained a deeper understanding of social organisation.

I also, individually, utilised institutional ethnography in order to make sense of the everyday experiences of my co-researchers. Conducting textual analyses on correspondence received from a Government Department laid bare the meaning behind institutional text and help to expose unspoken power structures (see 10.4.4 for a textual analysis of the reply to our complaint).

### 6.7 Other data collection methods

A number of different methods of data collection were utilised in addition to photography. This section discusses how meeting minutes, transcripts, field notes and journaling were used throughout the research to record events, thoughts and feelings, and also as a tool for reflexive, critical analysis.

#### 6.7.1 Minutes

Meeting minutes matter. They provide an official record of the meeting, noting who attended, time, place, topics discussed, decisions made and action items
allocated. Before most Photo-voice sessions I prepared a brief and very flexible agenda, which was emailed to all group members with email access so that they might know what was planned and to allow them to think of other topics for inclusion on the agenda. (Chris, Brendan and Anne had internet access and literacy skills sufficient to read the agenda.)

It was my plan that minutes would be taken during all Photo-voice meetings by one of my co-researchers. However, this did not occur. I was often without administrative support throughout the project and as most members lacked the literacy skills to take minutes, frequently my very rough notes jotted down throughout the meeting served as minutes which were written up in further detail afterwards.

Minutes were emailed to the Photo-voice participants, and also to Alex’s parents as Alex did not have internet access in his Group Home. Although Alex was unable to read the minutes he had asked me to email them to both his mother and father so that they could read them to him when he visited them on weekends. A copy of all minutes was also sent to my supervisor and other interested parties as required.

6.7.2 Transcripts

Generally the meetings of the Photo-voice group were recorded, with permission of all those in attendance, on a data recorder. On occasions I forgot to bring the data recorder to Photo-voice. Interestingly, these occasions appeared to cause considerable amusement to Andrew and built rapport between us. On the first occasion I forgot the recorder Andrew said “Oh Janice! You’d forget your head if it wasn’t screwed on” (Journal, 27/6/07). Thereafter he would often greet me at the start of our Photo-voice session with “Don’t tell me you’ve forgot the recorder again!” (Journal 24/10/07). And if I had, (or perhaps I’d forgotten to clear the recorder after downloading and it was unable to record, or batteries failed) Andrew would joke with me “Oh, you’re hopeless, Janice!” (Journal, 25/7/07). Such gaffes serendipitously served to establish a reciprocity and symmetry of relations, required for Participatory Action Research. They appeared to demystify and endear me to the group, (McTaggart, 1991). However, most often, the meetings were recorded. Information was later downloaded onto my computer and
transcribed. The auditory recording supplemented the transcribed data by reproducing the sound of the meetings, the giggles and mumbles, the tones of voice, the atmosphere that is lost once conversation is transcribed.

Several days after our meetings I would often listen to the taped recordings. Listening to the event at a later stage can alert the listener to details previously over-looked, such as who wasn’t talking, what topic dominated or how people reacted to certain subjects. It allowed me to reflexively gain a fresh perspective from the original experience of being in the mix of things as they happened.

As the group met together weekly, for several hours, over many months, the task of transcribing became very time consuming. I eventually stopped routinely transcribing the meetings. The recordings were saved chronologically, Statements that I thought were significant, because they confirmed or contradicted other data gathered, or they emphasised a point, were noted as quotes in my Journal for future reference. For example, after an hour-long recorded discussion with Heather37 (Alex’s mother) I noted several quotes in my Journal to alert me to the subject matter of that conversation at a later date. One such quote was

“I think meeting with [the Group Home Manager] is a really excellent idea ’cause Alex needs to understand why the rules are in place” (Heather, 24/9/07).

I was able to return to the correct recording to collect additional data or cross reference information. The data recorder was also used (with permission) to tape phone conversations. Significant conversations were also transcribed. One example of a conversation I regarded as significant was my discussion with Peter McGee, solicitor and legal advisor with the Intellectual Disability Rights Service. I was seeking legal advice on behalf of the group and did not want to forget anything that Peter told me. So, with his permission I taped the conversation and transcribed it also. I found that this was an effective way of reinforcing my memory of the discussion.

6.7.3 Field notes and journaling

Writing field notes and keeping a PhD journal were additional methods used. I commenced my Journal in 2006 in order to secure a record of my feelings and

37 The first use of pseudonyms other than those of the research team is indicated by bold type.
thoughts on events that had occurred and issues that arose. I found, as Sweet (1998) has noted, that it was an excellent means of critical reflection. Utilising journals as an additional way of recording data is a means of capturing the detail of what has occurred in the field with the lights on, off or filtered, metaphorically speaking. It provides a means by which researchers can look at an incident from a variety of angles. One perspective alone (such as meeting minutes), might present a situation over-shadowed by other influences (for example, the meeting minutes might unintentionally present an officious tone and a view of the proceedings from the top down, simply because of the manner in which they were recorded). Rich ethnographic descriptions of participant interactions with each other, recorded in field notes, can vividly expose a particular situation omitted from minutes. Utilising a number of information recording methods was a way of shedding new light on data and viewing it from different perspectives.

I particularly found journaling my reflections on what I had listened to of the recorded meeting beneficial. It provided me with a triple-loop learning experience\textsuperscript{38} - I had been submerged in the original meeting and distilled the experienced into written minutes. I then listened again to the proceedings after a few days (to provide a distance from which I could reflect upon the data). By journaling my thoughts on what I understood to be happening I was able to view the event from a different perspective (the third loop) and see things not evident before.

The Journal sometimes just took the form of field notes that explained what happened on the day, for example

\begin{quote}
“I presented before the Nepean Disability Forum today before a group of twenty service providers. A DEN\textsuperscript{39} employment consultant from Nova, Penrith, was very keen for me to address her Jobclub next Thursday…” (Journal, 5/5/07).
\end{quote}

Frequently the journal notes would take the form of a draft letter to my supervisor seeking advice or raising an idea for exploration. It provided yet another stance from which to examine a situation. I wrote not as the group facilitator, researcher or meeting minute taker but as a student speaking to a mentor and listening for

\textsuperscript{38} The adult educational principle of double-loop learning requires doing then critical reflection and revision (Schön, 1983).

\textsuperscript{39} DEN - Disability Employment Network refers to federally funded disability employment assistance services.
their thoughts in reply. Sometimes the “Dear Debbie” journal entries were actually sent and initiated a dialogue that exchanged information and ideas. But more often they were drafts which became deeply personal, too personal to share. But research is personal, and if it is to be transformative then researchers must find the means by which to safely, honestly and reflectively challenge their inner self (Cohn & Lyons, 2003). Journaling provided a safe place in which to lay out uncertainties, exposing my fears, confusions, theoretical and philosophical struggles and contradictions to scrutiny.

I also wrote poetry in my Journal as a creative means of “pushing at the edge” (Higgs, Titchen, Horsfall, & Armstrong, 2007, p. 295) of what I knew that I knew in order to reach the unconscious knowledge that I didn’t yet know I knew. Poetry is an organic research method that lets thoughts and feelings flow without conforming to the grammatical discipline of academic writing. The following example (discussed in further detail in 10.4.8) speaks of the difficulties I felt dealing with the highs and lows of IPAR.

Riding the Research Rapids
I’m flowing with the current happily,
sometimes even skimming across the top of the water very cleverly,
then I’m dumped by a wave.
I spend the next two weeks struggling to the surface again,
where the pressure is off and I can catch my breath.
Then, I’m being dumped again.
At the moment I’m riding the research rapids
With white knuckles in white water,
But I’m holding on.

(Journal, 20/8/07)

6.8 Analysis methods

6.8.1 The Convention as an analytical framework

The Convention was employed as an analytical tool for consciousness-raising discussions. By referring to the Convention the research team was able to judge whether or not perceived barriers breached human rights. The seriousness of one
situation, which had been minimised and dismissed by a disability service provider, was illuminated by the Convention. The research team identified service practice which breached internationally recognised human rights and declared it unacceptable. While the whole of the Convention was relevant, the Convention Articles below were particularly significant and formed the foundation upon which the research team took social action.

The Convention’s Preamble clearly articulates the right to self-determination, choice, decision-making and independence (United Nations, 2006, Preamble, n & o). Furthermore, the importance of access to the physical, social, economic and cultural environment, in addition to health and education as well as to information and communication, is stressed as necessary “in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms” (United Nations, 2006, Preamble, v).

The Preamble also recognises, as laid out in the International Bill of Rights, the responsibility of everyone (including the research group members) to promote human rights within their communities” (United Nations, 2006, Preamble, w).

The Convention’s General Principles reinforce the right to inherent dignity and autonomy (Article 3). It also reminded the team that awareness-raising and fostering respect for rights and dignity is everyone’s responsibility (Article 8.1a) as is combating stereotypes, prejudices and disablist practices (Article 8.1b) and promoting the capabilities and contributions of people with “disabilities” (Article 8 1c) (understood here to include those labelled with learning difficulties).

The group’s active dissemination of its research findings (explained further in Chapter 12) was a means of participating in the generation of “public awareness” (Article 8.2a). It nurtured a “receptiveness to the rights of persons with disabilities” (Article 8.2a i) and promoted “positive perceptions” of people with impairments (Article 8.2a ii) by recognising their skills, merits and abilities (Article 8.2.a iii).

Article 9 - Accessibility was another key point in the Convention applied in our analysis. The right “to live independently and participate fully in all aspects of life” reinforced to the group the responsibility of Governments, as well as themselves as citizens, “to ensure to persons with disabilities access, on an equal basis with
others, to the physical environment”. This includes access to transportation, information, and to other facilities and services provided to the public, including “the identification and elimination of obstacles and barriers to accessibility” (Article 9.1).

Identifying and informing authorities of such barriers was a means of active citizenship and of being part of the community (Article 19). The Convention highlighted the right to personal mobility (Article 20), respect for privacy and freedom from attacks upon their honour and reputation plus their right to protection from such attacks (Article 22). This was a significant issue (discussed further in Chapter 10).

Using the Convention as a tool for analysis added rigour as it was a means of assessing group perceptions against internationally recognised human rights instruments and provided a sound argument upon which the research team could base their rights claims.

6.8.2 Patchwork analysis

Patchwork analysis was a creative analytical tool I initially developed for myself in order gain an understanding of the degree of collaboration that had occurred during the social action stage (Stage 3) of the research project. It proved to be an accessible means by which the research group could quantitatively assess the collaborative nature of the research.

I employed the art of patchwork as a hermeneutic analytical tool with the intention of communicating with the collaborative spirit of the research and to visually analyse the extent of the IPAR collaboration. The patchwork-article created symbolised a research report, symbolically representing actions and events in colour coded fabric. How and why the patchwork process was undertaken is more fully explained in Chapter 11. It is positioned in the thesis after the completion of Stage 3 of the research (Chapter 10) as it speaks of an analysis of the research process.

The patchwork analysis was a successful method for rendering the abstract accessible to my colleagues. It enabled them to determine for themselves the degree of collaboration that had occurred during Stage 3.
6.9 Conclusion

Undertaking IPAR with collaborators who have the label of learning difficulties and are non-literate, is challenging. Many of the concepts are complex and traditional methods can be exclusive. IPAR requires accessible research methods. This chapter has provided an overview of the research tools metaphorically kept in the Photo-voice project camera bag. Some of these tools were for everyone to use while others were to facilitate my own critical reflection and research analysis. Photo-voice, as a creative, inclusive and flexible research tool was described. The theoretical foundations, practicalities and accessibility merits of Photo-voice have been explained along with its potential for building self-determination skills in the participants. Its adaptability to other research methods, such as metaphor and institutional ethnography, was discussed. There are ethical considerations that require attention when utilising such methods with a vulnerable people group. However, strategies are available which enable researchers to minimise risks.

While photography was a creative means by which to explore the world and analyse data, creative writing, journaling, minute taking and field notes were also methods used to illuminate barriers and research issues for consideration. A variety of writing techniques broadened the research vista.

Finally, it is important in IPAR projects to reflexively review the processes undertaken in order to assess how collaborative they actually were. Patchwork proved to be an accessible tool that communicated to all of us the extent to which the IPAR achieved its collaborative goal.

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In the following chapter I introduce you to the final preparations undertaken before the Photo-voice project could commence. It is entitled Loading the Film, in readiness for things to come.
Chapter 7 – Loading the Film: project preparation

“Be Prepared.”

Lord Robert Baden Powell (1857-1941)

7.1 Introduction

With the camera bag packed and ethics approval obtained the Photo-voice research project was ready to roll. The project would involve recruiting people aged over 18 labelled with learning difficulties to explore barriers to their self-determination by use of photography, initially over an eight month period. This chapter, called Loading the film, looks at the final preparation stages. It considers the personal training, participant selection criteria, promotional strategies and the recruitment of participants and assistants.

7.2 Gaining Photo-voice skills

In this section I consider the preparatory training and practical experience using Photo-voice I gained prior to commencing the research project.

In April 2006 I undertook a course in Photo-voice at the University of Technology, Sydney (UTS), in readiness for my PhD project. This introduced me to Photo-voice theory and practice. I learnt about the practicalities of the technique as well ethical implications associated with photography (National Health and Medical Research Council, et al., 2007). It was an opportunity to meet other Photo-voice practitioners, see samples of their work, hear how they had tried to use Photo-voice as a tool for social change, and to begin to establish my network of contacts. Interestingly, one practitioner (Tony Webb) told me that, in his experience, despite the enormous potential for social change, Photo-voice projects rarely progress past the exhibition stage (Field notes, 15/5/06). In his opinion, one of the major flaws of Photo-voice was that many people view the exhibition of the work as the ultimate goal. It is here where they present their photo-voices and yet they leave their articulated social issue for others to fix. Another Photo-voice practitioner (Gillian “Gill” Oxley) suggested that the build up to and effort involved in staging the exhibition drained the enthusiasm of participants. Some could just not face the
energy required for planning and implementing social action (Field notes, 15/5/06). This was valuable feedback that assisted my planning.

Following formal training at UTS I participated in a number of Photo-voice projects. The first project I joined, in a support capacity, was run by a disability advocacy service. Disappointingly, there was no social action goal for this project and it was viewed simply as an interesting recreational activity that would occur over a set time period. Participants had minimal input into the project. I noted that an IPAR Photo-voice project should allow group members to claim authority over decision making and be actively involved in program planning, setting the meeting agendas and goals.

In August 2006 I participated in another Photo-voice project suggested by a local Council as a medium through which a social problem of increased racial tensions resulting in violence, vandalism and social schisms, could be creatively and constructively addressed (Field notes, 18/8/06). The potential was certainly there, but much to the facilitator’s and my dismay, it became clear on the first day of the ten week project that the aim was to create a harmonious impression of the local area through the project photos rather than address the social issue of racism and violence.

My training in the underlying theories of Photo-voice and opportunities to participate as an assistant in two Photo-voice projects prior to starting my own research was very beneficial. I established a strong relationship with Gill Oxley, the Council Photo-voice Project facilitator, and was later able to recruit her support. Participation also gave me hands-on experience of what does and does not work in project facilitation. My position as an outsider observing the organisation of the projects alerted me to unquestioned practices that oppressed rather than facilitated self-determination. This also afforded me opportunity to consider participant issues from a different perspective and informed my UWS Human Research Ethics Committee application.

7.3 Research team selection criteria

The following section outlines the Photo-voice project research team selection criteria.
Local adults labelled as disabled

My research interest was specifically in accessing the views of people labelled with learning difficulties. Therefore, I established specific criteria for participants for my UWS Human Research Ethics Committee proposal. Participants were to be people labelled with mild to moderate learning difficulties, aged over 18yrs, from Western Sydney. They were to be eligible to receive support from disability services for people with mild to moderate learning difficulties as their primary impairment.

A person’s eligibility to such disability services was a means of confirming they met my selection criteria. This followed the example of Riddell, Wilson and Barton (2001) by avoiding a clinical definition of learning difficulties and instead adopted an “operational definition” (p. 5). It was not the purpose of my research to measure cognitive functioning or comment on who did or did not fit which label. In fact, I was uncomfortable using a label at all. However, in order to receive support services this specifically and socially labelled group of people do wear the label of learning difficulties. This label provides access to income and support as well as isolating and stigmatising them as other. They are treated differently because of the label (Goffman, 1963) and I was interested in what social barriers they thought existed that prevented them from being self-determined. If I wasn’t doing the impairment assessment then I would need to recruit people from services which already had. It was also my intention that the research process would facilitate opportunities to exercise self-determination and so I wanted the participants to self-select (as a deliberate, self-determined act) to take part in the project. They therefore had to self-identify as having mild-moderate learning difficulties.

I was not interested in levels of so-called impairment, so the selection criteria was not needs-based. Selection for the project was on a first-in-first-served basis.

Independent travellers with their own supports

The selection criteria also stipulated that people be able to travel to and from the project independently. I did not have the resources to offer taxi fares or to transport participants myself. If participants had secondary impairments (such as physical or sensory impairments) I had planned to provide support according to the expressed need of the participant, in order to assist them to participate in the
research. Participants needed to be able to communicate in English or have an interpreter. They also needed to have a support network of trusted people who could be contacted during or after a meeting if required. This was in addition to any counselling or support service that I might recommend.

Independent decision-makers

In contrast to traditional self-determination research methods, I did not seek referral of participants from disability services. A self-selection recruitment strategy was planned. Participants would not have a guardian and would be sufficiently competent to independently choose whether or not they were interested in the project topic and wanted to participate (National Health and Medical Research Council, et al., 2007). For the purpose of building self-determination I wanted independent decision makers who did not rely on a guardian.

7.4 Promoting the Photo-voice project

A number of marketing strategies to reach my target population were undertaken. These included preparing an extensive list of local disability contacts so that I could target the widest and most appropriate audience and send out emails (with promotional flyers attached) to those on the list. Brightly coloured flyers using a camera motif as well as a two-sided brochure were developed. These were distributed via email to 31 Disability Employment Network programs, 23 Transition-To-Work programs, disability service providers (including Disability Services Australia and Nepean Area Disabilities Organisation (NADO)), disability support teachers (at Western Sydney Institute of TAFE, Northwest Disability and the Thorndale Foundation) and three disability interagency forums, for distribution to their networks.

Emails were followed up a week later by a phone call to local disability services, TAFE teachers and forum coordinators in an effort to secure permission and book appointments to address their consumers, students and forum members. I believed that an opportunity to promote the project face to face with potential participants would be the most successful recruiting strategy.

My first presentation was to the Hawkesbury Disability forum. This organisation
had supported my initial university application to conduct the research and had been very encouraging. Grounded in human rights and the rhetoric of client empowerment my project spiel was passionate. I was convinced that my creative and emancipatory project would be a wonderful opportunity for those involved. I anticipated that the Forum members would flock to collect my promotional flyers and take them back to their various organisations. So, full of enthusiasm and optimistic (albeit naive) confidence, I stood before a group with representatives from twenty or so disability service providers, and shared my vision.

My Journal of 5/5/07 notes that they listened politely to my presentation. Several people asked a few appropriate questions. Their response, however, was rather underwhelming. They were not as enthralled by the project as I had anticipated. As I gave up the floor to the next speaker and returned to my seat it seemed to me that my audience had not got it. As my sweaty palms began to dry I wondered how many people would distribute the promotional flyers and brochures that I had handed out. Would they even tell their clients about the Photo-voice project? I was relieved and encouraged when a DEN worker spoke to me afterwards. She was excited by the idea of the project. Recently graduated with a degree in social ecology she had loved my “deconstruction of the concept of disability” and said she shared my vision for client empowerment. I was invited to speak to her service users the following Thursday at Jobclub (a prevocational training session).

I was encouraged by her response but concerned that my deconstruction of disability (which was an explanation of the social model) might not have been well received by others. Was it too academic? Had I become so familiar with this subject (which, in my experience, is still largely unknown in NSW disability services industry) that I had assumed too much of my audience? I had endeavoured to demystify the research by speaking in layman terms but perhaps the concepts had been too unusual and therefore inaccessible, even to service providers. It had been my first promotional presentation but a good lesson was learned. I decided to keep things much simpler next time.

Over a period of three weeks I promoted the project to disability recreational groups (such as Nepean Area Disability Organisation and Tuesday Night Club), Self Advocacy Sydney, the special educational unit at the Nepean College of TAFE, DEN services across Western Sydney and Transition To Work disability
programs, in addition to disability forums (for example Blue Mountains and Nepean Disability Forums). I also spoke with disability workers within Blacktown and Penrith Councils, the NSW Council for Intellectual Disability and People with Disabilities NSW. I posted flyers in local libraries and community centres in the Western Sydney and lower Blue Mountains area.

**Information session**

The culmination of the recruitment strategy was a public information session held at the proposed project venue in May 2007. It was attended by twelve disability service users aged 18-24 years old from across Western Sydney. It was from this group of people that the Photo-voice project was formed. The following describes what happened at the information session and how the group developed.

In preparation for the information session a Photo-voice display was borrowed from the Huntington’s Disease Carers’ Association. They had previously conducted their own Photo-voice project in 2006 and were happy to share their exhibit with me in order for others to see what the Photo-voice end-product might look like. The exhibit was displayed around the room for people to browse and read the captions. Everyone was asked to choose their favourite photo from the display and discuss why they chose it. I gave a presentation on Photo-voice, using overhead slides to explain the aims and purpose of the project, but the group appeared uninterested in the overhead presentation. However, they readily engaged in discussion about the Huntington’s Disease Carers’ Association display and were keen to discuss the photos displayed around the room. They also enthusiastically spoke out about social barriers to self-determination. They did not use the term self-determination but rather, discussed “having control of your life and doing things your way” (Kathy, 23/5/07). The group was also very keen to talk about how the project would work.

I was encouraged that many of those interested in registering for the project seemed to have a good understanding of social barriers and were eager for action. Examples of social barriers raised by the information session audience included:

“You get picked on at school because you’re different. It’s like racism” (Kathy, 23/5/07).

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40 A short-term Photo-voice group member.
“We got called spuds at school" (Bart, 23/5/07).

“Sometimes I have control of my money, sometimes I don’t. It is controlled by Mum and the carers” (Alex, 23/5/07).

“It’s a barrier that I have to go to bed at 8:30pm. That’s my bedtime, 8:30, but I’m 19 years old” (William, 23/5/07).

“I’d like to watch Law & Order but I can’t” (William, 23/5/07).

7.5 Recruiting helpers

Following the example of Wang and Redwood-Jones (2001) I sought the voluntary support of a local photographer to assist me with the first stage of the project. To secure the assistance of a photographer I contacted a number of local photography groups, professional photographers, the Visual Arts Department of the UWS and the Photography Department at the local TAFE. As a result, I secured the assistance of Alice, a delightful young woman in her final semester at TAFE and a professional photographer.

I was thrilled that Alice, just 21 years old, was able to speak to the group as someone their own age. Since the 1980s, disability literature has promoted the interaction of youth with diverse abilities (Bricker, 1978; Gaylord-Ross, Haring, Breen, & Pitts-Conway, 1984). Young people with impairments frequently do not like being supported by others who are not close to their age (Youth Disability Advocacy Service, 2008). In my Journal I recorded that

“I am very pleased to have these young helpers. It establishes the project as a more 'normal' activity rather than a ‘disability activity’, because the participants are engaging with peers who do not have a learning difficulty (generally these guys attend recreational groups with peers who all have LD). They tend to only deal with adults without LD” (Journal, 24/5/07).

The support of a trained photographer was intended not only to off-set the workload for me and provide a different voice to the project, but also to add a level
of expertise and quality. I had some Photo-voice experience but I am not a skilled photographer. I felt it would add credibility to the project and demonstrated respect to my co-researchers to provide them with a trained photographer. In reality, the photographic skills required to facilitate a Photo-voice project are minimal. However, that was not the point. I was inviting people to participate in a photography-based research project and I thought that it would be best practice to provide initial training and technical assistance from a professional photographer. This strategy was commended by Professor Geert Van Hove, Ghent University, Belgium (Correspondence, 7/2/08).

Wang and Redwood-Jones (2001) used professional photographic support. However, unlike those photographers, who also took an artistic role of encouraging the participants by “pointing out strengths and subtleties of their images” (p. 562) I considered this form of encouragement might be patronising. I believed that the group could critique and commend their own work. Peer-review or “Social persuasion” (Powers, Wilson, et al., 1996, p. 261) from a credible source is commended in self-determination literature as just as valid and as encouraging as that of a professional. Furthermore, peer-review provided another opportunity for choice, critical thought and making judgments that were not overly influenced by the thoughts of those in positions of power. The task of the professional photographer in my project was to share her skills through basic technical instruction, facilitating discussion on photographic ethics and advice on how to keep safe while photographing. She also displayed samples of her work to inspire the group. Alice only attended our meetings once, during the initial session.

Gill, was another helper I recruited to assist with the project. Gill was an experienced Photo-voice practitioner with whom I had previously worked. Gill generously offered her support whenever she was available.

As a result of an advertising flyer in the Windsor Library another young woman,
Alison, also offered to be of assistance, when she was available. Alison also had Photo-voice experience and although both helpers were unable to commit to every session, it was good to have a small number of support people if needed. Unfortunately, Alison was only able to assist the group for a short period due to work commitments.

7.6 Planning for attrition

The numbers needed for the project to be successful was a matter for consideration. The local Council Photo-voice project with which I had previously assisted had had a greater than one-to-one worker to participant ratio. This seemed unnecessary high. I did not want disability service providers to be involved in the research project. I wanted to create a safe environment in which the members were free to complain and criticise service providers if they wanted to. I believed that the group might feel constrained if there were disability service workers present in the team. I also wanted to encourage collaboration so that group members might support one another rather than relying on “support workers” for assistance. So, while I had no idea how many helpers I would be able to recruit, I planned for a 1:4 ratio of support workers to participants, based on my employment experience of group work within the disability employment assistance industry. Having worked with groups considerably larger than this, I expected that this number would be quite manageable. I planned for 50% attrition, based on Baker and Wang’s (2006) research which ended up with 13 out of 27 participants completing the project. My goal was to recruit an initial group of 15 participants, which may eventually contract to a group of eight. For this size group I would need one additional support worker. Reflecting upon the research I can now see that I would have been unable to manage a group of eight, let alone 15 members. My group of five (which was often only three members) was a challenge as we negotiated relationships as a group and endeavoured to develop communication competence. In addition, the personal issues raised were at times so distressing and demanding and my resources so lean that a group with any more participants would have been quite unworkable and possibly destructive to the aims of the project.
7.7 Conclusion

This chapter has provided insight into the preparations undertaken for the research project. I have considered my Photo-voice training and experience along with the selection criteria established for the project participants. How the project was marketed and helpers recruited were discussed. Based on the experience of others (Baker, T. & Wang, 2006) I planned for 50% attrition of participants.

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In Chapter 8 my research colleagues are introduced and the Photo-voice project narrative begins.
Chapter 8 – Shooting the Scenes: naming barriers

8.1 Introduction

In this chapter I take you on location and introduce the Photo-voice project team. Previously, the thesis has projected my voice – my concerns and motivations, my theoretical strategies and tools. Now, the team member’s voices emerge and describe what happened once the group was established and officially functioning.

41 James, Anne, William, Bart and Andrew are participant-chosen pseudonyms.
The Photo-voice project was planned to have three Stages. Stage 1 would explore social barriers using Photo-voice. In Stage 2 we would analyse our photographic data and identify specific research problematics, then our social action would begin in Stage 3. However, it unexpectedly progressed into a fourth Stage when the Photo-voice group decided to become self-determining and self-funded.

Chapter 8 presents the machinations of Stages 1 and 2. I discuss how roles, rules and relationships were established and constantly negotiated. Difficulties in undertaking Inclusive Participatory Action Research and of achieving true collaboration are also discussed. A gallery of social barriers is provided with my co-researcher’s explanations. The chapter concludes with the research group identifying their social barriers to self-determination as Public Transport and Rules that Restrict Us.

8.2 Stage 1: set-up

By May 2007 a group of six young people (2 females, 4 males) aged 18-24 years, with mild-moderate learning difficulties, had self-selected to form an IPAR team. Gill Oxley volunteered to help out when she could. The following profiles were prepared by the Photo-voice group. Everyone was asked to introduce themselves and their personal profiles were included in a project funding application (discussed in 12.5.7). Consent was given for their inclusion in this thesis. The group members each chose their own pseudonym: Bart, Andrew, William, James and Anne. James and Gill gave permission to use their photos in the thesis but were not available at the time the profiles were written to prepare their own. In order to provide an additional layer of privacy and protection to the group members, Bart Andrew and William have been further encoded as Alex, Brendan and Chris (not necessarily in this order) as required. On legal advice the Government Department responsible for the running of a Group Home is referred to only as The Department.
8.2.1 Meet the team

I’m Bart. I am the Photo-voice project’s treasurer and webmaster. I heard about Photo-voice at my Transition-to-Work\textsuperscript{42} (TTW) program in 2007. I am a Cert ii student in Information Technology at TAFE. It was my idea to set up the Photo-voice website. I enjoy being part of the group. I’ve opened up since joining Photo-voice and it has helped my leadership skills. Photo-voice has been a pathway to web design for me and I’m hoping for a career building websites. (Bart, Aug. 2008)

Hi, I’m Anne. I’m 19 years old and am studying web design at TAFE. I would like to get a job in IT. I enjoy graphic design, computers and photography. (Anne, Aug. 2008)

This is James and Gill. James, aged 19 years, was a member of the research team until September 2007 when he moved interstate.

Gill is an experienced Photo-voice practitioner with considerable experience in the disability field. Gill voluntarily shared her skills with the group and has been a great help over the past two years.

Hello, I’m William. I am 21 years old and I was a Break Thru TTW client when I started Photo-voice but now I’m a DEN client looking for work. I’ve been part of the Photo-voice group since it started in 2007. I enjoy talking with people and hope to start a career in retail soon. Photo-voice has helped me to improve my communication skills, learn team

\textsuperscript{42} Transition-to-Work is a NSW state government funded disability service program for school leavers 18-20 years old with impairments and assessed as not yet ready for open employment.
work and organise my time so that jobs are done on time. (William, Aug. 2008)

Hello, I'm Andrew. I'm 26 years old and am hoping to study hairdressing in 2010. I am a people person and I enjoy meeting and talking with others. Photo-voice has been a great way for me to make new friends, improve my photography skills plus learn how to work within a group, discuss issues together and cooperate with one another. (Andrew, Aug. 2008)

With the exception of two members, Kathy and James, who left during Stage 1 of the project, the number of people in Photo-voice group has remained constant from May 2007 to May 2010.

Kathy, stopped coming to the sessions after three weeks. No reason was given and the others in the group were indignant about her poor attendance and unreliability.

“She only signed up to get the camera” (Bart, 13/6/07).

“No one has heard from [Kathy] and so we do not know if she is sick or just away” (William, 13/6/07).

“She should have rung then” (Andrew, 20/6/07).

I explained that the cameras given to Kathy were hers to keep, as were all the photos that everyone would take over the course of the project. It was also perfectly OK for Kathy, or anyone else, to decide to stop coming. This message was reiterated throughout the project. The option to leave was a choice that was always available to everyone. James’ family moved interstate four months after the project began, and so his departure from the group was unavoidable.

Anne, on the other hand, had specific difficulties with the timing of the sessions and interacting with others. She did not function well in the mornings and for a number of reasons, found going to public places very difficult. We tried to
accommodate Anne by changing the times of our sessions but her various issues made travelling to the project meetings difficult for her. Anne attended sporadically providing computer expertise, but did not take any photos. She has maintained internet contact with me, receiving meeting minutes and various group updates as things happen, from time to time. Anne has also provided IT support with our webpage. Therefore, for most of Stage 1 the Photo-voice group consisted of four young men - Bart, William, Andrew and James, with Anne a “virtual” group member.

8.2.2 Getting started

According to Reason & Bradbury (2006) the first stage of a Participatory Action Research inquiry is to agree on the research focus. Our Photo-voice IPAR project was necessarily different. Our group’s focus would not become apparent until after the photos had been taken, analysed, codified and common barriers identified. This took time and patience. In the following section I discuss how the initial Photo-voice sessions were organised and the project timeframes established, in order for the project to move along efficiently, nurture patience and achieve its goals.

The Photo-voice project was advertised to run for approximately eight months. From May 2007 we met weekly for 90 minutes in a disability-accessible community building. I prepared the initial meeting agenda and sought group input regarding how the sessions were to be run. The agenda was quite loose and began with discussion of the collaborative nature of the project and ideas about what that meant to the various group members. Our initial session began by sharing individual and collective goals and expectations of what the project should, and could achieve.

“I joined the group cause I want to learn about photography and make friends” (Andrew, 23/5/07). “I did too” (William, 23/5/07).

“I just wanted a day off TTW” (James, 23/5/07).

“I’ve brought along my laptop computer and want to show you a power-point presentation I did of my trip to the Easter Show, cause I thought that maybe we could do something like this with Photo-voice” (Bart, 23/5/07).
"I want to help the environment because I’m a greenie. Destroying the environment is a barrier for me" (William, 23/5/07).

"I want to make a difference" (Kathy, 23/5/07).

People came with a range of expectations. Some were looking for a day off, others sought friendship, one wanted to improve vocational skills and others had broader social agendas to address.

While we all had different ideas about why we were there, each of us had deliberately chosen to be there and so building a sense of unity, purpose and shared responsibilities was one of my primary goals. One way of doing this and building a sense of ownership of the project within the Photo-voice group was by devolving power and sharing responsibilities with each other. I had hoped that some of the administrative duties would be undertaken by others. However, as no one was willing, able, or interested in preparing agendas, writing minutes or chairing meetings, these roles fell to me (shared on occasions by Gill, Alison and Alice).

Each meeting followed a similar agenda – review of actions from the previous session and business arising from those actions. A loose agenda gave flexibility to the sessions, which allowed for the unanticipated. For example, the agenda for 24/10/07 was simply to review the progress of a complaint we had lodged with The Department. As we reflectively discussed how ineffectual this action appeared to have been, Gill suggested we visit a local police station to find out how people lodge complaints with the police. A flexible agenda accommodated this unexpected excursion to the police station and made way for an unanticipated discussion on citizenship (Marino, 1997).

William suggested that “we could have a key topic each week” (William, 29/6/07) for discussion, on issues of interest raised by group members. A loose agenda provided flexibility for this to occur.

For example one session William arrived and said

“I’ve been asking about sponsors to people. I’ve been asking at my local pubs, if they’ll sponsor our group. They said ‘We’ll see about it’ and so I’m going to go and visit them again about it” (William, 29/6/07).
When asked if he wanted the topic of sponsorship placed on the agenda William said “Yes, I think we should talk about this” (William, 29/6/07) and it was raised as a topic for discussion with the group.

Meeting times

The meetings were held each week from 10:30am – 12 noon, during the school term. There appeared to be an expectation that the Photo-voice project would have holiday breaks along with TAFE.

“Will Photo-voice be on next week, ’cause it’s TAFE holidays? I can still come, but I’d like to go up to my mum's for the holidays” (Bart, 27/6/07).

I reminded the team that everything was a group decision, even meeting times. The team agreed that Photo-voice would follow the TAFE calendar (Minutes, 27/6/07).

Meeting structure

We began each session with morning tea, which generally consisted of a packet of biscuits and hot chocolate. Sometimes there is an initial sense of distrust and tension when a participatory research team is established as power relations are negotiated and team members get to know and understand the position of all players (Ospina, et al., 2004). This was not my experience. The first Photo-voice meeting commenced with a great deal of enthusiasm, excitement and good will. Starting with morning tea provided a friendly space for people to get to know each other. It also allowed time for late comers to straggle in without taking up important discussion and group work time.

The refreshments served an important ice-breaking function as people chatted together over their drinks. The informal atmosphere facilitated by the sharing of food and conversation was conducive to group bonding and the establishment of friendships (Horsfall, 2005).

Recording the proceedings

During the first session I sought permission to record the meetings, explaining that I would transcribe them later and keep an accurate record of the meetings, in addition to meeting minutes. The group agreed to this and were all aware
throughout the sessions that the recorder was on. As people called out silly comments or occasional expletives comments were made, such as

“Are you going to write that in?” (Bart, 30/5/07)

or

“Shh! She’s recording this you know” (Andrew, 30/5/07).

I explained that the conversations and the jokes were just as important as the serious discussions because they painted a picture of what the group was like and how friendships were developing and people were relaxing in each other’s company. It was then a regular occurrence each week to be inundated with a barrage of silly statements, for several minutes, as soon as the recorder was turned on. Bart particularly enjoyed this and his enthusiasm was contagious. He appeared to be ready with “Andrew eats dog shit” (Bart, 30/5/07) or “James smells his own farts” (Bart, 6/6/07) as soon as the recording light was on. There was a tussle of crude but basically harmless insults each week for several hilarious minutes, during which all the young men participated and of which all were at some time on the receiving end. However, no one was routinely targeted. The jibes were ridiculous and the group seemed aware that they were baseless and so were taken in good spirit.

I was not often the target, though Bart did chime in one session with “Janice eats dog shit” to which Andrew quickly replied “She does not!” (14/11/07). Andrew coming to my defence in such a decisive way indicated to Bart that he had stepped over the line. It also demonstrated to me that even after five months of collaboration, Andrew still clearly set me apart as different from the other group members, in a position of authority. “I’m only joking” (14/11/07) was Bart’s reassuring reply to Andrew and the group was allowed to move onto another topic of conversation.

I viewed this playful part of the sessions as a letting off of steam. The group did on occasions become very excited and rowdy during these first recording moments but generally they calmed each other down by saying “keep it down” (Andrew, 12/9/07) and reminding one another that people were in the rooms next to us. Gill and I did not join in the crudities, though we did try to set a standard of
behaviour that encouraged humour while maintaining respect. I hoped to develop a sense of camaraderie by non-censorship and to also minimise the power imbalance (which was inevitable in my position as project facilitator) by encouraging self-regulation and group-censorship.

8.2.3 Setting our first collaborative goal

It was not long into our first meeting that the group serendipitously set their first project goal. All the group members except Andrew had arrived together, driven to the project by their TTW trainers, who remained for the session. After I suggested that the trainers not attend further sessions, the group discussed the logistics of travelling to Photo-voice on their own. Some of the group had never before travelled to the suburb where our meetings were held. These members said that they would need support or “travel training” (William, 23/5/07) to get to Photo-voice each week. Kathy volunteered “Why don’t we meet at Blacktown Station and I can show the others how to get to Penrith?” (Kathy, 23/5/07). After I checked with the TTW trainers who were still in attendance, that this was a realistic proposal (they knew Kathy’s skills better than I did) the group agreed that Kathy should show the others where to go and that it was a good plan. Bart said “I already know how to catch trains but I could be a backup if [Kathy] was away” (Bart, 23/5/07). This was another good suggestion, indicating Bart’s willingness to be a leader and showing he was capable of anticipating issues and making contingency plans. Bart’s offer was also most welcome as Kathy stopped attending Photo-voice after three weeks. James and William relied on Bart to meet them and show them the way each week. This was a terrific start to the project. James and William had recognised and raised a problem (they would need travel training) and Kathy had proposed a plan that would involve most of the group. She had voluntarily offered to model commuter skills and the group had approved of this suggestion.

The group agreed that Kathy would be the travel-trainer (and Bart the backup), and so our first goal (to travel train those coming from Blacktown) and our first plan of action was made. It was encouraging that people established themselves as

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43 While James admitted that he did not know how to get to Penrith, William stated explicitly that he would need “travel-training”. I noted in my journal that day (23/5/07) that this was an interesting and institutional expression.
leaders with the support of the group so quickly. Group members engaged in open conversation with each other regarding the issue and how to address it and that the discussion was not over-ridden by any one person. This kind of initiative and problem-solving (which included little input from me) would occur repeatedly over the next three years. It was another timely and significant lesson which challenged the stereotype of people labelled with learning difficulties that I had brought with me to the project.

As a result of Kathy’s initiative and Bart’s support, by the end of Stage 1 (the exhibition) William was competently travelling on public transport on his own. Evidence of this is recorded in the minutes of 29/8/07 which note

“Janice to forward [William] map via email, of how to get to Richmond Club from the railway station” (Minutes, 29/8/07).

William achieved this without incident. At age 19 years old travelling independently was something which William’s parents had never allowed him to do before. William attributes this welcome level of independence to Photo-voice and when asked in 2009, stated “The best thing I’ve gained from the project is being able to travel on public transport by myself” (William, 24/9/09). Over the course of the project Bart would also take on the responsibility of travel training Andrew.

8.2.4 Setting timeframes

One of my aims for the project was that the group would develop towards self-determination. I hoped that evidence of such development might be seen in a project that was group-paced rather than driven forward by me. Self-pacing, or self-regulation (see Wehmeyer’s (1999) characteristics of self-determination in 4.3.3) may have been one step towards group self-determination. In the following section I reflect on the research group’s gradual willingness to set realistic timeframes.

During the initial Photo-voice session I encouraged the group to set their own timeframes for the project. Limiting the time allocated for completing actions, such as finishing a roll of film, was designed to facilitate the internalisation of goals and rewards associated with an internalised locus of control (Harter, 1981) for each person involved (Powers, Singer, et al., 1996). Alongside the loose agenda and
flexible meetings, designed to permit the project to evolve in whatever way the group chose, was the constraint of tasks that needed to be completed in order for the project to progress. There was a tension of freedom and responsibility that was to be managed through time-limited actions. Timeframes can create a space within which development and change can occur gradually.

Setting timeframes supported the IPAR need for patience (5.4.3). Also, no one would be expecting immediate results and space was provided within which to nurture trust and the sharing of ideas. Time-limited actions were also intended to support people to become self-regulating and assist them to work within set parameters.

The project was initially intended to last eight months, though the group later extended the timeframe (discussed in further details in Chapter 12). It has now developed into a small social group in its own right and was still functioning in August 2010.

Following a presentation on the processes involved in a Photo-voice project, listing stages that researchers must go through before they can proceed to the next step in the project, I initiated a group discussion asking for suggestions for timeframes within which to achieve the various activities. Two weeks was a popular time period offered by the group. Although Gill and I suggested that longer would probably be needed to achieve their objectives, the group decided that they would be able to complete their films within “two weeks” (Andrew & Bart, 23/5/07). They allocated “two weeks” (Kathy, 23/5/07) for processing the films, “two weeks” (William, 23/5/07) for story-telling, “two weeks” (Andrew, 23/5/07) for developing the picture board sequence. As a group we discussed the risk that all the group members might not achieve these goals and so agreed to be flexible. We could extend the timeframe if needed. I suggested we allow four weeks to research and secure an exhibition venue and six weeks for the planning, posting and receiving back of responses to invitations, to build some flexibility into the timeframe.

Devolving the responsibility of setting time-limited objectives to the group in the initial session was intended to reinforce the collaborative nature of the project and what that meant in practice. I suspect that two weeks (called out, almost in unison, by the group, as I raised new tasks to be achieved) was playful collusion
by the team rather than a rational, calculated estimation of time needed, but I was happy to accept their suggestions as serious, but flexible, timeframes. I stressed that the timeframes were open to change if we needed more time.

The two week timeframe for photographing was overly-ambitious and some members had not even begun\textsuperscript{44} photographing during that time. However, as the project progressed, and dates came and went, a better appreciation of the busyness of life and an understanding of the need for planning was gained by people.

“I’ll do that tomorrow. I was planning to do that yesterday, and I left my mum’s early so I could come home and do it, but then everything happened and I couldn’t do it. I’ll try and get it done tomorrow but” (Bart, 25/2/08).

As we talked about the work that was involved in achieving objectives over the course of the project, the team became better able (and more willing) to estimate more realistic time allocations for tasks as they factored in how Photo-voice responsibilities could be included in the daily lives.

“I’ll need more time as I have a lot of TAFE on this week” (Bart, 14/11/07).

“I can work on a Power-point [presentation] next week and have that ready by our meeting, after that one. Then you and me can look at it and get it ready by the Expo” (Bart, 7/8/07).

“I can speak to NADO\textsuperscript{45}, but I don’t go there for another few weeks” (Andrew, 13/2/08).

The following brief dialogue between Bart and William regarding how they might develop a Photo-voice Myspace page together, demonstrates time estimation and an awareness of the need to prioritise tasks. In reality, the estimation of “an hour” was grossly inadequate and the job of building a Myspace page proved too difficult for them.

\textbf{Bart:} “Making the Myspace, that will take…”

\textbf{William:} “an hour?”

\textbf{Bart:} “Maybe an hour, but we need the photos first.”

\textsuperscript{44} Eight weeks into the project my field notes expressed concern “James has not taken many [only 6] photos” (Field notes, 18/7/07).

\textsuperscript{45} NADO - (Nepean Area Disability Organisation) is Andrew’s recreational service provider.
Most weeks the Photo-voice group was able to keep themselves on track, working within the meeting agenda and pushing forward with activities that met objectives. However, particularly in Stage 1 of the project, on occasions I found it very difficult to maintain shared control in collaboration. At times I felt that the group became distracted from the task at hand and so I exerted my position of power. For example, the exciting prospect of building a group website arose early in the project. I obtained some quotes and we found that it would cost a lot of money, so the group discussed “How would we get that money”? (William, 13/6/07).

Sponsorship was suggested by the group, along with a substantial list of possible sponsors. The group discussed how they would “have to give them [the sponsors] a reason why they should sponsor us” (Bart, 13/6/07). The sponsorship debate took a considerable part of our meeting. It generated some great ideas and enthusiastic, inclusive dialogue but also threatened to distract the group away from photography and into actions around gaining sponsors. With regards to approaching a large corporate sponsor William suggested, “Well, we could do that today” (William, 13/6/07).

I over-ruled this idea, emphatically stating

“No, we’ve got to concentrate on getting photos. Because there is no reason to have a website if we don’t have an exhibition to put on it. So that’s our priority” (Janice, 13/6/07).

Reflecting upon the Week 3 transcript of the project, it was apparent to me that the unanticipated website suggestion took the project onto a tangent where William, Bart and Anne were considerably more confident and comfortable than I was. I suspect that asserting control as I did in the above instance stemmed from my unacknowledged fear of losing control of the project’s direction as much as from the practical need for photos. Asserting power in this way was anti-collaborative. It privileged my priorities over those of the group. It also demonstrated the vulnerability of the ideal speech situation (5.6.3) which I was trying to develop, disrupted so easily and unwittingly. Reading back through the transcript and reflecting on my reaction, in the week following that incident, I became aware of our different priorities. I had a vested interest in keeping a tight schedule. Although this was a collaborative venture I was the facilitator. I also had a PhD to
complete within a limited timeframe, which included launching the Photo-voice photographic exhibition. The other group members did not have a facilitator’s responsibilities and were not under that same pressure. They also didn’t have the facilitator’s power to over-ride suggestions, despite the rhetoric of being inclusive or collaborative, nor did they have a research degree to look forward to at the end of the project. Realising my dismissal of William’s suggestion was basically for my own benefit, I explained my behaviour and the time constraints to the group at the following meeting, hoping to make explicit my abuse of power, seeking their forgiveness, and also to gain their support in keeping me on an equal footing with them in the future. I reminded the group that

Janice: “We’re a team and if I start getting bossy, then that’s not teamwork. Please tell me if you think I’m being bossy... or if I sound like your mum.”

Bart: “Don’t worry about that. We’ll tell you.”

James: “Heck, yeah.”

(Transcript, 20/6/07)

Once a sizeable number of photos (hundreds of digital photos plus ten rolls of film) had been taken I was less anxious about not having enough photos to stage an exhibition. I had no objections when the group agreed to spent two weeks approaching local businesses for donations that might be used as “lucky door prizes” (William, 13/6/07) at their exhibition. Unfortunately, after a lot of cold canvassing of shops and restaurants no donations were achieved. This time had not been wasted and some good lessons in organisation were learned, discussed in more detail below.

Although the group’s initial plan was to complete Stage 1 of the project, culminating in the photographic exhibition, within three months, Stage 1 took four months to accomplish.

8.2.5 A Code of Conduct

The following section considers what was involved in the development of the code of conduct by the group. The code of conduct was an excellent example of a collaboratively drafted document, democratically negotiated through thoughtful, critical, dialogue, in plain English. A copy of the code of conduct is provided below.
In order to establish a respectful environment conducive to free and open dialogue, what might loosely be described as a Habermasian Ideal Speech Situation, I endeavoured to encourage i) equal rights of discourse, ii) absence of role privileges and iii) freedom from coercion and constraint (see 5.6.3).

To assist in promoting these egalitarian ideals I suggested to the group that we collaboratively establish a code of conduct. This document outlined the kind of behaviour that each research group member thought was and was not acceptable in the Photo-voice sessions. The code of conduct was a statement of shared values, agreed upon by consensus. Signatories of the code acknowledged that they were not solitary actors but were members of a collaborative “social group who orient their action to common values” (Habermas, 1984, p. 85).

Everyone was given an opportunity to contribute thoughts on what should or should not go in the code and all participated in the discussion of each point raised. Suggestions were drafted on one side of a white board by Alison as people called out suggestions and we debated their appropriateness. The code of conduct was compiled on the other side of the board with suggestions being transferred across once they were agreed upon. Suggested points for the code were not included until a consensus had been reached and everyone was in agreement. Quieter members were drawn into discussion by explicitly asking, for example, “What are your thoughts on this point James?” (Janice, 30/5/07).

This noisy activity generated lots of suggestions, some appropriate and others obviously just for a laugh. All suggestions were accepted for discussion (which the group found hilarious) and were written on the board. Many of the suggestions were humorous, for example “no farting” (Bart, 30/5/07), or “no sleeping during Photo-voice” (James, 30/5/07). This latter suggestion, like all the others, was scribed on the board for discussion. However, after some reflection, Kathy challenged this idea.

“We can’t have that as a rule. Some people can’t help falling asleep because of their medication (Kathy, 30/5/07).

Kathy’s thoughtful comment generated a pensive discussion. We talked about openness, honesty, and sincerity. In line with Habermas’ ideal of clear, comprehensible, truthful and sincere communication, the conversation also
reminded people that the code of conduct represented shared “value orientation” (Habermas, 1984, p. xxiv). It represented the group’s value system and how we would treat each other.

“At Photo-voice I reckon it should be one rule for all. Everyone the same... And what’s said in Photo-voice stays in Photo-voice” (Kathy, 30/5/07).

Although no lying was not explicitly articulated in the code an expectation of honesty was evident, with Bart at times doubting and sometimes challenging William’s account of events as excuses for why William was unable to complete tasks.

“As if” (Bart, 30/5/07).

“Funny about that, that’s what you always say” (Bart, 18/7/07).

“That’s bull shit William. I think you make up stories” (Bart, 29/8/07).

“No acting crazy” (William, 30/5/07) was another unusual comment that produced some thoughtful discussion about safety and respect. Out of this discussion emerged another rule in a similar vein, though more explicit: “Keep safe - no swinging on chairs, rough play, pushing”. In order to develop self-determination skills I felt that it was important that the group be encouraged to assume a protective role over themselves (Field, S & Hoffman, 1996). Therefore, I raised questions through the discussion regarding the consequences of acting crazy.

Being mindful of their behaviour and self-imposing limitations of not acting crazy or swinging on chairs was a means of Photo-voice group members taking charge of their own lives and actions.

James’ suggestion of “No obsessive swearing” (James, 30/5/07) initiated a discussion about language. We agreed to speak to one another as adults. Sometimes adults swear, but, with respect for others, everyone agreed to try to not swear too much. A portion of the meeting transcript of 30/5/07 appears below:

Bart: “Can we say ‘shit’ then?”
Janice: “... no one has stopped you so far.”
Bart: “But we won’t say the ‘f’ word.”
Andrew: “And we won’t call people dickheads, or names that are nasty.”
Janice: “No, we’ll try to be nice.”
Gill: “and respectful.”

(Transcript, 30/5/07)

People agreed to respect each other’s opinions and belongings. They should “take turns” (Kathy, 30/5/07) in speaking, and not “butts in or speak when someone else is talking” (Bart, 30/5/07). When discussing the Code with Andrew a few weeks later Bart explained the reason for not speaking when someone else was talking was “Cause it is hard for Janice to hear when she’s playing it back” (Bart, 13/6/07). This comment demonstrated Bart’s consideration of my hearing impairment and an awareness of what the transcription process required.

When the Code was complete each group member signed it. I displayed a laminated copy on the wall for everyone to see each week. The laminated copy of the code was eventually lost after about 18 months of usage (left behind in the room one week), but its principles were regularly applied by the group and raised by team members as incidents arose. For example, William often advised me “Hey, hey, hey, he’s swinging on his chair” (William, 20/6/07) when Bart regularly (though only momentarily) balanced on only two of his chair legs. Team members would remind each other to take a mobile phone call outside, they always rang to advise me if they were running late, and if the group became too boisterous and started to play roughly one of them would call out “No pushing!” (William, 20/6/09), and “Hey, no punching” (Bart to Andrew, 27/6/07).
Photo-voice Project

Code of Conduct

One rule for all

Be respectful (everyone has the right to their own opinion, everyone has the right to their own space, everyone is valued)
What is said in Photo-voice stays in Photo-voice (confidentiality)
Don’t take anyone’s picture without permission
No obsessive swearing
No name calling that is nasty
Don’t touch other people’s stuff without asking
No acting crazy – be sensible
If you can’t come or you’re running really late, ring Janice [Phone no.]
Keep safe – no swinging on chairs, rough play, pushing
If someone rings & it’s important, ask to take the call outside
Don’t interrupt, don’t speak when someone else is talking

Signed by

Figure 7 - Photo-voice Code of Conduct
8.2.6 Photographic training for the Photo-voice Group

Professional photographic support was something I believed would benefit the project. This section briefly discusses the photographic advice Alice provided in the workshop she facilitated and how a photographic consent form was collaboratively drafted by the group.

Alice was an inspiration to the group. She was young and pretty and passionate about photography. Alice brought a selection of photographs to demonstrate photos with repeating patterns, poorly placed subjects (people with their heads cut off), photos that made use of different angles and how some angles distorted the subject. In each instance Alice explained how the image was achieved or how the photo could have been improved. The major points she stressed to remember when taking photos on a disposable camera included:

- "Wind on the film
- Press the flash button on at the front of camera
- Stand 1 metre away from subject
- Hold camera still
- Have the light behind you (or to the side) but never directly in front
- Close-up shots often look better. Distance shots can sometimes include too much additional information which can distract from the subject
- Centre the subject
- Think about what you want the picture to look like" (Minutes, 23/5/07).

All the group enjoyed the training session, with one member confiding to me the following week “I wish she could be my girlfriend” (William, 30/5/07).

8.2.7 Photo-voice ethics and privacy

Through group discussion, facilitated by Alice, and role play facilitated by Gill, the Photo-voice team considered reasons why it was important to ask people for
permission before they took their photo. Drawing on the theme of everyone’s right to self-determination we discussed a person’s right to refuse permission to have their photo taken. To personalise this concept and make it concrete we talked about how the group might feel if someone took their photo even when they had said they didn’t want it taken.

“If I didn’t want my photo taken I’d tell them to get lost” (Bart, 23/5/07).

“Good on you. And that’s your right to say “I don’t want my photo taken”. Everyone has that right” (Janice, 23/5/07).

“If they took my photo and I didn’t want them to take it, I’d be upset” (Andrew, 23/5/07).

“If they took my photo I’d tell the cops” (James, 23/5/07).

Also discussed were reasons why some people might not want to be photographed. Examples raised included

“hiding from the police, photos being scanned into the internet and used for immoral purposes, photos being adapted and used to incriminate people, people not wanting their whereabouts made known and then having their identity exposed through the exhibition” (Minutes, 23/5/07).

I tried to discourage the photographing of other people. However, my co-researchers all wanted the freedom to choose what or who they would photograph. In the spirit of self-determination it was therefore agreed that no photos of others would be taken without a signed consent form by the person to be photographed (see Appendix 1). The consent form (discussed below) was composed in the language of the research group members. Each contributed to its composition and understood its purpose, content and usage. The research group’s level of understanding was demonstrated in the Photographic Participant’s Consent Form as its intention is clearly evident. Understanding was further checked through conversations with each member in which they explained why the form was needed. Observations during the ethics workshops also confirmed understanding. It was also agreed that, if necessary, photos could be ‘doctored’ so that people were de-identified. The group members demonstrated their commitment to respecting privacy when choosing photos to exhibit. For example, Bart commented
“Oh, I don’t think we can use that [photo] ’cause we’ve got someone coming out from the background” (Bart, 13/06/07).

On another occasion Bart and I deliberated over a particular photo to use:

**Bart** (looking at his photos): “What about this one”?
**Janice**: “Ahh, well, what do you think”?
**Bart**: “It’s got people in it.”
**Janice**: “Yes, it has.”
**Bart**: “When I took it, it didn’t look like it had people in it.”
**Janice**: “… when we blow it up, we could maybe crop off the people.”
**Bart**: “Maybe. We’ll blow it up first and see.”

(Transcript, 20/6/07)

The issue of privacy was raised as a barrier by Alex, who lived in a Group Home. He claimed the staff opened his mail and listened to his phone conversations. When asked why he wanted to photograph a security camera he answered “People watch you and there’s no privacy” (Alex, 20/6/07). The security camera was Alex’s metaphor for no privacy. Brendan warned Alex that he might “get into trouble” (Brendan, 20/6/07), “They might think you’re a terrorist” (Alex, 20/6/07).

It was appropriate that Alex be warned and the conversation demonstrated collegiality and support. However, following a group discussion on the ethics of photographing in a public space, we decided “it’s OK for [Alex] to take the security camera” (Chris, 20/6/07) if he chose to, informed as he was of possible consequences and the suspicions of others.

The warning demonstrated that the group was aware of photographic ethics and of their responsibly as social researchers. The research group was mindful of looking out for each other and keeping safe, and also considering the general public and the example they set as researchers under the banner of UWS.

Bart noted, “We can’t take photos at the railways and that, ’cause people might think we’re terrorists or something. They’ll wonder why we’re taking photos” (30/5/07).

After discussing how to avoid this problem Andrew suggested “We could ask” (Andrew, 30/5/07). The group decided to approach the Station Master and explain
why we wanted to take photos, seeking permission. We were referred to a Customer Liaison Officer within CityRail\textsuperscript{46}, who granted permission, provided we did not photograph passengers or staff. Bart’s legitimate reservations facilitated a responsible course of action.

Another example indicating the team’s awareness that they represented UWS during the research project is evidenced by Andrew’s question “Will you have to ask the Uni before we photograph in the city?” (Andrew, 3/10/07). He clearly understood our actions were associated with the university and that we were answerable to UWS. It also demonstrated an awareness of ethical consciousness to do the right thing.

**Collaboratively composing a consent form**

Freire stresses that if students were to find their own voice and speak about their world then it was important for them to do so in their own language. That is not to say that they should be restricted to their own vernacular. However, a fundamental principle of emancipation is the right to speak your own language and choose your own words. It was Freire’s belief that “the student’s own language was the means of developing a positive sense of self-worth” (Meek in Freire & Macedo, 1987, p. ix). Therefore, when the Photo-voice research group drafted the Photographic Participant Consent Form, they should use their own words.

Before drafting the consent form the group was charged with the responsibility to think about what they wanted the form for.

“So they know why we want to take their photo” (Bart, 23/5/07).

“To show [other people, such as Janice] that we asked them first” (William, 23/5/07).

They also had to think about why they needed the form.

“To protect people’s right to privacy” (Gill, 23/5/07).

“They can sign the form if they are OK about us taking their photo” (Bart, 23/5/07).

“That’s right. It demonstrates you have told them about the project and they’ve given you informed consent” (Janice, 23/5/07).

\textsuperscript{46} The public transport agency which operates train services in Sydney.
In my UWS Human Research Ethics Committee application, submitted prior to starting the research, I included a draft-sample of what the consent form might say. This draft acted as a framework for the group. A photo-ethics workshop comprehensively covered why we needed to use consent forms. The group consent form was a great achievement in collaborative decision-making and evidence of self-determining action. Although the research group’s consent form was contrived to a degree (as it was influenced by the draft form) this was unavoidable. Institutional compliance obligations meant that the consent form needed to contain particular elements to meet the UWS Human Research Ethics Committee standards. However, the final Photographic Participant Consent Form (Appendix 1) was written in language chosen by and agreed upon by the research group.

The research group unanimously agreed that all those who were to be photographed should first be asked permission of and that people had the right to refuse their permission. Respecting other people’s privacy was a key strategy for staying safe and avoiding conflict.

Issues of safety

Alice also facilitated a discussion on how to keep safe when photographing. The purpose of this discussion was to raise the group members’ awareness of dangers. In the following section I provide examples of the dangers anticipated as well as some strategies developed by the group for avoiding risks.

Raising the topic of personal safety with the team was an opportunity for them to brainstorm together what dangers they could anticipate and to work together to think of ways to avoid such dangers and keep safe when taking photographs. It was hoped that thinking of risks in advance would assist participants to make informed decisions regarding how to circumvent danger if it arose. For example, it was suggested that the photographers do not photograph illegal activities.

“If you photographed a drug deal you might end up getting bashed” (Bart, 23/5/07).

“People should check that they are safe before they take their photos” (Andrew, 23/5/07).

“Don’t take photos leaning out of windows, like the train” (Bart, 23/5/07).
“Or any moving vehicles” (William, 23/5/07).

“On the road or close to a ledge” (Andrew, 23/5/07).

“Don’t go out photographing alone... at night time” (James, 23/5/07).

Another suggestion was to photograph in teams. We frequently did this during our meetings, splitting off into two groups and going out into the local shopping centre so that people could assist one another with ideas about barriers and also with security. Figure 9 beautifully depicts cooperative photography and teamwork as William and Andrew compare images.

On one occasion when photographing in pairs Andrew raced ahead excitedly as he saw something that he wanted to photograph on the other side of the road. Gill, who was accompanying him, was able to reach him before he ran out onto the road. This incident generated a fruitful reflective discussion on safety that both Andrew and the group were later able to learn from. “We should take our time and be safe” (Andrew, 23/6/07).

We collaboratively worked to keep each other safe and our field trips were accident-free.

Going out into the community as a group or in pairs to take photos was also deliberate strategy for developing partnership skills (Powers, Wilson, et al., 1996). Self-determination does not mean independence. It is important for young people to learn how to take charge of their lives by developing strategic partnerships with others to advance their success.

Working together provided an opportunity for people to deliberately choose to place themselves in some of their photos. Rather than simply taking the photo they could choose to be part of the subject. Working with others in this way allowed them to be photographed dealing with a particular barrier (see Figure 10 of Andrew at the Automated Telling Machine (ATM)) or to emphasise a point (for example, Figure 36 of James standing outside the employment service because he was not permitted to seek work). Of course people could self-determine not to have their photos taken, as noted in the meeting minutes of 6/6/07.
Figure 9 - William and Andrew photographing in pairs (Bart 4/2/09)
“[Bart] suggested to [James] that [Bart] take a photo with [James’] camera of [James] pretending to withdraw money from an ATM. [James] did not want to do this as he said that he wanted to be responsible for all his photos. This demonstrated good self-regulation and self-realisation” (Minutes, 6/6/07).

![Figure 10 - Andrew at ATM but there’s no money (Bart, 6/6/07)](image)

Balancing rights and responsibilities

An ethical issue with which I struggled during the project was balancing the group members’ rights of self-determination with my duty of care. The following discussion provides an example of where my ideal of fostering an environment in which people could be completely self-determining was constrained by the responsibility to comply with legal requirements or institutional regulations.

One morning on his way to Photo-voice by train, James was reprimanded by another passenger (a teacher). James told us that the passenger had objected to James’ loud and disruptive behaviour, and “threatened to call the transit police” (James, 25/7/07). When James arrived at Photo-voice he was still angry over the incident. My Journal entry takes up the story.

On the drive to the library [James] had his elbow out of the car window. I asked him to bring his arm inside the car. I explained it was dangerous…James said “It’s OK.”

“No”, I insisted, “Please bring your arm in the car.” James ignored me and I felt that I had no choice but to put the [automatic] window up and use the child-lock on the doors and windows.

I was uncomfortable behaving like such a bossy-boots, especially using the child-lock and since he had just vented his annoyance at the teacher stopping him from doing what he wanted on the train - and because his involvement in the project was all about developing self-determination. However, I have parameters within which I must operate also. To allow him to exercise self-determination [putting arm out the window in this instance] impinged on my liberty & responsibilities as a driver. His refusal to obey the law might directly affect me both as a driver and as a researcher with a duty of care to keep him safe. Self-determination does not mean do what you
like, living in community with others requires some accommodation.

(Journal, 25/7/07)

The above incident may sound trivial. However, while there is a risk of over-analysis, it does demonstrate the difficulties researchers engaging in Inclusive Research encounter when faced with such behaviour. There were many incidents such as this. As a middle-aged woman, working with adolescents, I was mindful of how easily I could slip into mother mode or even disability trainer mode, unconsciously taking control and instructing people rather than working alongside them. I often had to consider my actions reflectively to ensure I remained collaborative and not authoritative. Journaling was helpful in enabling me to critique my own practice.

8.2.8 Shooting scenes

Following our photographic training all group members were issued with disposable cameras with which to name their social barriers by capturing on film those things which stopped them from having control and doing what other young people get to do. They were to do this on their own (without asking someone else what they should photograph) and in their own time. They were then to return their cameras to me for processing. I wrote their initials on the cameras so that they could be identified once they were returned to me for processing.
Some members preferred to use their own digital cameras, these were a better tool. They facilitated more accurate framing of the photographic subject and were more cost effective than disposable cameras as we did not need to print photographs that were not needed. Also, the group members were able to view their digital photos on a computer screen before printing. Storage of digital photos is highly convenient and their use in computer programs such as Powerpoint and Word is versatile. The disposable cameras generally produced poorly centred photos. Very few photographs from each disposable camera (average 4/27 exposures) were selected for discussion or enlargement. Films were processed and prints made in addition to burning photos onto CDs for computer filing at a cost of approximately $25 each, paid for from my student funding.

The group had initially set themselves a two week timeframe in which to complete a roll of film (though this later proved to be insufficient for some\textsuperscript{47}). The purpose behind this independent activity was simple. Self-determination is the antithesis of learned helplessness (Powers, Wilson, et al., 1996). While learned helplessness is an acquired behavioural disposition of passivity, self-denigration and an internalisation of devalued social status (Seligman, 1975), self-determination is said to develop from personal mastery and self-efficacious expectations (Powers, et al., 2006). Learned helplessness is linked to a lack of personal autonomy and perseverance when difficulties are encountered. It is also reinforced by environmental factors which encourage dependence through such things as limited choice-making opportunities, communications of low expectations by others and a lack of encouragement to strive to succeed (Powers, Wilson, et al., 1996). Therefore, in order to establish a research environment that encouraged self-determination people were given the opportunity to make decisions about what they would photograph with the expectation that they were all capable of doing this. If they were unable to complete their films in time they were encouraged to have an extension of time in order to do this on their own and also assisted to photograph in pairs and with the group.

In order to encourage self-efficacious expectations I saw it as important that I not only demonstrated the belief that the group members were capable of undertaking

\textsuperscript{47} Andrew’s enthusiasm was such that he completed a roll of film within 40 minutes of being issued the camera. He went on to take hundreds of photos using a digital camera. However James did not complete one roll during the eight week period prior to our exhibition.
the task but that their colleagues each thought one another capable of it as well. “Social persuasion” (Powers, Wilson, et al., 1996, p. 261) through the encouragement and praise of others (particularly credible peers) is an effective means of motivation and encouragement to self-efficacy. Social persuasion can also take the form of evaluative feedback and challenge. People who are persuaded that others believe they have the ability to achieve a task mobilise additional effort and accomplished the task, thereby reinforcing a notion of self-efficacy (Schunk, 1984). However, it is also vitally important that the individuals themselves believe that the goal of the task is achievable. Bandura (1986) claims that self-efficacy results from an awareness that one not only has the skills required to complete a given task but also that in doing the task the goal will be achieved. This is closely tied to Wehmeyer's (1999) notion of psychological empowerment and a key element of self-determination. Bandura et al. (2001) claim that youth with high self-efficacy are more likely to make decisions, attempt new things and see things through to completion.

Photo-voice proved to be an exciting and empowering medium for the group. Some were invigorated by the freedom to photograph whatever they wanted and by the removal of financial considerations. Andrew took dozens - possibly hundreds - of photos with a digital camera. Many were powerful images48. Regarding his disposable camera, Andrew boasted to the group “I used a whole camera up” (Andrew, 30/5/07). New cameras were issued as rolls were completed. When Bart received his second camera he asked “Another one? I’ve already had one. Are you sure?” (Bart 6/6/07). It was something quite new for him to be given a camera to use on whatever he wanted at no cost.

An interesting (and shocking) comment was made when discussing my research method with a social science academic prior to starting the research - the proposal was dismissed saying that I would just end up with photos of people’s feet. This comment proved to be highly inaccurate. None of the group took inappropriate photos and many of the poorer shots were the fault of the disposable cameras rather than the photographers. All team members took their Photo-voice researcher roles very seriously, producing interesting and valuable data.

48 Though, as might be expected, many were not. It takes considerable time to trawl through seemingly endless photos to find the perfect shot. This can be boring for other participants and is best done one-to-one with the photographer.
8.2.9 Downloading

Week by week the group arrived with photos to discuss. On occasions we accessed computers at the local library to download the digital photos (Figure 12 and Figure 13). On a number of occasions I also arranged for the group to use the computer training room facilities at UWS. Here, several group members utilised their information technology skills to download digital photos and later develop photo files of emerging barrier themes, draft invitations to the photographic exhibition launch and create a PowerPoint presentation of their work.

![Figure 12 - Bart sorting photos at the library computers](image)

![Figure 13 - William downloading data at the library computers](image)

8.3 Stage 2a: analyses

Once the photos had been downloaded the research progressed to Stage 2, the analysis of the photos and development of themes. The task of choosing photos involved more than simply allowing researchers a personal choice. It was an analytical process that required a wider perspective than self-interest. It required collaborative thinking, self-monitoring, critical thought and discernment. In this section I discuss how the group engaged in first and second level analysis of their photographic data.
8.3.2 First level analysis

A first-level analysis required each group member to choose which of their own photos they wanted to use to express their barriers to self-determination.

The digital photos were chosen by viewing them directly on a computer screen. Photos developed from disposable cameras came with an index card numbering the photos from the film. After returning the developed films to the group members they were able to view the photos and circle the numbered photo on the index card. Andrew, who had the highest support needs in the group, had no difficulty matching the photos with their smaller indexed copies. He exclaimed “I think this one is good, number 19, [a photo] of the Westfield sign” (Andrew, 13/6/07).

Photo selection was initially a matter of individual choice, though all group members considered aesthetics (such as lighting, clarity, subject positioning), how clearly the barrier was articulated in the photo, and issues of privacy.

The group demonstrated discernment in a number of ways. For example, they compared similar photographs before choosing the one they thought was the best.

“See that one? That’s a better bus one” (Bart, 13/6/07).

They discarded photos that were “too blurry” (Bart, 13/06/07) or “too dark” (William, 13/6/07) or poorly centred “most of it [the photo] is just sky” (Andrew, 20/6/07).

William discarded one photo saying “My eyes are closed, they [visitors to the exhibition] won’t like it because I’m too close [to the camera]. It’s supposed to be 3 metres” (William, 20/6/07).
Not only was William considering the subject of the photo, he remembered his photographic training and was able to critique the photographic process. Numerous photos were rejected because they included people in the background.

“No, not that one. It’s got those people in it” (Bart, 20/6/07).

On one occasion Andrew suggested a solution to the privacy issue with a photo he particularly liked, asking

“Can we crop off the people? ’Cause I got some people in my train one?” (Andrew, 13/6/07).

8.3.3 Second level analysis

After an initial culling of photos, leaving only the ones at which the group members wanted to look more closely, a second-level of analysis took place. This considered the story behind each photo, or perhaps a story captured by several photos. Collecting stories took many weeks. Gill and I sat one-to-one with the group members recording their stories with their permission (this is what is happening in James and Gill’s photo in 8.2.1). I also arranged to meet group members individually throughout the week so that more time could be dedicated to gathering rich descriptions of the intent behind the photos. At the end of the story-gathering process I asked each person what they thought the main issues in their stories were. The issues raised became potential themes that would determine how the photo should be categorised. I transcribed the taped stories and extracted captions for the photographs based on the discussions and issues raised. Captions were then brought to the meetings to be agreed upon or disputed by the story-teller. Once accepted as accurate and appropriate to the visual text, the caption and photo were set aside for sequencing and possible rephrasing if the photo could be fitted under more than one theme. For example, a photo of a Centrelink office fitted under the barrier theme of No Money in addition to the Government, Rules and Employment barrier themes.

Following a meeting with Andrew during which he sorted his preferred photos, sequenced them for display and recorded the stories behind his photos, he was very keen to tell the group about this achievement. “Guess what? I’ve organised my photos” (Andrew, 25/6/07). Following an explanation that Andrew had put his
photos in a sequence Bart commented

“But that sequence might change. We all might have photos that go with yours, [Andrew], and so the sequence will change as we find out what each other’s photos are” (Bart, 25/6/07).

This comment showed Bart’s understanding of the collaborative nature of the project, something Andrew had not yet grasped. At that stage Andrew was still very interested in his own photos and his own issues, rather than the commonality of issues being raised by the group.

Consciousness raising through critical dialogue

Through group discussion on each barrier we developed a clearer idea of social barriers. For example, initially Bart suggested his social barrier was packed trains in peak hour:

“You know how they’re packed in and there’s like, heaps of people in it, and there’s no seat. It’s stopping me from sitting down” (Bart, 6/6/07).

Naming public transport as a social barrier is not surprising. The Sydney public transport system has recently been ranked last out of 20 global cities (behind Mumbai and Mexico City) (PricewaterhouseCoopers, 2008). Crowded trains are a problem, but not specifically for people labelled with learning difficulties and while people might not get a seat, they are still able to travel from A to B. Bart then suggested a different example:

“It's like the train that's running late, and so now we're running late, to TAFE or something, and that's stopping us from getting there. When we're doing our best to be on time” (Bart, 6/6/07).

This was a better example as control was taken out of the commuter’s hands even after their best efforts to be punctual. However, greater insight was gained as others contributed their experiences of public transport, including a complete inability to read the indicator boards, use ticket machines or even understand the station announcer. Bart agreed that he also had difficulty reading all the notices.

Following Jurkowski’s practice, a Photo-voice group “member-check” (2008, p. 6) was held to discuss the themes identified in the analysis and gain a group consensus of the accuracy of the themes. For example, many photos spoke of a
lack of finances as a significant social barrier stopping group members from doing things in society that others do. Bart expressed this issue as “everything is too expensive when you’re living on a pension” (Bart, 20/6/07). Andrew said “some of the people, like pensioners, haven’t got much money” (Andrew, 20/6/07).

While high cost of living and limited income are different, though related, issues, the group chose No-Money as a shared theme emerging from their photo analysis. Similar negotiations occurred with the other themes. Bart had a particular difficulty with buses, for Andrew and James trains were a problem and for William it was taxis. Therefore public transport became a common theme. This form of analysis was based on a grounded-theory approach where categories are developed as they emerge from the data, rather than from pre-conceived categories based on assumptions of what might be discovered (Strauss & Corbin, 1997).

8.3.4 Third level analysis

This level of analysis involved amalgamating the team’s photos into common themes with further culling. I imagined that this might cause problems if people became too focused on wanting their own photos on display, but the group was very mature about the whole process. Theme by theme I placed the photos onto a table for the group to choose which most accurately depicted the issue they were raising. There were so many similar photos that it became difficult to remember who took which one. However, once selected they became group photos. No one was possessive about them and each photo was reviewed for both its aesthetic merit and relevance to the theme. For example, the whole group agreed that Andrew’s well-centred photo (Figure 15) should be exhibited to represent the Public Transport barrier.

The following section presents a sample of photographs in eight of the themed categories developed by the group. Further examples are available on our website www.penrithphoto-voice.net (screenshots are shown in Appendix 5.1).
8.4 Stage 2b: findings

8.4.1 Barriers limiting the control the group members have on their lives

No Money

Figure 16 - No money in the pockets, no money to spend. (Andrew 7/8/07)

Figure 17 - My wallet is empty ‘cause there’s no money. (William 31/7/07)

Figure 18 - This is a photo of money. Money is an issue for people on the pension. (William 31/7/07)

Figure 19 - Well, I don’t get pocket-money any more. Only the money that Centrelink puts in my pension. And even that, I can’t even spend that on what I want. It goes straight into my savings account. It’s controlled by my dad. He’s opened up an account which I can’t touch. Last time I heard it’s got three grand in it. (James 6/6/07)
Figure 20 - This is a photo of things I can't afford. (Andrew 31/7/07)

Figure 21 - Places I can't afford to go to. (Andrew 31/7/07)
Figure 22 - If I want something, I have to wait 'til Christmas or birthdays. (Andrew 20/6/07)

Describing the photo above Andrew exclaimed, “Clothes, expensive, money, what I can't afford. I can't afford heaps of clothes. I can't go out willy-nilly and spending heaps and heaps of money…If I want something, I have to wait 'til Christmas or birthdays” (Andrew, 20/6/07).

Figure 23 - You don't go out to restaurants when you live on the pension. (Andrew 20/6/07)
Rules that Restrict Us

"Rules are my barrier. Some rules are important… The rules in the home are not explained to me… The rules are not written down… 'cause I can't read" (Alex, 20/6/07).

Figure 24 - Some rules are important. (Alex 20/6/07)

Figure 25 - I'm not allowed in the kitchen. (Alex 20/6/07)
Other People

Alex named the things he was not happy with in the Group Home. He had symbolised the Group Home rules photographically using a photo of a house. Looking at the photo and pointing to the house Alex stated “The problems are all in there” (Alex, 31/7/07).

Alex also used the home to symbolise other people, the residents and staff, as people who restricted his personal freedom. Alex claimed that some staff were provocative and spiteful.

“He started on me first thing when he got in... And he said “I've got proof [Alex]” and he didn’t really have proof (because it wasn't true)... And so he rang my mum and he said “I don't think you should talk to your son... He tells lies about me.” (Alex, 31/7/07)

Alex claimed that the Group Home staff held grudges and repeatedly made threats to upset him:

“But on Friday [Fred, staff] came in, still going on about the day before... and I'm going to tell your mum” (Alex, 31/7/07).

“He does it to get me in trouble” (Alex, 31/7/07).

“The carers get me into trouble... I’m in trouble for everything” (Alex, 31/7/07).
Figure 28 - Penrith TAFE representing education (Bart 20/6/07)

“You get picked on at school because you’re different. It’s like racism” (Kathy, 23/5/07).

“Bullying is a barrier. Other people bully you when you’re in a special class or they know you go to a special school” (Bart, 20/6/07).

“I got bullied a lot…I still get bullied. Bullying is a barrier” (William, 23/5/07).

“We got called "spuds" at school” (Bart, 23/5/07).
Communication

Several common themes combined to make the barrier called Communication. These included a lack of local public telephones, the high cost of mobile phones and a Group Home rule prohibiting Alex from using the home phone or his own mobile phone.

“‘I’m not allowed to use the phone at home’ (Alex, 26/6/07).

“I’ve got a mobile but I’m not allowed to have my mobile. It’s not fair, because [Sean, another resident] is allowed his phone. My phone, it's got to be kept in the kitchen or the carer's office. When my mum wants to speak with me my mum has got to ring the house first and say to give [Alex] his phone. Then she'll ring me on my mobile” (Alex, 4/8/07).

“If I don’t have a mobile and I want to make a phone call I can’t make a phone call because there aren’t any public telephones around” (Alex, 26/6/07).

Other group members confirmed:

“There aren’t enough of them [public telephones] and they’re often broken” Bart, 26/6/07).

“I reckon they take them [public telephones] out because they want you to buy mobiles” Andrew, 26/6/07).

“Mobiles are expensive. They think that people can afford a mobile” (Bart, 26/6/07).

“Communication is a problem without telephones, you have to write letters” (William, 26/6/07).

Figure 29 - (Andrew 13/6/07)  
Figure 30 - William and the letter boxes (Andrew 13/6/07)
Government agencies (particularly Centrelink, the Tax Office and The Department) were named as cumbersome and restrictive institutions that limit people's ability to control their own life, due to regulations, form-lodging requirements, minimal financial support and reliance on written text to notify people of information. The above sign was photographed by James to represent the Government, which he saw as a barrier to him having control of his life.

The electoral poster had been liberally plastered over walls throughout the community and clearly identified the face of the local State Member of Parliament Karyn Paluzzano. However, when the photos were printed and ready for exhibiting, that particular politician was one of the people whom the group had chosen to invite to the exhibition launch. As a group we reflectively discussed how she might feel seeing herself displayed up on the wall, depicted as a social barrier.

“She might be embarrassed” (William, 23/8/07).

The group agreed that it was not their intention to embarrass her. It was not the individual politician who was a social barrier but the controlling nature of Government in general. Rather than embarrass Karyn Paluzzano or represent this
politician in a false light, the group agreed to download iconic pictures of the Prime Minister of the day, (John Howard) and the NSW Premier, (Maurice Iemma), to broadly represent the barrier of Government. Bart remembered “We can get them off the Government website” (Bart, 23/8/07).

Figure 32 - Maurice Iemma
NSW Premier 2005-8

Figure 33 - John Howard
Australian Prime Minister 1996-2007

Figure 34 - Penrith Taxation Office (Andrew, 13/6/07)

Andrew took this commanding photo of the Penrith Taxation Office because “The tax office are a barrier because they take your money” (Andrew, 13/6/07).
Another arm of Government named as a barrier was Centrelink (Figure 35). When sorting the photos with Andrew, Gill commented “How appropriate that there is a red light outside the Centrelink office” (Gill, 20/6/07). Other comments on Centrelink included

“Centrelink is a barrier. You have to wait in line a long time and the staff at Mount Druitt are no good. The computer always break down there” (William, 7/8/07).

“I had to go without my rent assistance payment for about six months because no one would believe me when I said that my pension was short. Centrelink is a barrier for keeping my money and the carers are too, for thinking I was telling lies” (Alex, 21/9/07).

Alex’s mother criticised the disablist Government procedures and systems for people with limited literacy:

“No one checked Alex’s statements for him. No one was listening to him when he said his payment was short. If he can’t read the form and The Department doesn’t give him the support, what can he do?” (Heather, 24/9/07).

Limited literacy and a lack of support meant that Bart ended up owing Centrelink money.

“I’ve got to pay back $2000 of mobility allowance that I didn’t even know I was getting” (Bart, 27/8/09).
Employment

“Some [disability] employment services said I couldn’t get a job”
(William, 20/6/07).

“There’s a lot of discrimination”
(Andrew, 31/6/07).

“I don’t want to be on this [Transition To Work] program. I would rather have a job” (James, 20/6/07).

“Some [disability] employment services don’t give you the right level of support you need to get a job and so they can’t really help you get a job”
(William, 20/6/07).

“I wasn’t allowed to get a job. They (the school and my parents) decided I should do this program instead”
(James, 20/6/07).

Figure 36 - James wants a job

Figure 37 - Nova never found me a job.
(Andrew 13/6/07)
Public Transport

Figure 38 - Buses are always a problem. (Bart 31/7/2007)

Figure 39 - Some people find bus timetables difficult to read. (Bart 31/7/2007)

Bus transport is particularly confusing for some people – timetables can be inaccessible, updated information advising commuters when buses are delayed is not provided and there is frequently nothing more than a small bus stop sign.
Figure 40 - The empty seat represents me waiting for the bus. When I'm sick of waiting, I just leave, myself. (Bart 27/6/07)

It is also hard if the bus stop has no seat because someone with a disability might not be able to stand for long, that's a barrier” (William, 7/8/07).

Figure 41 - Inaccessible signage (Andrew 20/6/07)
Figure 42 - You can tell what this sign means. (Andrew 3/10/07)

Figure 43 - Two indicator boards side by side were confusing (Andrew 26/6/07)

"I get confused because it's got two. I don't know which sign to read" (William, 7/8/07).

“The indicator boards go too fast. I can read, but not that fast” (William, 7/8/07).
Ticket machines (Figure 44) were found to be particularly intimidating (for all of us). When presenting at conferences to diverse audiences the group has found that most people find the machines challenging. (How much more so if you have difficulty reading text and following sequences?) William confessed “I can’t use ticket machines so I just don’t buy a ticket” (William, 7/8/07). (With no staff at his local station, what choice does he have?)

Figure 44

“...they are too expensive, and if you just want to go a short way, they won’t let you get in” (William, 7/8/07).

Figure 45 - Taxis were named as a social barrier (Andrew 20/6/07)

“The taxis stop me in life ’cause they’re expensive and I don’t have much money, so I’ve got to use vouchers. And some of the taxi drivers, they charge me too much. They should make me pay, half price, but they make it more than the half price” (Andrew, 26/6/07).
Communication skills of taxi drivers were also a barrier. William noted that their limited English skills caused them difficulty in understanding the way he spoke.

“Taxi drivers are a barrier. The drivers don’t speak English and sometimes they don’t understand me very well” (William, 7/8/07).

By the end of August 2007 the group had chosen 80 photographs to be enlarged and framed for the Photo-voice project exhibition entitled “Rights, Camera, Action!” The photos and their captions were professionally printed, framed and displayed in the exhibition according to the barrier theme that emerged from the photographic text analysis. Barrier themes were No Money, Rules that Restrict Us, Rules that Control Us, Other People, Education, Communication, Government, Employment, Public Transport and Taxis.

I asked the group to prioritise the barrier themes in order of urgency so that we could identify which one they thought most important and required investigation. I wanted to determine the barrier that was most common (hopefully a barrier shared by everyone) and which everyone agreed should be addressed as a matter of first priority. However, Bart suggested “we conduct a visitor’s survey during the photographic exhibition launch” (Bart, 13/6/07). The survey is discussed further on page 225.

8.4.2 Western Sydney exhibition

Planning the exhibition

The exhibition launch was something we discussed from the first day of the project and was a goal towards which everyone was working during Stages 1 and 2. It was an event that captured the imaginations of all the team and allowed their entrepreneurial talents to come to the fore. It was an experience that proved to be a valuable learning opportunity for us all. In this section I discuss how we planned for this event.

Choosing the venue for the Photo-voice exhibition was a team decision. We brainstormed venues, compiling a list of eight possible venues. After taking into account the time and day preferred by the team we could narrow the choices. The group unanimously decided Friday was the best day. “People go out on Friday nights” (Bart, 13/6/07). They preferred the event in the “evening so that workers
can come after work” (Andrew, 13/6/07). William used his mobile phone to find suitable dates in September 2007, telling the group

“7th September, 14th September, 21st September and 28th September are all Friday nights” (William, 13/6/07).

We agreed I would give these dates to the Council and see if the Mayor was available. The team was keen to have the Mayor open the launch.

They wanted a venue in close proximity to public transport and the central business district of Penrith (to attract more visitors). Eventually we came up with two favourite choices: The Joan Sutherland Centre and Penrith Library. The team allocated me the task of contacting the venues to find out costs involved, facilities available and the venue’s availability. On hearing my report, the group decided upon Penrith Library as the venue for our September launch. The Mayor’s availability on 14th September fixed the date.

Team work and good ideas

The Photo-voice team had many ideas for their exhibition.

“A red carpet... cutting a red ribbon” (William, 20/6/07).

“Wine?” (Andrew, 20/6/07; Bart, 29/6/07).

“Cold or hot food, because how would we heat the hot food up?” (Bart, 20/6/07).

“A live band playing cover versions of Midnight Oil songs” (William, 20/6/07).

To which Bart very practically suggested

“We could give them some thank you money... $100... for petrol” (Bart, 20/6/07).

Bart also suggested

“How about a gold coin donation? If people want to contribute to our costs?” (Bart, 29/6/07).

Given that we were planning to cater for the event and hire a live band this was a most welcome idea. William supported it and volunteered to be part of setting up the contribution box. “I used to know how to make cardboard boxes” (William,
Andrew suggested

“We could have a lucky door prize... a raffle to raise money” (Andrew, 13/6/07).

Freedom to plan the exhibition really captured the group’s imagination and generated weeks of activity. I found that the library would not allow a raffle but the lucky door prize idea was permissible and very popular with the group. Together they brainstormed what prizes might be suitable and how they would secure them. Suggestions included: meal for two at an RSL or Panthers Club (Andrew, 15/8/007), movie tickets (James, 29/6/07), bottle of wine (Bart, 29/6/07), gift voucher from Westfields (William, 29/6/07). The group decided to cold-canvas shops in their local areas asking for donations of items that would make suitable prizes. Bart requested I provide a letter of introduction “So they’ll know that we’re not just going to keep it” (Bart, 20/6/07). Andrew provided me with his club membership numbers and requested I write to a number of sporting clubs on his behalf seeking financial sponsorship for the project or donations in kind (such as meal offers). In this way I was frequently purposefully directed by the team to act on their behalf.

Following an unsuccessful week of cold-canvassing, the group set aside two Photo-voice sessions, targeting specific businesses, in order to secure some lucky-door prizes. This too was unproductive. The team critically reflected upon their actions to determine how they could have been improved. Although they had all had a laminated letter of introduction bearing our Photo-voice motif Bart noted “Some shops, like Westfields and that, said they only support school groups” (Bart, 18/7/07). James suggested that “they’re not going to just give stuff away” (James, 18/7/07). Through critical and reflexive dialogue the group came to recognise that even though we were a real group of people doing research, businesses seemed to prefer to support organisations such as schools and registered charities. This may be for many reasons including established reputations that can be trusted, taxation purposes or personal loyalties. Bart asked “why don’t we just buy a bottle of wine as the prize?” (Bart, 18/7/07). We all agreed that this was a very simple

49 Returned and Services League club and a local rugby league club.
50 A large shopping centre.
solution and so I purchased a $30 bottle of wine.

The experience of approaching businesses had been helpful. People admitted that this activity initially made them feel “shy” (William, 15/8/07). However, after approaching a few shop-keepers they said that they had gained confidence in how they promoted the project.

**Catering: cooperation, negotiation, compromise and fun**

The decision to cater for the exhibition produced excellent teamwork. The group worked hard to achieve consensus on decisions and share responsibilities. Alex volunteered to obtain quotes for cheese platters from Coles and Woolworths. This simple suggestion raised institutional concern within his Group Home, which actively tried to prevent his participation in this aspect of our project (see 10.4.1 Vignette 4). However, with the support of his mother, Alex gathered a number of catering options for discussion. Other ideas were also put forward.

“I was thinking we could do a fruit basket too” (William, 29/6/07).

“How about some Sara Lee cake as well? Cut up into squares” (Andrew, 29/6/07).

“Sushi rolls…Dips?” (William, 29/6/07).

“Are we doing finger food? What about KFC?” (Bart, 29/6/07).

“Wine and cheese?... Coffee and cake?” (Gill, 29/6/07).

After the various options had been thoroughly thrashed out Andrew declared

“OK, I’ll be the ticker and you guys can talk to me and tell me which of these we want” (Andrew, 29/6/07).

We then proceeded through a list of food options. Mindful of the exhibition audience Andrew asked “What do you think the Government would like?” (Andrew, 29/6/07). I commended the question as thoughtful but reminded the group, regarding the food “This is your exhibition… forget the visitors – this is your night” (Janice, 29/6/07). The following transcript extract demonstrates the negotiations that took place. The group is discussing what cake will be served at the exhibition launch.
Andrew: “OK. Chocolate?”
William, Bart: “Yes, chocolate.”
Bart: “How about wine?”
William: “Let’s just have tea, coffee, juice and water.”
Bart: “What about coke then.”
Andrew: “OK, Coke.”
Janice: “Alright then, jugs of coke, and we’ll need cups.”
William: “Will we do cans of coke?”
Andrew: “The Prime Minister won’t want to drink from a can. Cups are nicer.”
Bart (volunteering to source and purchase drinks for the launch): “What about if I can get cans on special?”
Janice: “I know Bart, but I think Andrew’s right, it is just a little bit classier to be holding a glass or a cup rather than drinking straight from a can.”
Andrew: “Yeah, I reckon.”
Bart: “Well I prefer cans.”
Andrew (presenting a rational argument): “No, we’re having important people coming and we should do it right.”
Janice: “OK, well you guys have to reach a decision and all agree. William what do you prefer, cans or cups?”
William: “Why don’t we have cans and cups?”
Janice: “Ok – good compromise – we’ll do both. All agreed?”
William, Andrew, Bart: “Yes.”
Bart: “We’ll get buckets and put ice in ’em, then have a water fight afterwards.”
William (laughing, getting loud and excited): “Yeah, really big buckets!”
Andrew (laughing): “We’ll have water everywhere!”

(Transcript, 29/6/07)

The Photo-voice group frequently engaged in open, rational discussions such as this. People were free to raise their own ideas, dispute suggestions asserting their own preferences, and to argue their point. Discussions were a fundamental feature of the project with negotiation and compromise key outcome goals.

An interesting debate arose while we were discussing the catering for the exhibition. Amid the talk about what to serve and how to do it on the night, the following conversation unfolded which revealed Bart’s egalitarian awareness of the need for social equity:
Bart: “What are we going to do? Are we going to be waitresses and take the food around?”

Andrew: “Well, with the Prime Minister and all the important persons, we can walk up to them and serve them.”

Bart: “Oh, you can’t have the bums, and all that, have to serve themselves but the Prime Minister - Ooo, we give it to them!”

William: “Or we could hire someone to do that.”

Janice: “Or why don’t we just have serve-yourself?”

Andrew: “Yeah, let’s do that, serve yourself.”

William: “Yes, then they can browse around and pick what they want.”

(Transcript, 29/6/07)
The suggestion to provide light refreshments at the launch was embraced enthusiastically by the group. Menus were thoughtfully debated and everyone was willing to participate in the purchase, preparation and cleanup involved in catering.

**Guest list**

They were also very eager to prepare an exhibition guest list. The group’s clear understanding of the human rights aspect of the project was reflected in their excited discussion around who to invite to the exhibition. We began planning an invitation list early as we recognised that important people are very busy. We would need to invite them early so they could plan to come. The first suggestion was “Peter Garrett always likes to go to these social things” (William, 6/6/07). William also suggested that Midnight Oil play at the exhibition. This was an exciting idea that was greeted with cheers and approval by all. The group thought that Bob Geldof and Bono would also be interested in our project. These important world figures are famous for their public concern for human rights and the environment. The group clearly saw them as allies who would share their concerns as this was a project concerning rights.

I reflected on these suggestions and wrote in my Journal

> On one hand I see limited realism but on the other there is vision that dares to dream. It is quite lovely, and so we’ll send out invitations to all those mentioned (maybe not Bob Geldof) and shoot for the stars” (Journal, 29/8/07).

We did in fact send invitations to Geldof, as well as Bono (whom William contacted through their fan club) and Peter Garrett. The group was excited to receive a reply from Peter Garrett expressing his regretful apologies.

Who else should we invite? We discussed as a team the benefit of holding the exhibition in September 2007, just two months away from the 2007 Federal election. Inviting politicians would give us an opportunity to raise issues that we would like them to consider. The group demonstrated their political awareness, James suggested “How about Morris Iemma [NSW Premier]?”, which was a great start to the brainstorming of our invitation list and showed his ability to generate relevant ideas. “And we’re all over 18” added William, making a clear link between

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51 Peter Garrett - Australian Federal politician, once renowned for being outspoken on social issues and the former lead singer of the rock band ‘Midnight Oil’.
the impending election and the group’s age (Transcript, 6/6/07). This triggered a
conversation about the democratic power people have in deciding who will run
their country, a power the Photo-voice group also participated in. I was surprised
by the level of political awareness that most of the group demonstrated.

William asked “Why don’t we get the Prime Minister & opposition leader to come
too?” James again suggested: “How about Morris Iemma?” and started a
conversation with William who asked “... and John Aquilina. Is he our local
member still?” I suggested that we could invite them all, though they might be
very busy, and suggested that we could probably get our local State Member of
Parliament, Karyn Paluzzano, to attend (Transcript, 6/6/07).

The invitation list was also to include people who might address the barriers raised
by the group. For the barrier of No Money Andrew suggested we

“Invite the boss of Westpac [bank] to come to our exhibition and invite the head of
Centrelink to come to our exhibition. They won’t know we have a problem unless
we tell them” (Andrew 29/6/07).

On the barrier of communication William suggested

“We should invite Telstra to come. We can tell them there are not enough public
phones and that people can’t afford mobiles, if they come” (William 6/6/07).

Visitor’s survey

One week as we were codifying the photos into barriers and discussing how not all
barriers could be explored, the following discussion occurred.

Bart: “How about we make a sheet for the visitors to the exhibition to complete, like
a poll and ask the visitors to the exhibition [about social barriers]? ...Then we can
explore whatever they think is the worst.”

Janice: “You mean, like a survey?”

Bart: “Yeah. Maybe we could number the photos or something, and give them a list
and then they could tell us what number... And we can put it up on the website too
and ask people to vote on the barriers... and then that would be the one we explore.”

Janice: “A survey into cyberspace! [Bart] that’s a great idea.”

William: Why don’t we get them to tick the ones they choose?”

Andrew: “Yeah, they could tick them.”

(Transcript, 13/6/07)
Bart’s basic computer training had provided him with insight into the usefulness of technology. The visitor’s survey and the web-poll were both very exciting ideas. (Eventually, Stage 4 of the project would involve developing a website (see 12.3) but this did not occur in time to influence the group’s decision on which barriers to explore. Even after we had developed the website, no one in the team had sufficient skills to build the web-poll – although we did create a gallery upon which website visitors could comment.)

The idea of an exhibition visitor’s survey was enthusiastically embraced by the group with members offering excellent suggestions regarding how this might be done. Andrew and William’s tick-box suggestion appeared to be an accessible method for innumerate visitors or those with sequencing issues.

William proposed we “download the digital photos and have them on the sheet” and Bart offered to “scan the photos” (Transcript, 13/6/07). A pictorial survey certainly sounded innovative and inclusive and I was encouraged that these two young men seemed to know how we might do it.

Andrew’s idea of a lucky door prize for exhibition visitors was quickly built upon by others.

“Instead of the lucky door prize we can tell them there’s a prize for someone who hands back the survey. That will encourage people to fill them out and hand them in” (Bart, 13/6/07).

To determine the winner William suggested

“We can pull their names out of a hat.”

Janice: “Don’t you think the surveys should be anonymous?”

Andrew: “Not if they want to win a prize.”

(Transcript, 13/6/07)

This highly pragmatic response from Andrew alerted me to the fact that we could design the survey so that people did not have to identify themselves on the surveys, unless they wanted to participate in the prize draw.

Once the group had identified the barrier themes, I asked them to select photos which might represent each theme. Various members pointed to photos and said
things like “How about this one” (Andrew, pointing to picture of phone booths 29/8/07). People readily agreed with each other’s suggestions. Once one theme photo was chosen another team member nominated the next. Separate photos were chosen to depict bus transport and train travel, plus separate photos were chosen for rising prices (No Money) and limited opportunities because of no money. Alex also requested we have photos showing Rules that Restrict, while Brendan chose Rules that Control. Before long they had provided me with a selection of 10 photos with which to develop the survey.

Following the group’s suggestion the survey requested participants to tick a box next to the barriers that were of concern to them.

Andrew suggested we have a box in the library for the placement of surveys, and volunteered to cover a box with paper to make it attractive. I provided some Photo-voice paper by printing off sheets covered with our Photo-voice logos (right), downloaded from “Clipart”. Andrew recruited help from his family to cover the box.

During the photographic exhibition launch the team handed out surveys, discussed the project with visitors, assisted with the serving of refreshments and worked together tidying up at the end of the evening. After the completion of the exhibition the group would tally the survey results.
The exhibition

The photographic exhibition was held in Penrith City Library from 14-28 September 2007. The team gathered early in the afternoon to set up for the 5pm launch. We enjoyed blowing up balloons, setting up the catering and displaying the photos in their themes.

The exhibition launch was opened by the Penrith Mayor Pat Sheehy and attended by academics from UWS, the local MP Karyn Paluzzano, local disability service providers, family, friends and the wider community – about 40 people on the night. The Photo-voice team handed out the visitor surveys as people arrived and invited them to return the surveys to the survey box (carefully decorated by Andrew). The
surveys also went into a 7pm draw and the lucky winner received a prize (bottle of wine).

Throughout the launch the research team mingled with the visitors and spoke about their work. Local MP Karyn Paluzzano offered to speak on the team’s behalf to both the NSW Minister of Transport and the Minister for Ageing, Disabilities and Home Care.

Although held in the library, daily supervision of the exhibition was not the library’s responsibility. I dropped in regularly to ensure the photos were still hanging. The team also decided to conduct the survey only during the launch.

Exhibition debrief

Our Photo-voice meeting after the launch of our exhibition took the form of a debriefing session with each member sharing thoughts on the event and discussing how it could have been improved. While we unanimously agreed that the exhibition looked “awesome” (Andrew, 19/9/07) and we had done a fantastic job, improvements could be made. In particular, we agreed that we had achieved the Photo-voice aim of getting the message out to those in positions with power to implement change (Minutes, 19/9/07). A summary of other comments made appears below.

<table>
<thead>
<tr>
<th>Positives</th>
<th>Negatives</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Exhibition looked wonderful, very professional</em> (Andrew)</td>
<td><em>Numbers in attendance were low</em> (Janice)</td>
</tr>
<tr>
<td><em>The balloons looked great and were easy to take down afterwards</em> (William)</td>
<td><em>Possibly Friday pm was wrong choice in time. Maybe should have changed this once we knew we were no longer having the band</em> (Bart)</td>
</tr>
<tr>
<td><em>Very positive feedback/comments received</em> (Bart)</td>
<td><em>Wrong venue for evening exhibit. A club might have attracted more people going out at night</em> (William)</td>
</tr>
<tr>
<td><em>Barriers were clearly expressed</em> (Janice)</td>
<td><em>Sarah [Disability Service employee] suggested we include captions to the Powerpoint photos as well</em> (William)</td>
</tr>
<tr>
<td><em>Surveys were completed by visitors</em> (Bart)</td>
<td></td>
</tr>
<tr>
<td><em>It finished early and so was an early night</em> (William)</td>
<td></td>
</tr>
</tbody>
</table>

(Minutes, 19/9/07)
We also tallied the survey results for each barrier. Of the 21 respondents, the most common barriers chosen were Public Transport (15) and Rules that Restrict Us (15). Unfortunately the survey was of limited use. Upon reflection its wording was too vague to accurately render the opinions of participants. It did not explicitly direct participants to prioritise their concerns. However, it was a useful learning experience upon which we could improve in the future.

8.4.3 Two main barriers identified

The Photo-voice team was pleased that the results of our survey mirrored the team’s common concern regarding public transport. At our 19/09/07 meeting it was agreed that the Photo-voice research focus would be the social barrier of Public Transport.

Interestingly, the survey results also highlighted a community concern regarding Rules that Restrict Us. This had been a particular concern to our colleague, Alex. Throughout Stages 1 and 2 of the project issues concerning disability service practices within Alex’s Group Home became alarmingly apparent to the team. As outsiders, we became very aware of the rules that restricted him. Chris proposed “I think we should go with [Alex’s] barrier. That’s important” (Chris, 19/9/07). It was therefore agreed that the group would investigate two barriers to self-determination. Our actions to address the barriers of Public Transport and Rules that Restrict Us are detailed in Chapters 9 and 10.

8.4.4 Central Coast exhibition

In December 2007 we held another exhibition, coinciding with the International Day of Persons with Disability on 3rd December 2007. I thought that this would be a fun way to end the Photo-voice project and would be an appropriate way to celebrate our achievements. Both Andrew and Bart requested it be held on the Central Coast, with Bart noting “then my mum would be able to come and bring all my brothers and sisters to see it” (Bart, 19/9/07).

Bart suggested Gosford Library would be a key venue. I contacted Gosford Council and was informed that there was “an exhibition space in the foyer of the Erina Centre” and “This sounds like a great exhibition for that foyer” (Manager of Erina Centre, 4/10/07). The Erina Centre, connected to Erina Library on the NSW
Central Coast, was located in a large shopping plaza. The group agreed to exhibit their photos in the Erina Centre and recognised it was a far superior venue to the Gosford Library. “Lots more people will see the photos here at Erina and there’s more room than at Penrith Library” (Bart, 3/12/07).

William suggested that the Break Thru TTW program in Wyong would be eager to attend our exhibition. Although Photo-voice had nothing to do with Break Thru, on William’s request, I contacted the Wyong office to see if they wanted to be involved by either bringing their TTW trainees to the exhibition or possibly assisting the group to erect and then dismantle the exhibition when it was over. Break Thru was very supportive of our group. Both William’s Blacktown TTW group and the Wyong TTW group visited the exhibition on the first day. William was especially proud of this and reminded me a number of times on the day of the exhibition that “The TTW group are coming up for the exhibition. I want them to see all our photos” (William, 3/12/07). When they arrived with a van-load of eight TTW trainees William guided them through the exhibition, explaining the photos. It was significant to the Photo-voice team that they were recognised as exhibiting photographers and social researchers by their peers (and seemed particularly important to William).

8.4 Conclusion

The end of Chapter 8 marks a significant transition point which can be viewed at various magnifications. Moving from telephoto to wide-angle:

In close up, Chapter 8 has provided a summary of what the Photo-voice group achieved during Stages 1 and 2 of the research project. The team members established roles and relationships and undertook photography and ethics training in readiness for the task of identifying their social barriers to self-determination. After collecting and analysing the photographic data we collaboratively planned, organised and ran two Photo-voice exhibitions to raise awareness of their concerns. Having then identified two specific research problematics, Public Transport and Rules that Restrict Us, the team was ready for action. In Chapter 9, I explain how the Photo-voice team researched their first social barrier.

52 Wyong is a suburb on the NSW Central Coast.
Lengthening the focus, within the Photo-voice project we are moving from Stages 1 and 2 (collecting and analysing the photographic data and interpreting the findings to determine specific Photo-voice research areas) into Stage 3 (actively researching and taking social action on specific barriers to self-determination).

Taking a panoramic view of the whole thesis, the foundations of human rights and inclusive methodology were laid in Part 1 – Rights. Accessible methods were developed and applied in Part 2 – Camera. In this final Part of the thesis, Action!, I describe how the group members explored their chosen social barriers and collaboratively took action to address the issues raised. The Photo-voice research progresses from a facilitated IPAR project to an emancipatory project, funded and directed by the IPAR team itself.

*  

From any perspective it’s now all about Action!
At the conclusion of Part 2 – Camera, the Photo-voice group had identified two research problematics to explore, Public Transport and Rules that Restrict Us. Part 3 – Action! will explain the how we investigated these issues and analysed our data. It will describe our actions, interactions and reactions.
Chapter 9 – Public Transport: exploration / investigation and action

9.1 Introduction

Public transport presented as a barrier to self-determination for the Photo-voice group, and also for most of our exhibition survey respondents. In Chapter 9, I deal with how the research group explored the barrier of Public Transport. I begin by sketching the context in which the barrier arises and provide an example of the issues faced by the group with data obtained from a public transport excursion. I describe how the Photo-voice method was introduced to institutional ethnography
so that the web of social organisation within the public transport system could be explored. Our social action taken to address the issue is also discussed.

9.2 Stage 3a: clarifying the barrier

The group’s concerns regarding public transport were many and varied. None of my research colleagues had their own means of transport. All relied on public transport, or assistance from others, to travel to where they wanted to go. The Sydney public transport system is not particularly good for most people who commute (8.3.3). However, for people labelled with learning difficulties the problems extend beyond trains running late, poor timetabling or cancelled services. The group collectively identified one problem with Sydney's public transport system as an unhelpful reliance on text-based signage and technology that assumes all the travelling public can read. But not everyone can read, so not everyone has access to the information displayed.

The research group photographically provided numerous examples of disabling text-based information displayed on the public transport system. In the following dialogue a number of barriers emerge, represented by Andrew’s photo of CityRail’s Next Train indicator screen (Figure 49).

Janice: “Can you read those”?
Andrew: “No, I have to go and ask someone.”
Janice: “And how does that stop you from controlling your life?”
Andrew: “Cause I can’t read them and so I have to go and ask someone…but then some of the station people are rude.”

(Transcript, 26/6/07)

Barriers arising from this dialogue include the use of technology that presumes literacy skills. Inaccessible information results in a loss of autonomy and creates a dependence upon others. Such dependence exposes Andrew to poor customer service (which may also indicate disablist attitudes).

During a discussion of alternatives to text-based information systems I asked the
“Communication is a problem with CityRail. The announcements on the platform - … you can’t always understand it. Sometimes they say ‘the first four carriages’ or ‘the last four’, and you don’t know which ones they mean. They should have better signs. CountryLink trains, they have ‘first carriage’, ‘second carriage’ and all of that. It’s very clearly marked on CountryLink. Why can’t they do that on CityRail?

“You know how some stations have the small platforms? Well I nearly fell out one time… There was no platform there. And I missed my stop. I nearly stepped onto the track ’cause I was in the wrong carriage. I couldn’t get off the train” (Bart, 13/6/07).

Andrew, Bart and William had difficulty with the indicator boards and Bart frequently found the audio announcements ambiguous. Both inaccessible technologies had ramifications that negatively affected the group members.

These examples are just two from a plethora of ways the research team members were unnecessarily disadvantaged on the public transport system. We saw our public transport issues as being directly related to both safety and civil rights since all the public should be able to access public transport information and technology such as timetables, ticket machines, indicator boards (in addition to things such as safety signs, toilets, disabled seating or warning notices). Without access to this information, people cannot be self-determining.

9.3 Actively exploring the barrier

9.3.1 The excursion

Following our September exhibition, our first action to explore the Public Transport barrier was to take an excursion on Sydney’s trains, buses and ferries. Public transport is a problem for people with impairments (Rego, 2010). The Photo-voice data obtained in Stages 1 and 2 of the research project (Chapter 8) identified a heavy reliance on textually-based technology and text-based information signage that is inaccessible to people who have limited English literacy skills. Although none of us was aware in October 2007 of the Disability Standards for Accessible Public Transport (Australian Government, 2002) or the NSW Government’s review of the accessibility of public transport system (Allen Consulting Group, 2008), we

53 Part of RailCorp, servicing country NSW and interstate destinations.
thought the public transport system needed looking into.

At our weekly Photo-voice meeting of 19/9/07 I suggested that the group go on a public transport excursion. We could continue to use Photo-voice to record all the transport text creating barriers for them and explore these as they were encountered when travelling on the public transport system. The group was very enthusiastic about the idea and debated what modes of transport we should use.

Air travel was jokingly suggested (an option I hadn’t thought of), but realistically dismissed by the group as they all agreed that costs would be prohibitive.

Andrew: “We could go in an aeroplane.”
William: “Or on a mystery flight?”
Bart: “Who’s going to pay for that?”
Andrew and William: “Oh yeah!”

(Transcript, 19/9/07)

They also discussed where we should travel to. Alex suggested “We could all catch the train up to my mum in Newcastle” (Alex, 19/9/07). However, I pointed out that since everyone lived in Sydney and the barriers they encountered were in Sydney, exploring Sydney’s public transport was probably our most useful option. It also meant that we could experience the train, bus and ferry services in a relatively short period of time. The group agreed to keep the excursion Sydney-based and all thought that a trip into the city of Sydney would also be a fun activity.

“Yes! Let’s go to the city” shouted Andrew (Andrew, 19/9/07). So, in October 2007 our group undertook an excursion from the outer western suburbs of Sydney into the city, a distance of approximately 60 km. During the excursion we travelled on the major modes of public transport - buses, ferries and trains.

I met Andrew at Penrith Station and we travelled together by train to Blacktown, where we met Bart & William. From there we caught a bus to Parramatta, then travelled by ferry up Parramatta River to Circular Quay, Sydney. The journey took approximately three hours. We explored the railway station and wharf at Circular Quay before catching the train home again. At the end of the day Andrew also caught a taxi from Penrith to his home, though the rest of the group did not travel on taxis for the excursion.
Figure 50 - Sydney Harbour (Andrew 3/10/07)

Figure 51 - Signage at Circular Quay (William 3/10/07)
Photographs were taken of the technology, signage and written instructions provided by the transport authorities (supposedly) to assist and inform the public. We found that some of us were unable to access (or understand) much of this information. Limited access to information limits opportunity for self-determination. Figure 51 demonstrates the visually dense array of signage to be negotiated by commuters.

9.3.2 Textual analysis

Covering their butts, propaganda, ableism

The Photo-voice group was keen to find text to photograph and as the day progressed they became increasingly enthusiastic. When a particularly inaccessible notice was found, such as the Penalty Notice of Figure 52, my colleagues became excited, shouting comments to one another such as “Oh look at this one. It’s really bad” (Andrew, 3/10/07).

![Figure 52 – “Look at this one, it’s really bad” (Andrew 3/10/07)](image)

When I asked what was bad about the Penalty Notice the group demonstrated considerable analytical skills and insight. They criticised the formatting of the text,
claiming

“It has too many words and they’re too little” (Andrew, 3/10/07),

“You can’t read across the page. It’s in columns... It’s boring too. The black writing on the white background. I don’t even want to read that sign” (William, 3/10/07).

Not only was the layout confusing and unattractive, but it was textually dense. The message of the text was lost in the volume of information given.

“No one is going to read all that. Who has time to read all that before they catch their train?” (Bart, 3/10/07).

I asked the group why the sign was there if people could not reasonably be expected to read all the information on the Notice.

“To cover their butts” (Bart, 3/10/07) was the insightful reply.

Following this in situ textual analysis we decided that the Penalty Notice didn’t actually inform anyone of anything, because it was poorly designed and too difficult to read. This meant that the sign was not information at all. It did not really inform the public of possible consequences associated with their travels. It was just words on a page. We also wondered if perhaps its purpose was to fulfil an obligation (thereby “covering their butts”), rather than to inform the public. Along with Bart, we suspected that the sign was there for the benefit of the authorities rather than for the travelling public.

The Photo-voice group identified numerous inaccessible texts which we believed might significantly affect the lives of the non-reading public and could mean that they were unable to travel safely or independently – even if they were mobile and could learn how to use the transport system. We recognised that limiting opportunity for independence was a means of limiting self-determination. But not all signage was poor. The large Tickets and Trains sign (Figure 42) used pictures to complement the text.

“You can tell what this sign means” (Andrew, 3/10/07).

Unfortunately, most signage was found to be exclusive to the Photo-voice team and perhaps also to the non-English-reading public.
In contrast to the “boring” black and white signage of Figure 52 described above was Figure 53. We textually analysed the larger sign shown in the Figure, commonly referred to by our group as “the spaghetti sign” (Andrew, 3/10/07).

“It’s colourful... glossy... I think it’s interesting” (William, 3/10/07).

“Well I think it’s confusing, what does it say? ... and look down there [pointing to the tiny disability notice beneath the sign]... that’s a little one” (Andrew, 3/10/07).

The larger sign was interesting and colourful, but it was also confusing. What did that tangled spaghetti mean? What was its purpose? I read the sign to the group. It gave an explanation of why Sydney trains run late. It was glossy and eye-catching and, if size means anything, its message appeared to be more important than that of the much smaller sign beneath it, which asked that the seat be vacated for disabled passengers.

We compared the large and small signs and I asked the group which sign they thought cost more to produce and which one was more important.

“The big one” (Andrew, 3/10/07).

“It’s printed with five colours, that’s expensive” (Bart, 3/10/07).

“They just want to look good... they’re just excuses” (Bart, 3/10/07).

The spaghetti sign in Figure 53 is propaganda. It serves the interest of the organisation (RailCorp\textsuperscript{54}) in trying to justify “delays at Sydenham” and across the

\textsuperscript{54} The NSW State-owned corporation which provides passenger rail services.
transport system, but is not particularly helpful. The sign dwarfs the disability signage, implying the RailCorp’s priorities are more about looking good than ensuring disabled passengers have adequate seating. Tucked away beneath the spaghetti sign, the disability sign looks like an after-thought.

We also critiqued the Sydney Ferries sign shown in Figure 54. When asked for whom this sign was meant, Bart replied “Us” (Bart, 3/10/07). However, after further discussion Bart said

“This sign says ‘Attention Sydney Ferries Customers’ but it should say ‘who can read English’ ‘cause people who can’t read, and visitors, and that, they can’t read this sign. And that’s not fair” (Bart, 3/10/07).

Bart had recognised an unspoken assumption embedded within the text – that all the travelling public can access the information on the sign. However, this barrier not only excluded people who could not read at all, but also those for whom English is not their first language – who might speak English but not read English. Andrew could not read and he exclaimed “That’s unfair” (3/10/07).

He demonstrated an awareness that those who cannot read the sign were still part of the travelling public and had a right to be able access the information on it. This information should, therefore, be made available to them in a format that they can access. Through discussion it was evident the group understood that it was the inaccessible signage and technology, rather than their individual impairments, that disabled them as commuters and created a barrier to their self-determination.

Bart’s observation that overseas visitors could be also disadvantaged by this sign was an encouraging indication of his awareness of the breadth of the exclusivity of the text. Its inaccessibility was the disabling barrier that had nothing to do with impairment.

We found the sign in Figure 55 peculiar.
“That’s stupid. Who wants to know where the toilet isn’t? It should say ‘Toilet this end’, and have it down there” (Bart, 3/10/07, pointing to other end of carriage).

The group discussed how the sign in Figure 55 could have been improved. Bart suggested removing the sign and placing one which included “a picture of a toilet” (Bart, 3/10/07) at the appropriate end of the carriage. Better still, William suggested “the gents sign” (Transcript, 3/10/07). These suggestions were far superior to the CityRail sign as there are internationally recognised symbols for toilets.

The team then began to brainstorm how the problem of inaccessible signage could be improved and what helpful advice we could feed back to those in charge of the public transport system. They eagerly suggested images to represent words and places. Pictorial signage of the Sydney Opera House was already around Sydney Harbour. The group decided that landmarks such as the Opera House were easy to represent pictorially.

However, they encountered difficulty when trying to think of pictures that might best represent other information – place names for example. Waiting for our train at Circular Quay station that afternoon, the group began brainstorming how to reconfigure the indicator board with pictures for suburb names, such as Bankstown: “You’d need a picture of a bank and a town” suggested Bart. Bart
also suggested that Hornsby could be represented by a horn and a bee. “But how would we do Penrith?” asked Andrew, “or Wahroonga?” I added (Transcript, 3/10/09).

A fruitful discussion took place during which the group members began to realise that making all signage accessible was a difficult task. We also came to the realisation, as with Shakespeare (2009), that some barriers were not necessarily the result of ableism, discrimination or oppression. They were the result of living in a complex society. Functional limitations (such as not being able to read) resulted in some barriers which are not easily removed. With this observation the mood of the group changed from enthusiasm (while brainstorming ideas of pictures to supplement place names) to being a little subdued. Bart reflectively said “Maybe it is just you can’t have pictures on all signs” (Bart, 3/10/07).

This observation shows great insight. Bart had recognised the limitations of pictorial representation on signage. It did not mean that nothing could be done. Some signs could be improved, just not all signs. In discussing our role of identifying social barriers I reminded the group that it was not our responsibility to come up with solutions (though hopefully we could make some useful suggestions). Our task was to highlight the problems we identified to those charged with the responsibility of making the public transport system accessible to all the public.

**Excursion debrief: critical dialogue**

At our next regular Photo-voice meeting (17/10/07) the group reviewed over 80 photographs that had been taken on the excursion. Their enthusiasm had significantly waned by this time and it was difficult to engage the group in the process of analysing the photos. I was keen to see what else we could find captured on the visual text so they could better read their world and view it with a more critical gaze (Freire, 1998). In his earlier work, Freire describes sketches and pictures as coded representations of an “existential situation” (1996, p. 86). I encouraged the group to decode their photographs and to not only explain what they saw but consider why things in the photos were as they were. Drawing also on Smith’s social theory (Smith, D., 1990) I sought to facilitate a critical discussion to illuminate how our lives are organised outside our knowledge and control and to
gain insight into institutional domination and subordination. Conversations were generated by asking questions such as “Why is this notice on display? Who benefits from this notice and who doesn’t benefit? Why do you think they don’t want people to stand on the seats of the ferry?” By the end of the session we had decided that many of the notices were to do with safety issues. Notices included

- No skateboard riding, no smoking, no standing on seats
- Do not travel between carriages or attempt to force exit on trains
- In an emergency or if train is delayed, stay within the carriage and await instructions
- Manual handbrake on trains is for emergency purposes only
- Fire alarm
- The location of the emergency Help Point on the railway platform.
- Unattended baggage warning signs.
- Safety instructions for boarding the ferry.
- Instructions to ferry passengers to keep clear of gangway when entering or departing the wharf.
- Lifejacket storage and instructions for donning lifejackets.

(Minutes, 17/10/07)

For the group, the crux of the issue behind the safety signs was that an inability to access such important information significantly disadvantaged non-readers and put them at risk. For example, our group found the life jacket notices in Figure 56 confusing. Even good readers might ask “Life jackets stowed behind what?” or “What is an aft passage?” Knowing where life jackets are stowed is important in a
ferry accident. The group came to the conclusion that while those who erected the sign might not intentionally seek to disadvantage non-readers, a disregard for their safety was evidenced by the inaccessibility of the information.

Other notices included:

- platform information (such as For Airport Line change at Central, Platforms 22 & 23, Toilets, Way Out)
- wide access gate instructions
- timetables for buses, trains and ferries
- reminders to have a valid ticket and the consequence of fare evasion
- ticket information such as TravelPass 2007 (a combined train bus and ferry ticket)
- information about track-work and cancelled services
- the need for cash only when purchasing a ticket on board a ferry
- concession fare information.

Applying the Convention

During the excursion debrief critical dialogue (above) on the importance of the information contained in inaccessible notices I had introduced the Convention to the group, including Article 9.1.Accessibility (United Nations, 2006e) which emphasises the human right of “access, on an equal basis with others,.. to transportation, to information and communications”.

The Photo-voice group considered that all of the information in the safety and other notices described above was also very important as they could be financially disadvantaged by not purchasing a cheaper ticket, might leave from the wrong platform, get lost or be charged for fare evasion by the police. They considered this information to be just as relevant to them as other members of the travelling public (Journal, 17/10/07).

Social organisation: invisibly interacting with trans-local ruling relations

By applying Smith’s institutional ethnography methods (Smith, D., 1990; 2004 and section 6.6 of this thesis), the research team was able to dialogically discover unknown actors within the public transport system with whom they unknowingly
Rights, Camera, Action!

interacted. Through discussion the group considered signage. We considered questions such as “Who put the sign there and why? Who gave those instructions? Why do you think they did that?” It was decided that while the signs may have been erected by local staff, the instruction to put up the notice would have come from “higher up in the [organisational] ladder” (Bart, 17/10/07). Through this discussion the group members discovered for themselves the complex concept of ruling relations (without using that terminology). Through critical dialogue, the group decided that the safety notices were erected because of influences from authorities outside the Transport Department. These influences included

“The Feds” (Bart, 17/10/07),

“Work Cover” (William, 17/10/07),

“Health Department” (Bart, 17/10/07),

“The police maybe?” (Andrew 17/10/07).

We also spoke about fares and who it was that decides the prices. This decision is not the station master’s or the ticket inspectors’. I explained that such pricing decisions were made trans-locally by the Independent Pricing and Regulatory Tribunal of NSW (IPART). It is IPART’s responsibility to regulate the fares that transport utilities charge (Independent Pricing and Regulatory Tribunal, 2007). IPART is an outside influence – a ruling relation with which commuters interact invisibly and unconsciously every time they buy a ticket. People interact unknowingly with ruling relations all the time and travellers’ behaviour is coordinated by these relations. For example, where Cash Only is required when purchasing a ferry ticket, travellers must ensure that they have the right amount of cash in their wallets before starting the journey. This can mean accessing transport information to check timetables and fares for ferry travel and going to the bank to withdraw the cash from their bank account – all before they even begin their journey. These actions are coordinated by ruling relations, such as IPART and Sydney Ferries.

We also discussed other trans-local influences, such as occupational health and safety regulations that are imposed from an institutional level. The group
discovered that many actors were subtly involved in coordinating if, when and how people, including themselves, travelled throughout Sydney.

By photographically naming barriers such as ticket machines and life jacket instructions we were able to expose some of the hidden influences on everyday life, which assisted the group members to make better sense of their lives and gain a broader understanding of the tools of power. The process was an excellent way of raising consciousness and helped the group to read their world (Freire & Macedo, 1987).

9.4 Addressing the barrier

9.4.1 Contacting the authorities

The following week, the Photo-voice group prepared a strategy for addressing the issues they had raised. They decided that letters should be sent to Sydney Ferries, Hillsbus (as this was the particular bus service on which we had travelled) and RailCorp. They also decided that the NSW Minister for Transport should be informed of our dissatisfaction with the general public transport system. The letters included both text and photographs, the latter allowing the group’s photo-voices to be heard directly by the recipients. All letters received replies, the Minister thanking us for our input and our recommendations. The group was particularly encouraged to be advised that

“... RailCorp has instituted the “Golden Mic Awards”, an awards scheme designed to encourage frontline train and station staff to use the microphones effectively by providing clear, high quality and timely announcements at stations and on trains” (Correspondence, 5/2/08).

Whether or not this initiative was the result of our comments is uncertain. However, the group was pleased to have raised their concerns with the authorities and to know they had been heard.

9.4.2 Liaising with the Independent Living Centre of NSW

In December 2007 the group was contacted by John Evernden, Access Consultant for the Independent Living Centre of NSW. He had been referred to our group by the Western Sydney Regional Organisation of Councils (WSROC).
Representatives from WSROC had attended our photographic exhibition and had been impressed by our work. We were very encouraged. People in the community knew of and were talking about our work, and were recommending us to others. John Evernden was developing an “Access Awareness” program aimed at creating a totally accessible public domain, and sought our input. Our data were subsequently included in their disability access report called “You’re Welcome” (Evernden, 2008a).

John’s attendance at our meeting in January 2008 demonstrated that the Photo-voice team had knowledge and an audience. He offered to promote our project to other groups who might be interested in hearing about what we had done. He also encouraged us to make a submission to the review of the NSW Disability Standards for Accessible Public Transport (Allen Consulting Group, 2008). John said

“A submission from your group would be important so that the authentic voice of those with learning difficulties from the community was heard” (Transcript, 16/1/08).

The team was excited about this idea. “Yeah, let’s do it” (William, 16/1/08).

John recommended that we write to the Australian Human Rights Commission (AHRC) and tell them about our project. Later that year John discussed our research at an international conference in Montreal, describing it as “a powerful pictorial essay” (Evernden, 2008b).

9.4.3 Writing to the Australian Human Rights Commissioner

In January 2008 the Photo-voice team directed me to write to the Disability Commissioner, Graeme Innes to tell him about our work. We received this encouraging reply

“Commissioner Innes has asked me to thank you for your helpful letter. We are certainly interested in pursuing improvements to information access in public transport through the current review process and submissions such as yours will assist us in that objective” (Correspondence 25/1/08).

As I shared these comments with the group they were all impressed to find that such important people as the Disability Commissioner were not only listening to them but valued their comments and were pleased to hear from the group.
“That was nice of them” (Andrew, 16/1/08).

“It’s good they read our letter and wrote back. I wouldn’t think they would” (Bart, 16/1/08).

“It was good that we had something to say” (William, 16/1/08).

William was right. Our letter didn’t just tell them the issue. Using our photo-voices we named the issue and graphically demonstrated unnecessarily disabling barriers to self-determination. William’s comment also indicated that the team members were starting to dismantle their assumptions about themselves.

The group demonstrated a growing awareness that what they had been doing together was actually real and relevant social research. It wasn’t just a program, or a recreational activity. They were knowledge makers. What they had to say was valid and supported by documentary evidence.

9.4.4 Reviewing the Disability Standards for Accessible Public Transport

An “easy-to-read” form of the Disability Standards for Accessible Public Transport Review was available on the internet, along with a plain English questionnaire seeking information from “people with an intellectual disability” on issues they had with public transport (Department of Infrastructure Transport Regional Development and Local Government, 2007). The group discussed how being included in the consultation process was in line with the Convention’s aims for inclusive development programs. The Review was also treating

“persons with disabilities as rights-holders, equal members in society, who are as engaged in development as they are targeted by it” (Global Partnership for Disability and Development, 2008).

We contributed to the Review of the Disability Standards for Accessible Public Transport by completing the questionnaire (in each person’s own words) and sending a written submission, supplemented by photographic data, expressing our concerns.

The timing for this review was ideal for our Photo-voice group. It provided an opportunity to contribute to a political process which would directly affect the transport system. The team was able to respond as interested and informed
citizens whom the transport system negatively affects.

9.4.5 Acting individually

In addition to group actions the Photo-voice project empowered individual group members to take individual social action. At our Photo-voice meeting of 20/6/07, Bart reported to the group that he had undertaken his own social action regarding public transport.

“You know how all the buses are being slow?... I sent Westbus an email saying ‘Why are all the buses being slow and arriving late?’ And they said they were sorry. They sent me a reply, and then they keep on doing it [running late]. So I said “If they’re going to keep on running late I’m going to go to Busways – that will resolve this issue!” and they haven’t sent me a new one back [a reply] – but the buses have improved” (Bart, 20/6/07).

I asked Bart if he thought that his social action of speaking out had made a difference.

“Well, from 50 minutes late down to only 5 minutes late… I reckon they’re improving” (Bart, 20/6/07).

Whether or not the improved running time of the buses was a direct result of Bart’s social action is unclear. What is highly significant about this story is Bart’s motivation to engage in social action. He pursued an issue and was willing to share his actions with us.

The team was thrilled to hear that he had acted upon his conviction that the service just was not good enough. “Good for you!” (James, 20/6/07). Bart had set an example to the others by his actions and shown that speaking out could be beneficial. It was a great example of self-determination.

9.5 Conclusion

Having identified public transport as a social barrier limiting the self-determination the Photo-voice group members could exercise in their lives, an excursion on Sydney’s public transport system provided the opportunity to purposefully explore this barrier. In particular the research team considered text-based signage and technology. Using critical dialogue and textual analysis we found that an ableist reliance on text-based signage and technology unjustly disadvantaged travellers
who cannot read English, including putting their safety at risk. We named this ableist practice as “unfair” (Andrew, 3/10/07) and something we should not have to put up with.

The group noted that signage was sometimes used by the public transport authorities in their own self-interest, such as meeting legal obligations or for propaganda rather than for genuine public information. Through such things as insignificant disability seating signage, we gained the impression that disabled travellers were also of a low priority to RailCorp.

We operationalised the Convention by comparing it to the examples of the public transport barriers identified by the group and detected a breach of Article 9.1 Accessibility as there was a lack of “access, on an equal basis with others, to transportation, to information and communications”.

Using methods from institutional ethnography, the research team began to unravel the web of social organisation within the public transport system. We gained greater insight into how trans-local ruling relations coordinate the everyday behaviour of commuters. This increased the team’s understanding of the tools of power.

Recognising the right of every member of the public to public information on a public transport system, the Photo-voice group confronted the issue we had identified. We exercised citizenship and gained a deeper understanding of democracy by raising our concerns with the transport utilities, Government transport authorities and our elected Government representatives. We raised our issue with the AHRC as a matter of civil rights and provided our research findings to the Review of the Disability Standards for Accessible Public Transport. We also shared our findings with the Independent Living Centre and informed their Disability Access program.

Gaining immediate and tangible outcomes for an issue involving public transport is probably not realistic, although indications that the problem of communication on the railways was being addressed were encouraging. Numerous personal outcomes arose from our social action, not the least of which was the raising of our consciousnesses to inaccessibility issues on public transport. I certainly was
not aware of the issue of inaccessible signage and technology and had previously thought of access issues in terms of the built environment.

In parallel with our Public Transport barrier research we had also been investigating the Rules that Restrict Us barrier. Towards the end of 2007, Chris had become concerned that

“It looks like the Photo-voice project has been side-tracked by [Alex’s] issues. I’m not saying they aren’t important, but we started to investigate public transport …but we seem to spend most of our time now on [The Department] and [Alex’s] stuff” (Chris, 14/11/07).

Actions for both barriers unfolded concurrently but Public Transport was a relatively straightforward barrier to investigate. The action of writing letters to people fell to me and our research was concluded relatively quickly. In comparison, the second barrier had consumed much of the group’s time during our weekly meetings and took much longer to address.

I prepared a diagram in order to graphically demonstrate to the Photo-voice group all that we had done to explore the Public Transport barrier following our Photo-voice exhibition (updated version shown in Figure 57). Upon review, the team agreed we had done quite a lot (Minutes, 3/12/07).

* 

The following chapter tells how the Photo-voice team explored the Rules that Restrict Us barrier and provides an IPAR case study (fraught with difficulties). It tells of advocacy/action and analysis for our colleague Alex.
Figure 57 - Actions of the IPAR team for the Public Transport barrier to self-determination
Chapter 10 – Rules that Restrict Us: advocacy / action and analysis

"Where, after all, do universal human rights begin? In small places, close to home – so close and so small that they cannot be seen on any maps of the world. Yet they are the world of the individual person; the neighbourhood he lives in; the school or college he attends; the factory, farm or office where he works. Such are the places where every man, woman and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere. Without concerned citizen action to uphold them close to home, we shall look in vain for progress in the larger world."

Eleanor Roosevelt, Chair of the Human Rights Commission
(National Coordinating Committee for UDHR50, 1958)
10.1 Introduction

The Photo-voice research group recognised, with Eleanor Roosevelt, that human rights begin in the small places. We decided that it was “important” (Chris, 19/9/07) to take “concerned citizen action” on human rights, beginning with Alex’s home. In this chapter I discuss how the group became advocates for our colleague Alex and the difficulties we had dealing with issues that arose during that process. These difficulties included harassment, intimidation and the recriminations which occurred as we endeavoured to lodge complaints and support Alex to become a self-advocate. Throughout the Photo-voice research project numerous incidents came to light which were extremely distressing. With permission of those involved, this chapter tells Alex’s story. It also tells the group’s story of how we supported him in the processes of advocacy, and it tells my story as I endeavoured to analyse what was happening. These stories (which unfolded in parallel with the events of Chapter 9) interacted in a necessarily nonlinear way. The structure of Chapter 10 reflects this complicated interweaving of events.

10.2 Stage 3b: Alex

10.2.1 Dealing with the unexpected: aggravation, intimidation and retaliation

Alex, one of my co-researchers, lived in a Government-run Group Home. He had identified a social barrier, which we called Rules that Restrict Us, as a chief obstacle stopping him from having control of his life. This barrier turned out to include a host of restrictive and oppressive practices, aggravation, harassment, intimidation and a “culture of silence” (Freire & Shor, 1987, p. 121) within the Group Home. Many of these issues came to light in the very early stages of the Photo-voice project (Minutes, 30/5/07).

There were two Group Home rules that Alex found particularly irksome which related to his interactions with another resident, John. The first rule prohibited Alex from entering rooms within the Group Home when John was present without a staff member. After further questioning and discussion we discovered that this rule was designed to minimise Alex’s risk of harassment and abuse from John, whom Alex claimed “touches me inappropriately” (Alex, 21/9/07).
The second rule prohibited Alex from travelling in the Group Home vehicle when John was also in it. Alex advised us that this rule resulted from an incident that occurred while travelling with three other residents and two staff (one driving). Alex told the group about the incident, also recounted to me by Heather (Alex’s mother). Heather said that John had pulled his own trousers and underpants down, climbed across the seats of the van and sat on Alex, which caused a considerable commotion and great alarm to Alex. Heather lodged a complaint which resulted in a directive to Group Home staff that Alex was not to travel in the van with John (Heather, 24/9/07). Implementation of this directive has meant that Alex (not John) must catch a taxi to outside activities involving the residents, such as going to the pub. Alex has been financially and socially disadvantaged by this directive. Alex said he thinks this is unfair since it was not his fault John sat on him (Alex, 31/7/07). Furthermore, Alex said

“If I don’t have much money that week and can’t afford a taxi, then I can’t go to the pub, even though Mum got me taxi vouchers” (Alex, 31/7/07).

This rule also did not protect Alex from ongoing, daily abuse from John. Week by week Alex would arrive at Photo-voice and bring to the team new allegations of abuse and harassment from this resident and also from a member of staff.

Sometimes these reports were of physical abuse, for example

“It happened again last night... [John] pulled my pants down” (Alex, 26/9/07).

Sometimes there were verbal threats, as in the following sticky-tape incident.

“[John] said ‘I’m going to wrap you up with sticky-tape so that you can’t get out of hospital. Then I’ll stick needles in your bottom and in your private parts and in your boobs’... then [John] touched me on my bottom... I called out for [John] to stop but by this time [Fred] was in the kitchen area and so he did not see what happened... then [John] said he’d lock me outside (which he’s done loads of times)” (Alex, 17/10/07).

Other reports included both residents and a staff member, for example:

“When I was coming out of the bathroom I met [Fred], [John] and [Sean, another resident] in the hallway. I only had my towel on. And [Fred] and [John] started teasing me saying ‘pull his towel off him [Sean], we want to see his dick’. But they didn’t get my towel off because I held it tightly at the back... I don’t remember if [Fred] was actually telling [Sean] to pull the towel off or not or if it was just [John]...
They all thought it was funny... No, I didn’t think it was funny” (Alex, 18/11/07).

Alex also told of intimidation by staff, for example:

“[Fred] came home and... he started on me first thing when he got in, he said he was going to ring my mum and tell my mum about me buying lunch with the money that she gave me. And I said ‘I didn’t use that money’ and he said ‘I’ve got proof [Alex]’... That was a load of crap. He didn’t have proof ‘cause I didn’t use that money. I used the other money I already had at home. And he wouldn’t believe me... He was telling lies about me” (Alex, 31/7/07).

Both Alex and his mother claimed that staff would “stir him up” (Heather, 18/11/07), for example:

“[Fred] says to me that he’s going to ring my mum and ask her out for dinner, or he says ‘I’m going to screw your mum’ and it gets me really upset” (Alex, 31/7/07).

Heather asserted that

“Some male workers excite clients to riot... [Fred] is notoriously provocative and stirs [Alex] up. He speaks sarcastically to [Alex] and then thinks it is funny, but [Alex] does not get the joke and takes it seriously... [Alex] remembers what [Fred] has said and repeats it at a later stage. [Fred] told [Alex] that he was taking me out for dinner. When [Alex] brings this up weeks later [Fred] will deny it and accuse [Alex] of lying because [Fred] did not say that today” (Heather, 24/9/07).

Another incident reported to the group by Alex concerned a breach of privacy and his reluctance to address this issue for fear of an inevitable disagreement with Fred:

“On Monday [12/11/07] I asked [Val, staff] if I had any mail and [Val] said yes. Then [Fred] told [Val] to open my mail and give me the letter. I didn’t say anything ‘cause I did not want to get into an argument with [Fred], ‘cause I thought that [Fred] was already annoyed with me... ” (Alex, 14/11/07).

Another example of Group home staff breaching Alex’s privacy was provided in Alex’s claim that when he took phone calls from his family in his bedroom “the carers listen through the door” (Alex, 31/5/07) and later raise issues with Alex about which he had spoken to his mother in confidence.

These examples are but a few of many. Alex’s mother has confirmed the ongoing nature of John’s inappropriate behaviour and the Group Home staff’s refusal to take Alex’s accusations seriously. She claimed that
“Staff dismiss [John’s] behaviour... staff claim that Alex invites [John’s] attention” (Heather, 24/9/07).

Heather also spoke of the male staff member’s tendency to aggravate Alex with sexually orientated jibes. Heather said that the staff deliberately provoked Alex as a strategy to support their claim for more staff (Journal, 24/9/07).

From the limited interaction I had with staff at Alex’s Group Home it was evident that they were at times disrespectful and bossy. On one occasion after a Photo-voice meeting, while the group stood with Alex waiting for Group Home staff to collect him, a staff member arrived and overheard part of our conversation. Alex was asking “Will you be buying us lunch Janice?” She immediately interrupted Alex with “No she won’t. Other people don’t have to buy you lunch, you’ve got your own money” (Field notes, 24/8/07). The interruption was rude and disrespectful. It was an inappropriate way to address Alex, especially in front of his peers.

10.2.2 Dealing with disclosure

Alex’s disclosure to the group of accounts of ongoing sexual harassment and intimidation meant that at times I was very worried when my colleague went home to an environment where I suspected he would be victimised and at risk – but where else was he to go? This brought our Photo-voice Code of Conduct principle of confidentiality (What is said in Photo-voice stays in Photo-voice) into conflict with my other moral and legal responsibilities as research project facilitator to advise the appropriate authorities. The research project had been established on the basis that confidentiality would be maintained, but in the instances where I believed that my co-researcher was at real risk of harm I found myself torn between conflicting ideologies.

Further, it was often only after a Photo-voice meeting was over and the group gone, when I was alone with my thoughts and writing up the Minutes or my Journal, that the awfulness of Alex’s plight was fully recognised. I was then able to reflect on what had been disclosed. At times I was almost overwhelmed with distress. I felt compelled to act and the need to do so appeared urgent, but I also wanted to confer with the group so our actions could be decided collaboratively – but they had left for the day.
I was also struck by the thought that perhaps I was being maternalistic, thinking that it was my personal responsibility to rescue Alex. Shouldn't I support him to be a self-advocate and save himself, but then wasn't he asking the group for assistance?

Wondering how to deal with disclosures of this kind responsibly, I sought advice from more senior UWS staff. On one occasion, Alex disclosed a sexual assault. He said that he had reported it to the Group Home staff. However, he reported that they had said to him

“it was my own fault for not calling out loud enough, or they would have stopped it” (Alex, 26/9/07).

Distressed by this account and concerned for Alex’s safety, I spoke with Professor Moira Carmody from UWS. Professor Carmody has a background in intellectual disability services and experience dealing with cases of sexual assault of people labelled with learning difficulties. She was very clear about my responsibilities to the research participants. I subsequently took the issue to the Group Home Manager (who I found was already aware of it) and advised that if The Department could not inform me of how they intended to ensure Alex’s safety and prevent this incident reoccurring then the matter would be taken to the police. This matter joined our long list of complaints to The Department. I listed the following reasons why research project confidentiality might need to be breached in this case:

- This is an ongoing issue and I am aware that [Alex] is living in a situation where he is at risk.
- [Alex] has no power to call the police and report the assault – he is not allowed to use the phone.
- [Alex] did report the incident to staff, who wrote an incident report - but [Alex] believes he was told it was his fault for not calling out loudly enough.
- Incident reports have been written in the past and have not stopped the offense.
- [Alex] has reported this incident to his Photo-voice group for support.
- [Alex] is one of my research participants and has disclosed information that is of a criminal nature to me. As the principle researcher I would be complicit in covering up the assault if I did not act upon it.

(Journal, 26/9/07, emphasis in original).
A series of phone calls to me from Departmental officials followed, advising that sexual counselling would be put in place for all residents of the Group Home and that a male psychological support worker would be assigned to the Group Home to support Alex as well as to provide counselling, sexual education and training for all residents. While this response has certain merits, the Department’s policies and programs were anchored in a medical model that constructed Alex as deficit – in need of programming, training, counselling, monitoring and reporting. However, this medical model did not factor into its diagnosis the contribution, to both Alex’s behaviour and the uncritical practice of Group Home staff, of disabling institutional labelling and prescribed rules – which are “bleached from the diagnostic frame” (Slee, 1997, p. 56). Perhaps the problems were actually being caused, reinforced and/or perpetuated by the Group Home labels and rules themselves.

Incidents such as those related above could not have been foreseen in my UWS Human Research Ethics Committee submission since the specific social barriers to self-determination were unknown prior to the commencement of the project. Also, although the Disability Services resource booklet (6.3.4) I had given to all my colleagues was a useful tool, it was inadequate for Alex who could not read and had no access to a telephone by which to contact appropriate services.

10.2.3 Opening old wounds

Once accounts of these appalling incidents were brought to light and the frequency of them realised, the group agreed that something needed to be done. One group member proposed “I think we should go with [Alex’s] barrier. That’s important” (Chris, 19/9/07). Freedom from oppression was Alex’s right and such barriers to personal “control of [their] life” (Alex, 19/9/07) – barriers to self-determination – were very important issues to confront.

However, dealing with Alex’s issues revived memories of similar abuse experienced by another member of the group. We had unexpectedly opened old wounds. The other co-researcher confided to me privately that they found the discussion very difficult as this was a situation they had experienced as a child. They voluntarily (and unobtrusively) withdrew from the discussion, although they stayed in the room when Alex talked about problems in the Group Home. Once alerted to this situation I reminded my colleague that they were free to leave the
room whenever they were uncomfortable and suggested alternative activities they could do, such as purchasing supplies or sorting photos in a different room, so as not to draw attention to their absence. However, they were determined to support Alex to resolve the issues – as colleague, advocate and friend. I was encouraged by this display of solidarity, though I did also remind the whole group that people were always free to leave the room, ask to change the subject or stop the conversation if they ever became uncomfortable. Furthermore, the group was reminded of the Disability Services resource booklet. Privately, referral to counselling services and legal advice was offered to both group members.

10.2.4 Following up incidents

Over the course of the Photo-voice project our group considered what rights were. We did this through discussion and by reviewing the Convention and the DSS. Campbell describes discussion (conversations) as “the digestive system of thinking theoretically” (2009, p. xiii). The group’s discussion of Alex’s issues was a means of breaking down (deconstructing) and challenging ideas and identified a number of human rights concerns. For example, Alex’s Group Home rules restricting access to rooms within the house (when John was in them or to the kitchen (10.4.1)), to its vehicle (when John was in it), to public transport (10.4.6), to his phone (10.4.1) and to opportunities to gain life skills associated with food (8.4.2 and 10.4.1) were not “just the way it is” (Alex, 19/9/07). These rules could fall under the Convention’s Article 9 - Accessibility, which specifically states that measures must be taken

“to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies.”

Alex’s stories of staff intimidation (10.2.1) evidenced breaches of Convention Article 15 - Freedom from... degrading treatment or punishment, and DSS 10 - Protection of Human Rights and Freedom from Abuse. His complaints against John also demonstrated that staff were in breach of DSS 10 as well as Convention Article 16 - Freedom from exploitation, violence and abuse...

Convention Article 20 - Personal mobility covers Alex’s concern for living in an isolated location without travel training (Minutes 19/9/07) while privacy issues were
in breach of Convention Article 22 - Respect for privacy and DSS 4 - Privacy, Dignity and Confidentiality.

Our social action, with Alex’s consent (and his mother’s knowledge and support), took the form of contacting The Department to discuss and clarify his concerns, and lodging many complaints regarding apparent breaches of Alex’s rights in the Group Home. Recriminations often occurred in the Group Home after these complaints were made. The following is an account of what happened after Alex told the group about the sticky-tape incident (described in 10.2.1).

The incident should be understood in the context of two young men with significant support needs and limited cognitive function – who are housemates but not friends, one of whom is an alleged bully and the other his regular victim – conversing alone in the Group Home garden. Alex had been discussing an impending hospital stay, about which he said he was quite nervous. John appears to have capitalised on Alex’s apprehension by turning the situation into a threat.

The sticky-tape threat was certainly disturbing. It sounded somewhat ludicrous but I thought that its bizarre nature actually added to its credibility – I wondered “Who would make up a story like that?”

I asked Alex if he had reported the threat to Group Home staff, but he replied “No”. When asked if he was going to report it, Alex replied “they might tell me it was too late to complain about it now”. I then asked Alex if he would like our group to complain on his behalf, to which he said “Yes” (Transcript, 17/10/07).

Alex’s display of psychological disempowerment provided a sad glimpse into his impression of the service provision in the Group Home. He obviously thought that complaints must be made immediately and that he had left it too long. His understanding of the way things worked in the Group Home and the perceived prospect of a fruitless outcome actively discouraged his self-determination by impeding his willingness to complain.

On behalf of the whole group, and with Alex’s approval, I contacted the Group Home Manager by email (also copied to the Regional Manager) to express our concerns. A reply was received the same day advising that a comprehensive report had been requested on what had happened that day in the Group Home.
and seeking my contact details. I received a phone call the following day from the Regional Manager advising

“We are following up what had or had not happened at the house yesterday, if anything did in fact happen, though it doesn’t look like it did” (Field notes, 18/10/07).

I was repeatedly advised during this conversation that

“[Alex] is someone who likes attention from others and likes to talk about his situation with others… He likes attention” (Field notes, 18/10/07).

That evening I received a distressed call from Alex’s mother who said recriminations were occurring and that she had travelled 250km down to the Group Home to help Alex sort things out. Heather said

“It must have been after you put in your complaint because the staff were initially amicable but they became extremely hostile to [Alex]. They said they had spent an hour together discussing the report they had been asked to make. So in other words, [Fred] and [Yasmin, also staff] were in cahoots with each other, getting their stories right… They gang up on [Alex]. The two staff spoke over the top of [Alex] and wouldn’t let him get a word in edge-wise. I had to stop them and ask them why they were speaking to him like that. I asked them ‘Why is this happening?’” (Heather, 18/10/07).

Heather said that the staff felt threatened that Alex had lodged a complaint about them. She stated

“I told the staff that the complaint was not against them, it was trying to get [The Department] to address the issue of [John]. [Alex] was not blaming staff for inaction. He was saying what [John] had said and done to him… and even [Fred] said [John] had been worse that morning” (Heather, 18/10/07).

Heather advised me that [Fred] had said “nothing happened and that’s what I’m putting in the report” (Heather, 18/10/07). She said that staff claimed John had not been left alone in the yard with Alex, no threats had been made, there had been no chasing through the house, and Alex had not been forced to lock himself in his room.

“They side with their staff over [Alex]. It’s his word against theirs” (Heather, 18/10/07).

Heather also confided
“The staff were very aggressive towards [Alex], even in front of me!... It worries me to think what they are like to him if that's what they're like even in front of his mother!” (Heather, 18/10/07).

This was a difficult situation. Our complaint appeared to have made the environment in the Group Home more hostile towards Alex and caused Heather to make a dash down to Sydney to support him – all without a positive outcome. I was struck with a sense of guilt and helplessness. Our attempted advocacy had made life more difficult for Alex.

The ramifications of our complaint certainly verified Alex’s reports to our group that staff “don't believe me” and that “they tell lies about me” (Alex, 31/7/07). They also confirmed Heather's statement that staff “gang up on [Alex]” (Heather, 18/10/07).

If Alex’s account was correct (and we had no reason to doubt it) then significant human rights breaches were occurring, involving the abusive resident, Group Home staff and The Department in whose care Alex lived.

On many occasions, as our continuing complaints process heightened tensions in Alex’s Group Home and made life more difficult for him, I asked Alex how far he wanted us to go. I wanted to be sure that tackling the barrier was what Alex wanted. Although my principles said "never for the sake of peace and quiet deny your own experience or convictions" (Hammarskjöld, 1964, p. 85), these were Alex’s experiences and very unpleasant for him. It would be oppressive to impose my principles upon him. Should we persist with the complaint? Were we making things too difficult for him? Would he like the group to stop complaining on his behalf? Time and again, Alex insisted he wanted “The group” (Alex, 20/9/07) as advocates.

“I would like your help” (Alex, 17/10/07).

“I'm sick of it. I want the Photo-voice group to help me stop this” (Alex, 23/1/08).

Alex’s accounts were disturbing and once aware of his situation the group wanted to support him. He clearly lived in an oppressive environment, with one group member noting “that place is weird!” (Chris, 23/1/08). It was made worse by the belief that, due to limited housing options, there was no alternative appropriate accommodation for Alex (Heather, 24/9/07). I asked myself “Do we remain silent
or do we stir up the hornet’s nest? It’s easy for me to rattle chains and protest about The Department since I don’t live there, but where else can Alex go?” We faced genuine human rights issues and had a moral obligation not to ignore them, especially in light of Alex’s repeated pleas for support. The following section details our advocacy efforts to have Alex’s concerns dealt with and problems in the Group Home resolved. Although it was a very long time coming, we did eventually achieve some very positive outcomes.

10.3 Advocacy / action

“I could go on about all the negative things that happened to me and my friends… but I think the most singular, most frightening thing, and the most de-valuing, was the fear of speaking out.”

Robert Martin (2009)

Armstrong (2002) has noted that self-advocacy is frequently limited to the notion of consultation and education, which can perpetuate the stigmatisation of people whose identity is constructed and constrained by the label of having learning difficulties. However, self-advocacy can also be a citizenship tool and a means of negotiation and resistance which can assist people to destabilise and challenge the labels imposed on them and, as a result, reconstruct the construction of learning difficulties. Rising to Armstrong’s challenge for self-advocacy to move “beyond a model of citizenship based on participation” (2002, p. 343) the Photo-voice group engaged in social action that critiqued ableist assumptions and disablist practices within Alex’s Group Home. This section of the chapter tells the group’s story of our advocacy actions – how we discussed the issues and pursued a range of strategies to have Alex’s grievances heard. The process was difficult, distressing and often disappointing. However, it was also destabilising for the institutional structures constraining Alex’s life. Our advocacy actions discovered evidence of disablism. The group challenged the disablism social construction of learning difficulties and served to disrupt, albeit not completely dismantle, stereotypes and disabling labels.

10.3.1 Advocacy actions

Following the Photo-voice research group’s decision to “go with [Alex’s] barrier” (Chris, 19/9/07) and look exclusively at Alex’s issue – effectively as a case study
of the Rules that Restrict Us barrier to self-determination – we compiled a list of all the issues in the Group Home that Alex wanted to address. Alex raised many points for inclusion as we drafted the list. These included restrictions on movement within the house and access to phones/property/money/transport, as well as isolation, lack of privacy, lack of life-skills training, lack of immediacy in grievance procedures and inflexible and intimidatory staff practices. We went through each point with Alex, discussing and noting examples of the issues (see Appendix 2 for further details). For example, “[Alex] enjoys food and loves to cook. However, he is not allowed in the home kitchen.” Alex was asked how he wanted to pursue these issues. He requested that before we did anything we should speak with his mother, Heather. At 24 years of age Alex did not have a legal guardian, Heather was Alex’s person responsible 55.

I discussed with Heather the group’s decision to pursue Alex’s barrier of Rules that Restrict Us, noting each of the points on our list. Heather supported Alex’s claims, stating that his parents “have had ongoing issues with the staff and their lack of flexibility with the rules” (Heather, 20/9/07). Her concern was that The Department supported staff claims over resident complaints, implying that the voice of some was privileged above others within The Department. This suggested a hegemonic structure that “looked after its own” and gave only lip-service to its supposedly transparent feedback and complaints procedure ([The Department], 2005). Heather warned us that, in her experience, reprisals were inevitable. “You don’t want to know what goes on behind those closed doors!” (Heather, 20/9/07). These comments supported Alex’s earlier allegations to the Photo-voice team of intimidatory Group Home staff practices.

As our first course of action, Alex suggested that we “talk to [the Group Home Manager] about it” (Minutes, 20/9/07). I contacted the Group Home Manager by phone, on behalf of our research team, and arranged for her to attend our next Photo-voice meeting (26/9/07) to discuss issues concerning Alex’s perceived barriers to self-determination. Alex had been given the option of having the meeting on his own, accompanied by me or another group member as support, or supported by the whole team. Alex chose the whole team.

55 The NSW Guardianship Tribunal prescribes that a person responsible has to be identified by the treating practitioner. Heather has been identified as Alex’s person responsible because she is “a relative or friend who has a close personal relationship with the person” (Office of the Public Guardian, 2009).
Chris suggested that we also invite our local MP Karyn Paluzzano to this meeting as she had recently offered her support as an advocate. Combining these ideas, I suggested that we send the Group Home Manager a list of Alex’s concerns prior to the meeting and also send a copy to the MP, at this stage just to keep her informed. My aim was that the Photo-voice group should pursue this issue on its own, without relying on others to act on its behalf. (By involving the Photo-voice group, Alex himself was not relying on others to act on his behalf, but was self-determining the course the investigation would take and the advocates who would act with him.) If unsuccessful, we could take up Karyn Paluzzano’s offer of advocacy at another time. The group agreed to this so I asked permission of the Group Home Manager, while negotiating the meeting, for a copy of Alex’s concerns to be forwarded to her and our local MP. The Group Home Manager agreed to this and a letter was forwarded to both parties. The Group Home Manager was unaware of the nature of Alex’s concerns, simply that they were social barriers to self-determination, as perceived by Alex. For inclusion in the letter (see Appendix 2) Alex provided examples of ways in which he felt Group Home implementation of its rules unnecessarily limited his self-determination.

I contacted the MP’s office and spoke to her staff advising that the letter to be sent to Karyn Paluzzano was only for her information and that we did not want her to intervene at this stage. I reiterated this in writing.

“If the group is unsuccessful in resolving the issues listed, we will call upon you to advocate on our behalf” (Correspondence, 25/9/07).

My purpose was to emphasise the project’s aim of promoting self-determination. In hindsight, providing such an extensive list of complaints to the MP was probably an error of judgment on my part. While I had anticipated that this would extract a quick and efficient response from The Department, it may in fact have heightened their defensive response to us. Our letter set in motion a sequence of events which, like dominos falling, followed its own course and which we were powerless to stop.

Concerned by Heather’s comment about “what goes on behind those closed doors!” (Heather, 20/9/07) and in preparation for the meeting with the Group Home

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56 Karyn Paluzzano had attended our Photo-voice exhibition on 14/9/07.
Manager, I contacted the Community Services Division of the NSW Ombudsman’s Office. I was seeking advice on how to pursue these issues with The Department while avoiding reprisals in the Group Home for Alex. The Ombudsman’s Office counselled me to advise the Group Home Manager of my concerns that there be no negative repercussions for Alex as a result of our letter. They encouraged me to inform The Department that I had contacted to the Ombudsman’s office for advice, stating that “if [Alex] was unhappy with the outcome he can put in an official complaint” (Correspondence, 24/9/07).

However, our meeting with The Department did not eventuate. Once the letter was received the meeting was postponed until 10/10/07, and later cancelled by the Regional Manager. The Regional Manager refused to meet collectively with the group on the grounds that such a meeting might breach Alex’s privacy or that of other residents. It was recommended that only Alex, his mother and I meet with The Department to discuss Alex’s concerns. However, Alex’s explicit wish was for the support of the whole Photo-voice group. Denying this request demonstrated an apparent disregard for Alex’s wishes. It seemed to me that The Department was deliberately limiting Alex’s advocacy network. Although probably unwittingly, they were also demonstrating a lack of preparedness to support people labelled with learning difficulties develop self-determination through social action and advocacy. By refusing to meet with our two other colleagues The Department evidenced disrespect for both Alex and his chosen advocates as well as a lack of respect, or at least poor understanding, of the collaborative nature of our research – even though this had been clearly explained. It also indicated that perhaps within The Department there was a culture that preferred to deal with an academic rather than with people labelled with learning difficulties. Furthermore, in correspondence to The Department, we explicitly stated that the

“Photo-voice group is aware of the need to protect confidentiality and we will therefore endeavour to speak broadly on issues without naming specific residents or staff” (Correspondence, 26/9/07).

If I could be trusted to protect the privacy of others I saw no reason why the rest of the group should not also be trusted. On behalf of the whole group I refused The Department’s offer to meet with me individually and reiterated Alex’s preference for group advocacy.
When Alex disclosed another episode of abuse at the Group Home, I reported a sexual assault upon Alex by a fellow resident to the Group Home Manager. In response, I received a phone call from The Department’s Customer Liaison Officer and an email from the Group Home Manager advising the matter was being “investigated” (Correspondence, 26/9/07). Although I was informed later that the matter had been dealt with, similar incidents continued to occur in the Group Home.

Heather attended our Photo-voice meeting on 17/10/07. Together, the group reviewed our original letter to the Group Home Manager. We discussed our inability to meet with her or the Regional Manager. I suggested that we go beyond the local authorities and inform The Department’s Head Office of our concerns. We could do this by lodging an official complaint form. This was an alternative action that might ensure that details of our complaint were not just kept locally. The team decided to submit a Departmental complaint form that included much the same content as our earlier letter. One group member said “we can all sign it” (Brendan, 17/10/07), recognising that this would be a collaborative action. Hopefully it would also force The Department to acknowledge and respond to the Photo-voice group rather than just to me. The official complaint process required that we wait one week for The Department to acknowledge its receipt. The complaint form requesting a group consultation and collaborative resolution of the issue was lodged on 18/10/07.

On 17/10/07 Alex also advised our group of “the sticky-tape incident” (10.2.1 and 10.4.1) and requested our support to have this complaint dealt with also. Again, on behalf of the group, I lodged another complaint.

The nature of Alex’s complaints was very serious and incidents occurred regularly. As another possible course of action to take, I suggested that we contact the Intellectual Disability Rights Service (IDRS) for advice. Heather agreed that we should pursue all avenues (Minutes, 17/10/07). I contacted IDRS and spoke with their legal advisor on 23/10/07. He stated that The Department’s privacy/confidentiality argument could be dismissed if individual confidentiality agreements were signed by Alex, as the self-advocate, and each of the Photo-voice team members. I was told that these documents should be worded in simple English confirming that Alex gave permission to each specifically named team.
member to be his advocate. I drafted advocacy/confidentiality agreement forms which were signed by the Photo-voice members and hand-delivered to The Department on 27/10/07, along with another request to meet with The Department to discuss our concerns. These have never been acknowledged.

IDRS also told me that The Department had no legal grounds upon which to deny Alex the right to as many advocates as he wanted. Furthermore, they suggested that if The Department refused to meet with us as a group, we should pursue our complaint with the NSW Ombudsman. We could also request that the Community Visitor investigate the Group Home. I presented all these ideas to the group when we met together on 27/10/07. However, they decided “Let’s wait the full week for [The Department] to get back to us” (Chris, 27/10/07). Alex stated “If we don’t hear back, then we can go to the Ombudsman” (Minutes, 27/10/07).

When the waiting period had expired without response from The Department, the Photo-voice group lodged a complaint with the NSW Ombudsman’s office. While it might have been impossible for us to overcome all of Alex’s barriers or to fix a broken system, we could expose the need for change, stimulate reflexive community-based service delivery, trouble the way knowledge was made and challenge people to question their assumptions about the people labelled with learning difficulties (Mykhalovskiy & McCoy, 2002) – and so we were going to try.

10.3.2 Going to the Police

Initially, our efforts to have Alex’s list of complaints efficiently and effectively dealt with yielded very few results. Four weeks after submitting our first complaint we still had not secured a meeting with The Department and little had changed in the Group Home. One co-researcher suggested that the group investigate how people lodge complaints with the local police. Alex was apprehensive about visiting the police. Although we stressed that this was just an information gathering activity and that Alex did not have to lodge a complaint with the police, he was very fearful that John and John’s mother would find out “and they’d go berserk” (Alex, 24/10/07).

Alex had strong apprehensions about John’s mother and had previously expressed anxiety that she would find out that Alex had put in another complaint after John had sexually assaulted him, saying “she’ll go ballistic” (Alex, 26/9/07).
Before deciding what to do, Alex requested we speak to Heather. I lent Alex my phone (the Group Home restricted his access to his own phone) so he could ring Heather and explain what the group was proposing to do. Heather approved, but warned that if a complaint was made it might be like “letting the bull out of the paddock” (Heather, 24/10/07), meaning that we might start something that could get out of control. Alex told his mother “We’re not going to complain, we’re just going to talk to them” (Alex, 24/10/07).

The group went to the police station. As we waited to speak to someone Alex was visibly upset (rapid breathing, shaking) and becoming anxious. I took Alex aside from the group and sat with him as he discussed his concerns. I tried to reassure him that this was just seeking advice and we were not making a statement, not writing anything down. He asked “What if [John’s] mother finds out?” (Alex, 24/10/07). I told Alex that it was none of John’s mother’s business what Alex does in Photo-voice. She didn’t need to know, no one needed to know. We did not need to tell people we were there. I reminded Alex that he was a citizen and allowed to make enquiries at the police station. He was not doing anything wrong. Alex was also reminded that we did not have to be there if he was not comfortable about it. “No, it’s OK, we’re here now. Let’s do it” (Alex, 24/10/07).

The group met with Constable Cook who spoke calmly and explained that since Alex “lives with the perpetrator, it was a domestic affair” (Journal, 24/10/07). He told Alex that if the resident abused him Alex could ring the police and they would come and arrest the man.

There was a problem. Alex did not have access to a phone. The policeman suggested that Alex walk to a local phone booth and phone the police. He gave Alex his card with the local police station number on it. If Alex had no money he could ring 000 and tell them his address so that the police could go to the Group Home. He told Alex to wait for the police outside his Home.

It was helpful advice, and might have been useful in a less restrictive environment than the Group Home. However, Alex did not have access to a phone to make calls (this was another Group Home rule about which we complained, see Appendix 2), or even a public phone booth, as he was not permitted to walk out of the Group Home without a staff member.
Another course of action suggested by the police was taking out an Apprehended Violence Order against the perpetrator of harassment in the Group Home. Constable Cook explained the implications of this. As we returned to the Photo-voice room that afternoon everyone agreed that it had been a successful trip to the police station. “That’s another possible strategy up our sleeve to refer to if needed” (Gill, 24/10/07).

10.3.3 Distressing ramifications

Later in the afternoon I received phone call from Heather. She was upset and asked me to ring Alex. She said Alex was home alone and that he had got himself very anxious. The staff had rung Heather because they lost his medication and he didn’t have any PRNs57. They asked Heather if they should give Alex his stronger medication since he had no PRNs. Heather said

“I told them ‘No. Go to the chemist and get him some more PRNs. Don’t go for the extra strong meds if they are not necessary’. Apparently Alex had told [Val] that they had been to the police station and [Sean] had overheard. Now he was concerned that [Sean] will tell [John] about the police station” (Heather, 24/10/07).

Heather said that Alex was getting stressed and had told her that he wanted to kill himself. Heather told me that while Alex was distressed he had asked the staff member if he could ring his mum. The staff member said she would need to check with the Group Home Manager, but when she did the Manager advised her that Alex could wait until tomorrow (his designated day) to speak with his mother. Heather emphasised that the phone program was to protect her from constantly receiving calls from Alex, but if he really needed to talk with his mum she was quite prepared to speak with him. “The staff just needed to use discernment” (Heather, 24/10/07).

I phoned Alex as soon as I could. He was home, alone.

“He told me that he wanted to kill himself because then he would not need to deal with [John] always touching him, with [Fred] getting him upset and thinking that he was telling lies, with The Department who was doing nothing to help the situation and would not return his mum’s calls – he wouldn’t have to worry about any of those things if he was dead” (Journal, 24/10/07).

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57 PRN is an abbreviation of the Latin term pro re nata, meaning “according as circumstances may require” (Blair & Ramones, 1998). Andrew is given psychotropic medication to calm him down, as needed.
I told Alex that his mum loved him and that she didn’t want him dead. I said that everyone at Photo-voice loved him and we did not want him dead either. I said that the Photo-voice group was trying to support him with his complaint. I didn’t really know what to be saying in such a situation but I emphasised that no one wanted Alex to hurt himself.

Alex told me that his mother was very concerned that The Department would move him out of his current Group Home and into “Marsden”\textsuperscript{58} (Alex, 24/10/07). It was evident that Alex was dealing with many difficult issues and fears.

**Photo-voice blamed for Alex’s distress**

Following my conversation with Alex, I phoned Heather to let her know I had spoken with Alex. My impression of Alex’s state of mind after we talked was that he was not going to harm himself. However, I was no expert and also had a duty of care to report this incident to The Department. They needed to know that he was home alone (the Group Home staff were out at the chemist), without support and very distressed. I phoned the local office of The Department responsible for the Group Home and spoke to the Regional Manager. She was aware that Alex was upset and said

“Alex has been upset since attending your Photo-voice project, because they had been to the police station and Alex had been told not to tell anyone about this, but he has told everyone and now he was concerned that he’ll get into trouble, because he had been told not to tell” (Journal, 24/10/07).

This accusation came as a surprise, and sounded like something from the schoolyard. I explained to the Regional Manager that Alex had not been told “not to tell anyone”. It had been said that others did not need to know we had been to the police because it was none of their business. He certainly was not in trouble.

**10.3.4 The Department closing ranks**

Later that evening I received another call from Alex’s mum. She was very upset and worried for Alex. She said that both the Group Home Manager and the Regional Manager had been to the house late that afternoon and had asked Alex if he wanted to move out of the Group Home. She said that they had suggested that

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\textsuperscript{58} Heather advised that Marsden is an institution from which she believes she would have great difficulty getting Alex out once he was admitted there (Heather, 24/10/07).
Alex could live closer to his parents.

Heather said “They are undermining me” (Heather, 24/10/07). She was worried because two Managers spoke with Alex without him having a support person or advocate present. She said that they were offering him something (to move closer to his parents) that they couldn’t fulfil, but might get him removed from his current residence. If they could get Alex to say he did not want to live there anymore, and there was no other accommodation available, Heather said she feared that he might be institutionalised. She warned me “[The Department] are closing ranks and trying to isolate Alex from his support people” (Heather, 24/10/07).

10.3.5 Alex’s primary problem preventing self-determination

We could not have anticipated how distressing the day would become for so many of us from simply having visited the local police. The Department’s response on a number of levels was quite unsatisfactory. How had Alex’s medication been lost? Why were they so quick to resort to a stronger alternative? If Alex was so distressed, being pushed to the brink of his coping skills, what harm was there in allowing a phone call on an “unprogrammed” day? The staff in the Group Home appeared to lack the authority or flexibility or discernment to know when to make judgments that might override the telephone program. His mother obviously didn’t mind if Alex rang her and this indicated a lack of knowledge of both Alex and his mother on the part of the staff.

The management staff certainly appeared defensive. It seemed to me that they thought Alex and the Photo-voice group were trouble-makers and that The Department would be better off having nothing to do with us.

Reflecting on this incident, I realised that the difficulties our group had with The Department were all part of the social organisation of the Photo-voice group’s social barriers to self-determination. We had mistaken the problematic and had been looking too intently at Alex’s specific barriers which had led to the complaint – but that was just the starting point. I suspected that The Department’s obstructive cancellation of meetings and repeated refusals to meet with the group was an even bigger barrier that needed exploring. Resolving issues with The Department was a barrier for Alex, but it was also a barrier for our group – and possibly anyone who endeavoured to be an advocate or self-advocate against this
Department. Their prevention of our group from pursuing the smaller barriers to self-determination was actually a much larger problematic (which will be taken up again in section 10.4).

### 10.3.6 Outcomes and incomes

Our first complaint had been lodged on 21/9/07. By ten weeks later, when we had still not achieved a meeting with The Department to discuss our concerns, and the sexual harassment and intimidation were continuing, and recriminations were making life difficult for Alex, the group had become demoralised. We had seen some improvements in Alex’s level of freedom. For example, Alex was provided with a house key to wear so that John could not lock him outside anymore. John was moved into a flat located on the same property as Alex but outside Alex’s immediate Group Home, which reduced his contact with Alex and the risk of harassment. In addition to these improvements, the rule regarding Alex’s mobile phone had been reviewed and changed to permit Alex to have his phone when not in the house or when left alone in the house. He had also been told that he would be allowed in the kitchen and taught food-preparation skills. These liberties testified to the power of naming and indicated that Alex’s testimony had been believed and acted upon by the Group Home authorities and that our advocacy on Alex’s behalf was producing positive social change. However, when Alex arrived at Photo-voice one day without his phone, complaining that Fred said “I would not need it” (Alex, 14/11/07), we recognised that the liberties gained were not consistently made available. (As of July 2010 Alex was not permitted in the kitchen (Alex, 21/7/10)). Furthermore, continued hostile staff attitudes and restrictive practices towards Alex occurred, moving Chris to comment

> “Just when we thought we were having some good outcomes, we’re now having incomes. Things are going back to the bad-old-ways” (Chris, 14/11/07).

This clever use of language – the appropriation of the word “income” to mean a loss of ground in our social outcomes – was insightful. It did appear as if we were taking one step forward but two steps back. Progress that was promised (such as Alex’s access to his mobile phone) was illusory as it was being denied to him by some staff.

Knowing how to respond to these ongoing deprivations was very difficult. Our
complaints often seemed to cause recriminations in the Group Home for Alex. We disrupted an already dysfunctional environment (6.3.4). Doing so led to continued discriminatory recriminations for Alex.

10.3.7 Defensive Departmental response

The Department’s response to the Photo-voice group’s complaints generated an additional problem. We found both the Regional Manager and the Group Home staff to be defensive every time we raised a new issue. Alex told our group “The staff are not allowed to speak with us [the Photo-voice group], they’ve been told not to talk to you [Janice]” (Alex, 29/10/07). In the light of this information I noted that

“The more we pursue the complaint the less likely we are going to be in securing interviews with [The Department] staff or perusing reports” (Journal, 29/10/07).

Why The Department was being so defensive was baffling.

“[The Department]’s unrelenting refusal to meet with the collective Photo-voice group is puzzling. They claim it is to protect [Alex]’s privacy. They may want to protect [Alex]’s privacy in case something that he has not anticipated is said in front of the group. I’ve warned [Alex] that the meeting might raise other issues that he doesn’t want us to know about. However, they are not allowing him the opportunity to choose whether or not to have a group of advocates or whether or not he wants to share personal information with us. Surely that’s his choice?” (Journal, 18/10/07).

10.3.8 Poor procedural processes

Another difficulty we had in dealing with The Department was that they did not follow their own prescribed complaints and grievances policy. Department policy stipulates that

“If your complaint needs to be investigated further [The Department] staff will keep in regular contact to update you on how things are progressing, at least every 10 working days or as agreed with you” ([The Department], 2005, p. 1).

This simply did not happen. Regular emails were sent by me from our Photo-voice email address to The Department to follow up our complaints. Some of these emails lodged new complaints, others sought acknowledgement of the complaint lodged, while still others requested advice on how investigations were proceeding. Rarely did The Department respond to our complaints within the prescribed
timeframe, and then generally only when the complaint was lodged directly to the Group Home Manager by phone. Following our complaint lodgements of October 2007, follow-up emails were forwarded to The Department on 16/11/07, 18/11/07, 23/11/07, 31/12/07, 30/1/08, 13/2/08 and 27/2/08. We never received a response from The Department within (their promised) 10 working days. When they did contact me it was only ever in response to our repeated enquiries.

The Department’s tardy responses did not surprise Alex’s mother, who noted

“It’s quite deliberate I’m sure. They want you to give up... They want you to go away… They wear you down” (Heather, 17/10/07).

Rocking The Department’s boat

When we had tried all the avenues we could think of, Chris again suggested that we go to our local MP, Karyn Paluzzano (Minutes, 31/10/07). It was agreed that I would draft a letter and request a meeting of the group with the MP.

On Monday 26/11/07 the Photo-voice group met with Karyn Paluzzano at her office. This was an exciting opportunity for the group to “meet someone so important” (Chris, 26/11/07). Karyn promised “I will speak to my friend, Kristina Keneally [NSW Minister for Disabilities] on your behalf” (Field notes, 26/11/07).

We gave Karyn a copy of the letter we had received from the Ombudsman’s office dealing with our complaint (one area covered was The Department’s refusal to meet with our group, see 10.3.1). Also included was a copy of the Ombudsman’s letter to the Director-General of The Department responsible for the Group Home, recommending “local resolution” and suggesting The Department meet with Alex and one other advocate (discussed in 10.4.2). We showed Karyn this puzzling recommendation and asked her if she thought we were being unreasonable by insisting that The Department meet with the whole group and not just Alex and one other person. Karyn said that she did not think it unreasonable.

“I can’t really understand why they are making it such a sticking point… As far as I can tell, you’re really only asking to meet with them and I can see nothing wrong with that” (Field notes, 26/11/07).

We came away from that meeting feeling that we had an ally. Alex commented, “She was really nice” (Alex, 26/11/07). We hoped this action would “certainly rock
the boat with [The Department]” (Gill, 26/11/07)59.

I was contacted by a Departmental representative on 3/12/07. She had been asked by the Regional Director (above the Regional Manager) to review the complaints we had raised in relation to Alex and asked to meet with me (Correspondence, 3/12/07). That day the group was launching our second Photo-voice exhibition (8.4.4) and we were also celebrating the International Day of People with Disabilities. I asked the group what they would like me to do. Alex suggested “Meet her and ask her to meet with us” (Alex, 3/12/07). One member also said “go and talk to them, then they might start to do something” (Brendan, 3/12/07). We were unsure if this heightened interest was the result of the intervention of our MP or if our original complaint of 21/9/07 had finally made its way into the hands of someone investigating of our concerns. However, it did look like something was starting to happen.

So, on 9/1/08, I met with The Departmental representative, presented our documentation of complaint letters and Alex’s original list, expressed the difficulties we had experienced while trying to support Alex to self-advocate and, once again, invited The Department to meet with our group. I was assured that a thorough internal investigation was underway and that “a report would be compiled within the month” (Field notes, 9/1/08).

Reflections

How were we as a research group to negotiate these experiences? How might they inform the group research and my own research, and how might our research inform these experiences? We were not prepared to accept The Department’s dismissive response (10.2.4)

“Alex is someone who likes attention from others and likes to talk about his situation with others” (Field notes, 18/10/07)

to Alex’s attempts to draw attention to a case of ongoing abuse.

59 It should be noted that throughout this long saga to have Alex’s complaints addressed, meetings were happening between The Department, Alex and his mother. Each time the Photo-voice team raised a serious allegation against Group Home staff or the resident, Heather was consulted by The Department and the issue reviewed (though still not necessarily resolved). What we had been unsuccessful in achieving was for The Department to speak with our group and to allow Alex his choice of advocates.
According to Alex’s testimony to our group, this same Regional Manager had also advised him that

“You don’t need to go to the police [Alex]. If you have a problem you can speak with the carers” (Alex, 31/10/07).

In order to make sense of what we had done and were doing I chose to employ institutional ethnography as a way of analytically exploring the social organisation of Alex’s experiences and The Department’s processes. Utilising institutional ethnographic textual analysis methods, some of which we had previously used with success (9.3.2), I endeavoured to unpack the hidden curriculum, the underlying message in The Departmental correspondence. I hoped to discover unstated but implied messages in The Departmental correspondence we had received. Also, with the group and individually, I utilised creative tools such as poetry and personal journaling as useful lenses through which to analyse our Rules that Restrict Us research experiences and their implications. How we made meaning of the mess is described in section 10.4.

10.4 Analysis

In this section I outline some of the analytical methods the group and I used to analyse the data we had gathered while pursuing Alex’s complaint. Some of the analysis was collaborative and some I undertook individually. The social organisation of Alex’s Government-run Group Home was explored through Institutional ethnography via four vignettes (10.4.1), each of which demonstrates how the barriers to Alex’s self-determination were textually mediated.

In 10.4.2 I reflect upon the interaction of Discourses (as in 2.2.3) encountered during this phase of the Photo-voice project and what Smith refers to as “the intertextuality of discursive texts” (Smith, D., 2004, p. 195). Entitled Textual bondage and disempowerment, relationships of power and knowledge are deliberated, repression as a textual practice is discussed, as is how objectifying social practices can silence differing voices. I argue that The Department’s silencing strategies were the primary social barrier to self-determination and an overarching problematic. The ways in which the ruling relations disarm critics by the prioritising of some texts over others is discussed, along with an account of our
persistent efforts to be heard.

We were notified (and dissed) by The Department when its internal investigation of Alex’s complaints was completed (10.4.3), leading to my textual analysis of The Department’s correspondence (10.4.4). The research team’s response to The Department’s underwhelming and uninformative document speaks of the team’s increased self-confidence, determination and solidarity (10.4.5).

Following a literature review (10.4.6) and collaborative discussions which result in emergent findings (10.4.7), inclusive and creative analyses are presented in the form of two poems (10.4.8). Poem 1 was a collaborative composition and provided an opportunity for reflection. Poem 2 was composed by me as a means of working through the very difficult issues with which I was confronted on this research journey. Further emergent findings are detailed in 10.9-11.

Though deeply discouraged at times, our group developed a strong sense of camaraderie and resilience through our research difficulties. Section 10.4 also speaks of strength in solidarity and celebrates our achievements.

10.4.1 Four vignettes demonstrating textually mediated barriers

In order to clarify the issues surrounding what Alex saw as restrictive rules a list was compiled (detailed in Appendix 2). Writing the list from Alex’s standpoint positioned him as the knower within his own body (6.6.1) and as an active participant in his interaction with others and the Rules that Restrict. I endeavoured to explore each restrictive rule from Alex’s perspective, starting with his own account of how he experienced the rule and then seeking to discover how things worked together to occur in the way they did. Such an approach brings the ruling relations into view and actually “discovers the ruling relations” (Smith, D., 2004, p. 4, emphasis in the original).

The following vignettes explore three of the prescribed Group Home rules by use of institutional ethnography.

Vignette 1: Alex’s mobile phone rule

“I'm not allowed to have my mobile. It's not fair, because [Sean] is allowed his phone. My phone, it's got to be kept in the kitchen or the carer’s office. When my mum wants to speak with me my mum has got to ring the house first and say to give
Alex said that he thought the phone rule was unfair and a barrier to him from having control over his life. In order to clarify and trace where the phone rule came from I raised the matter with the Group Home Manager while speaking with her on the phone. Explaining that we were exploring the rules Alex did not understand and found restrictive I discovered that this highly prescriptive telephone rigmarole was part of Alex’s phone program (Appendix 3). The Group Home Manager confirmed Alex’s description of the rule, advising that Alex received calls from particular family members on specific nights of the week and that this was the only access he had to his phone.

A web of institutional texts co-ordinated Alex’s everyday world, dictating where he lived and with whom, what he ate, where he went and what he could or could not do. It informed the practice of disability service staff who worked in Alex’s Group Home. The phone program forms part of a larger institutional text, the Individual Program (IP).

Although we challenged this phone program through our complaints, initiating a review and subsequent changes to the program which provided greater access to his phone, Alex was still constrained by both the text and the willingness, or ability, of staff to follow and implement the new program. A complaint from our group when changes were not implemented triggered a reminder to staff of the new program. We were then advised by the Group Home Manager that “procedures regarding phone [were] being adhered to by all” (Correspondence, 23/11/07).

I contacted The Department on behalf of the group, asking

“What strategies have been put in place to ensure staff adhere to the new phone procedures? How and where are these procedures documented so that all staff are aware of the processes required?” (Correspondence, 23/11/07).

A reply to this correspondence was received on 3/1/08, including copies of the new phone program and Departmental staff directives concerning it. These documents were institutional texts which the Photo-voice group considered together with data gathered from conversations with Heather, Alex and Group Home staff. In doing so I identified a number of contradictions. For example,
amendments to the phone program – negotiated by The Department with Alex and Heather, then recorded in a communication book (another institutional text which recorded daily activities and staff duties, to which we did not have access) – made by the Group Home Manager had not been transferred to the printed phone program document. This document was what Group Home staff referred to and it informed their practice. Since the physical document was not updated, neither was their practice. Therefore, when Alex asked to take his phone when coming to Photo-voice, his request was refused on the grounds that staff thought he would not need it or it contravened the (outdated) phone program.

This breakdown of information transfer caused problems for Alex when casual staff, who lacked specific Group Home knowledge, were on duty. Alex reported that these staff differed from day to day. His claims that “They don’t know anything” and “They often get it wrong” (Alex, 19/9/07) imply that casuals lacked the knowledge gained from regular attendance at staff meetings and from working closely with the same people every day. Such knowledge includes residents’ temperaments and clues to their moods, an awareness of resident group dynamics and when to let something slide rather than pursue a point. It also seemed that casual staff were not in the habit of reading through past entries of the daily communication book which informs staff of occurrences from previous shifts (Heather, 17/10/07). A brief review of the previous shift’s notes was generally thought sufficient. Casuals relied on prescriptive written directions to order their work schedule. They relied on the phone program to instruct them on Alex’s phone usage. In this case, it appears that they were not aware of the contradictions. Permanent staff also failed to implement the new procedures, it appeared that they too were oblivious to the problem.

Following our further complaint that Alex was not being given his phone when out in the community (Correspondence, 18/11/07) a Departmental email was sent to permanent staff, marked of high importance (Appendix 3). It stated that staff were to ensure Alex

“has his mobile phone on him AT ALL TIMES when not in the unit or alone in the unit…. This has been agreed to by [Alex], his mother and [The Department] as per message in the communication book for staff previously” (Correspondence, 3/1/08, emphasis in original).
However, because they were not Departmental staff, casual staff did not receive this email as they were recruited through an external agency. Consequently, casually worked without knowledge of the reiterated new phone arrangement, relying, as noted above, on the printed phone program to coordinate their practice. As a result, Alex sometimes arrived at Photo-voice meetings without his phone — and frustrated. He was powerless to speak against the printed authority of the phone program, even though he knew it to be incorrect. It was an institutional text which demonstrated the powerful ruling relations at work in the Group Home and to which Alex had to conform. Inconsistency in the application of the phone rules caused great stress for Alex and limited his opportunity for self-determination.

Vignette 2: Rules as defensive tools

It could also be argued that institutional texts provided a convenient smoke screen for staff shortcomings. On one occasion a casual staff member failed to collect Alex after our meeting. At the time, Alex commented that they were “agency staff” (19/9/07) and he knew that they would forget to collect him. We were unable to ascertain whether or not this was because some casuals did not refer to the communication book for their instructions or because insufficient instructions had been provided. When they failed to arrive I phoned the Group Home several times without success. Alex suggested that the staff might be out in the car with a mobile phone and that he ring his mother for the staff members’ mobile phone number so that we could contact them. (This demonstrated initiative and warranted affirming, I acknowledged this to be a good idea.)

At Photo-voice the following week, Alex advised us that the staff member had completed an “Incident Report” (Alex, 24/10/07) on him because he had breached his phone program: i) he had rung his mother and ii) spoken to her on the wrong day! Deflecting attention from Group Home staff, it seemed the staff member had used the Incident Report as an institutional tool of defence. The incident report recorded and evidenced alleged poor behaviour and non-compliance with an institutional text (the phone program) for the future reference of others. Contrary to notions of natural justice, Alex had no right of reply to these accusations.

An Incident Report is an example of an institutional text that does not go away. They are developed without resident input and form part of an accumulated file
that can be used by the ruling authorities against residents to demonstrate declining behaviour. Alex claimed that the threat of an incident report was used by staff to control residents’ behaviour (Alex, 24/10/07). The profile created by the Report on Alex’s phone use was inaccurate but authoritative because of its status as an institutional text. Rather than comment on and affirm Alex’s helpful initiative to call his mother, the institutional text served to undermine his self-determination.

Vignette 3: Sexual harassment

Alex’s exclusion from rooms in the Group Home because of Alex’s claim that “[John] touches me inappropriately” (Alex, 21/9/07) has been discussed previously (10.2.1). Alex regarded this lack of freedom within his own home as a barrier to the control he had over his life.

Alex’s use of the term “inappropriate” is institutional language. It was not in keeping with his usual vernacular as he rarely used words of over three syllables and then not without difficulty. The word “inappropriate” sanitises – indeed minimises – regular, unsolicited, unwelcomed, touching (i.e. sexual harassment) from John. In a textually coordinated environment the “inappropriate” can be managed. Rules were used to textually minimise personal harm and ensure that duty of care could be demonstrated. When rules were breached the blame fell upon Alex for putting himself at risk. The Department was not questioned as to why it continued to house John, who was known to prey “inappropriately” on Alex, in the same Group Home. Could it be that to admit that sexual harassment was occurring would implicate the Group Home (and The Department) in allegations of neglect for having exposed residents to abuse? If so, this would be a direct breach of industry standards (also a textually-mediated code of practice) and a crime under NSW law (still more text).

However, that such a rule had been made, coordinating where and when Alex could enter rooms of the Group Home, is evidence of an awareness of the problem and a refusal to remove the cause of the problem. Alex was subjected to unwelcome, uninvited and “inappropriate” behaviour on a regular basis. He frequently reported the incidents to staff and claimed that there had been numerous Incident Reports written. But these were ineffective in generating

60 DSS 10 - Protection of Human Rights and Freedom from Abuse.
positive change, effectively being used for record keeping. Over the three years of the Photo-voice project I continued to hear reports from Alex of John’s “inappropriate” behaviour and our group lodged many complaints, following the institutional textually prescribed procedures. This approach did little to stop the abuse. In fact, Alex was even blamed for the lack of action.

“it was my own fault for not calling out loud enough, or they would have stopped it” (Alex, 26/9/07).

I also sought advice on Alex’s behalf from the Disability Abuse Hotline (as the institutional text prohibited Alex from making the phone call himself). I asked what could be done to remove John from the Group Home so that Alex was not under daily threat of abuse. Although very sympathetic, the hotline staff replied “Where will they put him? They would just be transferring the problem from one Group Home to the next. There’s not much they can do about it” (Field notes, 3/1/08). I seriously questioned whether this was a satisfactory response. It seemed that all the Government’s rules and policies and resources could not protect someone entrusted to its care.

Vignette 4: Not permitted in the kitchen and laundry

Alex enjoyed food. He loved to cook when he visited his mother at her home, but he was not permitted in the Group Home kitchen – no residents were. A barred security door prevents access to the kitchen. Alex saw this as a social barrier to the control he had over his life.

In preparation for the catering of our Penrith photographic exhibition (8.4.2), Alex volunteered to get some quotes for cheese platters from two supermarkets. Later that day I received a call from the Group Home Manager advising me that Alex was
not allowed to be involved in this catering activity (Field notes, 27/6/07). The Manager explained that when Alex was very young he had been misdiagnosed with Prader-Willi Syndrome (a complex medical condition, frequently accompanied by an obsession with food and eating) as he had a food obsession. For this reason The Department limited his contact with food. She described Alex’s interest in catering for our exhibition as “a worrying development” (Field notes, 27/6/07) – Alex had simply volunteered to obtain two quotes. DNA testing had previously confirmed that Alex did not have Prader-Willi Syndrome (Heather, 24/9/07) and this was known to the Group Home Manager, but the label was still used to justify the food restrictions placed on Alex and which formed part of his IP. As for so many people who are labelled, it remained a “fixed point of reference to guide professional treatment, educational programs, and the guidelines by which [Alex’s] conduct will be interpreted” (Linneman, 2001, p. 54).

I was very surprised by this. Meeting with Alex every week, sharing morning tea and occasionally lunch together as a group, I had not observed any indication of a food obsession or lack of restraint near food or a heightened interest in even discussing food. His demeanour did not resemble that of others with Prader-Willi Syndrome with whom I had worked. Nevertheless, as also identified by Barry Percy-Smith (2007), institutional practices actively undermined Alex’s participation in the Photo-voice project and were clearly a barrier to his self-determination.

It appeared that the misdiagnosed label of Prader-Willi Syndrome was part of a text that was attached to Alex and which had followed him for the past 16 years. The text was originally imposed on Alex through a medical Discourse. When others read the text they activated it, assuming stereotypical symptoms of Prader-Willi Syndrome then allowing those assumptions to influence how Alex was received by them and possibly determining his behaviour with them. In this instance the Group Home Manager became the proxy for the Prader-Willi Syndrome label and allowed it to coordinate her decision-making regarding Alex and food. The Manager perpetuated the medical ruling relations that originated the text by using it to dictate what Alex was and was not allowed to do.

The Photo-voice group learned through discussion with Alex that he and other residents were not taught life skills, such as shopping for food or cooking simple meals. Alex said “the carers do the shopping on the internet” (Alex, 31/7/07).
Although we were not able to explore why online shopping was the preferred option it appeared to reinforce Goggin’s notion of “social apartheid” (2008, p. 1). It also appeared to be an overt breach of the DSS, in particular DSS 2. (Individual Needs\textsuperscript{61}) and DSS 5. (Participation and Integration\textsuperscript{62}). The objective of DSS 2. is to achieve the maximum level of independence for each service user in the least restrictive way (NSW Ageing and Disability Department, 1998). Limited opportunities to develop independent living skills – and a barred kitchen door – seemed very restrictive. Furthermore, the Group Home staff-managed online shopping option restricted opportunities for residents to learn about foods – the varieties available, prices, labelling – and to go into the community to do everyday activities that other members of the community enjoy as a normal part of life.

The inability to acquire cooking skills directly resulted from Group Home residents being prohibited from entering the kitchen. Although Alex’s mother had requested over many years that a “restrained food program” (Heather, 24/9/07) be included in his IP, this had not happened – indicating that The Department had a limited regard for her input despite DSS 9. (Family Relationships\textsuperscript{63}).

Through conversations with Group Home staff I found that other institutional texts influenced the decision to bar residents from the kitchen. While one staff member blamed Alex’s “food obsession”, another informed me that the kitchen was a “safe room” (Field notes, 31/7/07) to which staff retreated when residents became violent. They claimed that this was why the security door had been fitted. I wondered why the staff office was not considered as a safe room. Fortified by a number of institutional texts, staff spoke of their right to a safe workplace under NSW industrial law and occupational health and safety regulations. I do not dispute that right. However, it appeared that these institutional texts were being used to over-ride a resident’s rights to normal living conditions and to develop independent living skills. The industrial relations Discourse, which is inter-textually supported by legislation, appeared to carry more weight than the humans rights

\textsuperscript{61} “Disability Service Standard 2: Individual Needs. Each person with a disability receives a service which is designed to meet his/her individual needs, in the least restrictive way” (NSW Ageing and Disability Department, 1998, p. 20).

\textsuperscript{62} Disability Service Standard 5: Participation and Integration. Each person with a disability is supported and encouraged to participate and be involved in the life of the community (NSW Ageing and Disability Department, 1998, p. 44).

\textsuperscript{63} Disability Service Standard 9: Family Relationships. Each person with a disability receives a service which recognises the importance of preserving family relationships, informal social networks and is sensitive to their cultural and linguistic environments (NSW Ageing and Disability Department, 1998, p. 145).
Discourse (also supported by legislation and underpinned by principles of normalization). Apparently an industrial voice silences a human rights voice.

As the laundry was situated off the kitchen, residents were not permitted in there either and so did not learn how to manage their own laundry. This further demonstrates how powerful texts can be in mediating what happens, where and by whom. If residents are not permitted to manage their own laundry then these tasks must be allocated to staff and written into the staff work routine. This appears to confirm Wolfensberger’s (1989) earlier suspicions of how residential staffing positions are secured (2.4.4).

Vignette summary

Our investigations and my textual analyses indicated that institutional texts were used to prescribe staff practice and coordinate residents’ lives. Institutional language minimised and managed problems within the institutional setting. The authority of the institutional voice of text was actively used to silence residents and to undermine their autonomy. The application of institutional labels had the power to construct their identity (for example as food-obsessed), control residents’ activities and limit their choices - even when a label was known to be inaccurate.

Inadequate institutional communication strategies and faulty administrative processes meant that unwarranted authority became invested in an inaccurate text. The inaccurate phone program had the power to undermine the ability of staff, particularly casuals, to provide quality service. It also undermined the credibility of residents. Finally, it was found that ruling parties prioritised some texts over others for their own convenience. These are examples of institutional forces that shaped, subjugated and coordinated Alex’s life and were barriers to his self-determination (Mykhalovskiy & McCoy, 2002).

10.4.2 Textual bondage and disempowerment

“Any situation in which some individuals prevent others from engaging in the process of enquiry is one of violence.”

Paulo Freire (Freire, 1996, p. 66)

In this subsection I consider the ways in which the ruling parties within the institution (The Department) used their power to tie the research group’s hands
and block our research path, stripping us of investigative power. My language of violence within this subsection reflects what the Photo-voice team perceived to be deliberate defensive strategies deployed by The Department to silence us. Again, an institutional ethnographic approach was a useful means of analysing our story.

Alex’s house rules were an invisible barrier. Although there were institutionally-known rules, clearly conveyed in Alex’s list – such as Not allowed in the kitchen (Appendix 2) – and supported by institutional structures such as the barred kitchen door and associated staff practices, Alex told the group that the rules were not written down. The reason given for this was because the residents could not read (Journal, 4/8/07). This indicated that the rules represented what Mykhalovskiy and McCoy (2002) refer to as an institutional force. They coordinated Alex’s life, dictating where he could and could not go in the Group Home, what he could and could not do. Were these rules related to a prescribed lifestyle program that had been developed? Had Alex misunderstood some of the rules? Initially, the group did not know the answers to these questions and needed clarification.

On behalf of the group, I tried on many occasions to arrange for The Department to meet with us and discuss the concerns Alex had raised. They repeatedly refused to meet with us as a collective, though they said that they would meet with Alex, his mother and me. That arrangement was contrary to Alex’s wishes and was not founded on any reasonable argument. The Department’s response to the group’s complaints can be described in terms of textual bondage and disempowerment. The following are reflections on the Photo-voice project’s interaction with a number of Discourses during the complaint process and on the way both the group’s actions and institutional practices were coordinated and sequenced by Discursive texts.

After reviewing “Some tips for making a complaint” (NSW Ombudsman, 2004), the research group was aware that evidence for Alex’s claims would be expected by The Department (Minutes, 17/10/07). This expectation required (and therefore coordinated) that the group undertake a particular kind of record keeping behaviour and provide examples in our letter.

Reflecting on the language utilised in our correspondence to The Department, I recognised the influence of the disability industry Discourse. My experiential
knowledge of the disability industry, which is coordinated by and subject to associated legislative texts including the NSW Disability Services Act 1993 (DSA) (NSW Government, 1993) and the DSS, influenced my decision to draft our initial letter of complaint (Appendix 2) using The Department’s institutional language. Naively, I thought that approaching this juggernaut with tough talk in their own language, would demonstrate that the Photo-voice group was a force to be reckoned with. In retrospect, I now realise I should have heeded Audre Lorde’s mantra that “the master’s tools will never dismantle the master’s house” (1997, p. 380). In our letter of complaint, the various issues listed by Alex were presented with the comments such as “We feel this does not accord with the principles of normalization”, or “This is in breach of NSW Disability Service Standard…”.

I fell into the trap of establishing what Smith terms the “hegemony of juridical discourse, with its language of allegations, evidence, due process and so forth” (Smith, D., 2004, p. 196). I say trap as, having couched our complaint in this way, we became captured by the text. Reacting to our complaint text The Department replied in like manner, using the institutional language of policy and the DSA, and thus took control of the agenda. For example, in an email from the Acting Manager Accommodation & Respite:

“The complaints raised are specific to the service delivery in the group home and will be reviewed against current Policy and the DSA Standards. To address the complaints in an open forum could possibly breach the confidentiality of other clients in the group home, it would be appreciated if the issues raised by [Alex] could be generalised for discussion in the Forum rather than identify individual clients or staff of the unit” (Correspondence, 26/9/07).

However, as The Department also cancelled our scheduled meeting and refused to meet with the whole Photo-voice group, it was clear that they had the power to stipulate the conditions under which they were prepared to discuss Alex’s concerns. They insisted that they would only meet with Alex, his mother and me, to avoid breaching the privacy of others (Correspondence, 15/10/07). This appeared to reveal a disablist attitude, one that privileged the academic over our other two colleagues (labelled as having learning difficulties) who were apparently mistrusted to respect privacy and confidentiality. Even though we appealed this overtly discriminatory decision (complaint lodged 18/10/07), The Department refused to reconsider.
Given what we experienced as The Department’s intransigence, a group decision was made to invoke the power of the legal Discourse. What the group recognised as “stupid,… wrong,… unfair…” (Transcript, 19/9/07) and “weird” (Chris, 23/1/08), I demonstrated were possibly human rights breaches under the Convention and the DSS (Minutes, 17/10/07, 14/11/07, 23/1/08). It was my opinion and my colleagues’, explicitly argued in our complaint of 18/10/07, that The Department’s stance was in breach of legislative standards and the Disability Discrimination Act. The Intellectual Disability Rights Service (IDRS) could find no justification for The Department’s refusal to meet with the whole group (10.3.1). Following legal advice and in compliance with judicial practices, we sought to increase our negotiating power through legal texts in order to secure a meeting with The Department. Each member completed and signed confidentiality and advocacy agreements which were hand delivered to the local Departmental office. We believed that to ignore our explicitly articulated decision to have a group of advocates support Alex in his complaint would be a breach of DSS 3 (Decision Making and Choice) and the dignity and respect component of DSS 4 (Privacy, Dignity & Confidentiality). However, receipt of the confidentiality and advocacy agreement documents was never acknowledged by The Department. Instead, they continued to insist on only meeting on their terms.

They had the power to ignore our voices. It seemed that their armour was impervious to all our strategies. The Department used institutional text (DSS 4: Privacy, Dignity and Confidentiality) to justify not meeting with all of us, whilst ignoring our use of the same text (DSS 3: Decision Making and Choice). Apparently Standard 4 trumps Standard 3, but who makes up those rules?

The Department had authority to limit our communications. They dictated what we could speak about, to whom we could speak and which of us was permitted to be heard. The authority imbued in institutional texts (such as The Department’s privacy procedures) restricted what we could speak about. For example: The Department refused to discuss the accusation that John sexually harassed Alex as

64 Disability Service Standard 3: Decision Making and Choice. Each person with a disability has the opportunity to participate as fully as possible in making decisions about the events and activities of his/her daily life in relation to the services he/she receives (NSW Ageing and Disability Department, 1998, p. 26).

65 Disability Service Standard 4: Privacy, Dignity & Confidentiality. Each service user’s right to privacy, dignity and confidentiality in all aspects of his/her life is recognised and respected (NSW Ageing and Disability Department, 1998, p. 32).
this would breach John’s privacy (Correspondence, 26/9/07).

The power to set the communication parameters was strengthened by an authority to restrict with whom we could speak. We were effectively gagged. Our group was prevented from speaking to Departmental staff in order to investigate our research problem. Departmental staff were also instructed not to speak to our group. The scheduled meeting with the Group Home Manager was cancelled by the Regional Manager. Alex claimed that Group Home staff who spoke with him about our complaint were removed (Journal, 31/10/07). Breaching the will of the ruling authorities had significant consequences for these people also.

The institution determined who could have a voice. It had the power to refuse to recognise and communicate with us as a group, even when this was the express desire of Alex and communicated to them in writing. To proceed with our investigation it seemed we had no choice but to adopt more covert data gathering methods, including use of Alex and Heather’s insider information and my field notes of interactions with The Department – in line with Diamond (2006).

In response to the Regional Manager’s refusal to meet with our group we decided to lodge an official complaint with The Department head office. Even in this action The Department’s institutional coordinating powers dictated the specific forms that must be filled out, which questions had to be answered and the documents that had to be submitted. It supposedly paved the way by which we, the complainants, should travel – but our experience was that it blindfolded us along the way.

Departmental text claimed to be “committed to handling complaints in a fair and open way” ([The Department], 2010). However, the complaints process itself was clearly in breach of these terms, as seen in The Department’s refusal to communicate with us as a group and the lack of acknowledgment of our correspondence. I was told that an internal independent investigation would be conducted and I would be duly informed of the outcome (Correspondence, 31/10/07). Although all correspondence was signed by me “on behalf of the Penrith Photo-voice group” the correspondence received back from The Department was only ever personally addressed to me, never to the group. On behalf of our group, I contacted The Department approximately every two weeks over a six month period to follow up the progress of its investigations. After six
months of not hearing of any outcome or resolution, it seemed evident that our issues were being “suppressed at the level of [The Department’s] institutional order” (Smith, D., 2004, p. 197).

This gave us all a great sense of powerlessness. In group discussions, the Photo-voice team referred to The Department’s ignoring of our letters as “unprofessional” (Gill, 24/10/07) and downright “rude” (Alex, 24/10/07). We wondered whether to raise this as a complaint issue as well. From our perspective, it painted a picture of either an overworked and/or dysfunctional Department that could not keep track of correspondence or of an arrogant Department that felt no need to acknowledge correspondence when it did not suit them.

We also expected that The Department would at least comply with their own textually mediated procedures which stipulated “[The Department] staff will keep in regular contact to update you on how things are progressing, at least every 10 working days” ([The Department], 2005, p. 1). Given the gravity of some of our complaints (sexual assault and intimidation), we felt that lodging additional complaints because staff had not formally acknowledged our correspondence or were not following due process was petty (Minutes, 24/10/07). We were also fearful of putting The Department offside and causing further reprisals for Alex in the Group Home. By not complaining about The Department’s tardy work practices, we were unconsciously yielding to the power of the culture of silence. Not only were our hands tied so that we could do nothing to pursue the complaint, not only were we gagged so that we could not speak, but our powerlessness was emphasised through their silence. We could not make them speak with us.

We found the opposition to group advocacy most peculiar. We did not believe we were asking much, just to sit down and talk. We could see no legitimate reason why The Department should not meet with us as a group, it seemed the power of (their) institutional norms over-ruled (Alex’s) personal choice. A discussion with Departmental staff from Head Office eventually revealed that The Department would not meet with the Photo-voice group because we had “no standing” with The Department. One sympathetic staff member said that he regretted that The Department’s position probably went right against what the group was trying to achieve (advocate with Alex as a group) but it seemed we were apparently using the wrong definition of group advocacy. The Department’s understanding of group
advocacy seemed to be a group of people who shared a common problem, such as all being residents of the same Group Home. He claimed that in that case The Department would definitely meet with us (Field notes, 3/1/08).

As only Alex lived in the Group Home, and the problem was not a Photo-voice group problem, The Department would not recognise this as an instance of group advocacy. It was an individual instance and warranted individual advocacy. The staff member said that The Department would not even recognise the title peer advocacy. We were apparently speaking the wrong language, though no one had pointed this out to me before.

Next we brought our issues before the NSW Ombudsman. Conversations with the Ombudsman’s office, after they had contacted The Department, suggested they had been presented with a truncated version of the story in order to present a different history, one in which I was cast as an obstructive and disgruntled complainant. This different history did not present the group as the collaborative complainant at all. In their letter, the NSW Ombudsman’s office stated

“I understand from my conversation with [Department staff] that [The Department] has made several attempts to arrange a meeting to discuss Ms Ollerton’s concerns, suggesting that the meeting be limited to Ms Ollerton, [Alex] and his mother to protect the privacy and confidentiality of other residents of the group home. Further, [The Department] advise that Ms Ollerton has to date refused the offers of a meeting” (Correspondence, 22/11/07).

The Department had evidently omitted to advise the Ombudsman’s office that it was Alex’s express wish to have the whole Photo-voice group meet with them and that The Department had refused his request.

However, we found that The Department had an institutional ally in the Ombudsman’s office. The Department’s history of events was acceptable to the mediator and did not require their further scrutiny. In email correspondence to me the Ombudsman’s office stated

“It is appropriate that one support person be present, as the purpose for doing so is to provide [Alex] with support in having his concerns addressed rather than allowing others’ input into the process, which could potentially take the focus away from [Alex’s] complaint issues. This would be a less complex process, and more likely to succeed, with fewer participants” (Correspondence, 7/11/07).
The Ombudsman’s office recommended “local resolution” meaning that The Department, Alex, and one support person should meet to discuss their differences. Privileging the institution above the less powerful service user, the Ombudsman agreed with The Department’s meeting conditions. As one or two advocates was the institutional norm, they were not obliged to step outside the norm by accommodating a request for three advocates (even though this was Alex’s chosen option and one of the reasons for our complaint). Compliance with institutional norms thereby denied Alex his choice, restricted his options and constrained his self-determination. Although the disability rights Discourse is intertextually fortified by State (Disability Services Act 1993), Federal (Disability Discrimination Act 1992, (Australian Government, 1992)) and international (the Convention) law, and we could state Alex’s legislated rights upon which his claim of a social barrier to self-determination was based, still the service provider was not obligated to accede to Alex’s right of choice as there was an absence of text-based instruction specific to this instance. There was no text to direct them to go outside the norm and they apparently would not set a precedent of cooperation.

We felt ostracised and discouraged, silenced and ignored, because we did not speak the right language. We experienced what felt like an institutional battery of silencing tactics which now included binding, gagging, blindfolding, concealing, restricting access and communicating in a language with which not everyone was familiar and where our definitions were unilaterally and without explanation determined to be incorrect.

We explored every avenue available to us to secure a meeting with The Department. We wrote to and also met with our local Member of Parliament, requesting that she be an advocate for our group to the State Minister for Disabilities. We wrote directly to the State Minister for Disabilities expressing our disappointment with her Department’s handling of our concerns. We consulted with the NSW Council for Intellectual Disabilities, the Intellectual Disability Rights Service and our local Federal Member of Parliament. On behalf of the team I contacted 34 advocacy organisations seeking advice as well as consulting academics in the Disability Studies field. We even wrote to the Disability Discrimination Commissioner. All the while, Alex would bring weekly accounts of abuse or harassment and oppressive and vindictive staff practices. None of our
own efforts was effective in getting The Department to sit down with our group to clarify Alex’s concern about the rules.

10.4.3 Dissed by The Department

In March 2008, six months after first raising our concerns, The Department notified me that their investigation had been finalised.

“The investigator’s report identified a number of systemic issues at the group home which require attention. I have requested that an action plan be prepared to address these issues. As the action plan may address issues beyond those raised by you, [The Department] will not be able to provide you with a copy of the plan” (Correspondence, 19/3/08).

It was an impressively uninformative letter, addressed to Ms Janice Ollerton and not the Photo-voice project, who were the original complainants. It ambiguously acknowledged “systemic issues” without specifying what these were or how they would be addressed. It clearly stated that the action plan would not be available to us and set no timeframe within which the issues needed to be resolved. We were surprised (and annoyed) that there was not even a “thank you for bringing this to our attention”. We were underwhelmed, but not surprised as we had already been repeatedly dissed by The Department. The experience of raising a complaint with The Department responsible for disabilities had been extremely disabling, discouraging and frequently disappointing. However, on his request (Alex, 23/1/08), as a team we had stood beside Alex and assisting him to speak out about his issues – and we had eventually been listened to. Our collective voices had prompted an investigation by a Government Department of its own services and now, according to the letter, something would be done.

The following is a textual analysis of the letter we received from The Department, using Lois Andre-Bechley’s (2007) template to explicate the power structures and meaning behind institutional text.

10.4.4 A textual analysis of The Department’s reply to our complaint

I was reminded by Lauri Grace that “official texts are neither passive nor neutral; they actively organise and coordinate local activities” (2005, p. 38). From the document received, the information given and withheld, it was evident that the Government Department responsible for the Group Home was doing just that. By
withholding information they were actively coordinating our local activities and outlining what the research team could and could not do and know. To better understand how this occurred I undertook a textual analysis of the letter to find out exactly what was happening in that letter.

Author/Source – this was an institutionally produced letter printed on Departmental letterhead. It did not come from the Group Home or the Regional Office but from the Regional Director of the Metro North Regional Office. The letter was dated 19/3/08, referenced DO817042 and personally signed.

Orientation of the text – coming from the Regional Director this text had authority. The application of this authority was used to make it a regulatory text which denied our group access to additional documentation. The text explicitly stated “[The Department] will not be able to provide you with a copy of the [action] plan”. The text intersected with a number of other texts including the original complaint lodged 18/10/07 and an “investigator’s report”. It also refers to a (yet to be prepared) “action plan” that promises to address unspecified “systemic issues” and, later in the letter, a document providing “details of the operation of [The Department] group homes”. The text relies upon the investigator’s report as evidence for claims made within the letter and as authority by which this text can prevent the Photo-voice group from gaining access to the action plan.

The letter was the result of an investigation generated by a complaint individually signed by each group member. However, the letter was personally addressed only to Ms Janice Ollerton and not to the original complainants, nor to me on behalf of the Photo-voice group. It pointedly ignored the repeated claim made by the Photo-voice group that our complaint was undertaken in terms of Alex’s request for group advocacy.

Organisation of the text – the text was well organised, commencing with the reason for the letter – to inform me that the review of complaints raised by me had been finalised. It pointed out that an (unspecified) number of (unspecified) systemic issues requiring attention had been identified, without naming what these were. It informed me that an action plan would be developed to address the problems. It also explicitly stated that I would not have access to the action plan as “the action plan may address issues beyond those raised by you”. It outlined in
dot points, using broad descriptions, some of the actions to be taken. These were

- Development of procedures for involvement of clients in meal preparation and shopping.
- Development of procedures to assist clients in identifying community leisure activities.
- Provision of staff training on Disability Standards.
- Provision of Protective Behaviour training for all clients.
- Referral for a Behaviour Clinician or Psychologist to conduct a Lifestyle and Environment Review for each client.
- Updating of all clients’ Individual Plans (Correspondence, 19/3/08).

We were not told what the problems were, how systemic issues would be addressed and within what timeframe, how long since the client’s IP had been updated, or if/when/how the issues would be reviewed to evaluate the success of the action plan.

Access to text – the text was written in technical language and utilised euphemisms such as “a number of systemic issues at the group home” to broadly conceal specific problems that had been identified. It used in-house terminology and generic phrases such as “Lifestyle and Environment Review”, “staff training” and “Protective Behaviour”. Such language is jargonistic and its implications are inaccessible to readers unfamiliar with what these terms mean within the context of The Department. Given that the research group was comprised of people labelled with learning difficulties and who had limited literacy skills, it was evident that access to the text was not intended for them. The content of the letter was deliberately and institutionally veiled for its readers.

Information exchange – minimal information was exchanged in the letter. Although it responded to the original complaint text it did not address the specifics of that text or the textual complaints process. It did contain a token mention of the Photo-voice group, offering to provide – at an unspecified time and which has never been received – (irrelevant) details of the operation of [Department] Group Homes “to assist in understanding the services that are provided”. The letter ignored our answer to The Department’s complaints form question “What would you like us to do about your complaint?” to which we had stipulated:
“We would like [The Department] to meet with our group to discuss the issues raised” (Correspondence, 18/10/07).

This request was tacitly refused by The Department in the letter. We had also stated

“We would like [The Department] to work with us to find ways of improving the situation”. (Correspondence, 18/10/07)

This request was also ignored, with no acknowledgement whatsoever.

“We would like [The Department] to listen to our suggestions” (Correspondence, 18/10/07).

This request was also ignored.

“We would like our complaint acknowledged in writing so that it can be formally recorded in our Photo-voice Project documentation” (Correspondence, 18/10/07).

Acknowledgement was received two weeks after lodgement, on 2/11/07. However, The Department’s letter of 19/3/08 did not refer to the lodgement date of our complaint or the fact that it took six months to complete.

The suggestion that an “action plan be prepared to address these issues” is intended to allay concerns and assure the reader that the problems will be dealt with – but without specifying how, or by whom or within what timeframe.

Resulting action - the letter was distributed to the Photo-voice group via email as soon as it was received. It did not require the reader to respond in any way. It provided contact details for further information on the action plan, thereby creating the illusion of allowing the reader to follow up these details for themselves if they chose to. However, I was well aware that further enquiries would be fruitless as it stated “[The Department] will not be able to provide you with a copy of the plan”.

10.4.5 Group review of The Department’s reply

The letter was read to the group in the first Photo-voice meeting of April 2008. The Minutes note the following points regarding The Department’s reply:

- It was not addressed to the group, demonstrating [The Department]’s continued refusal to acknowledge the whole Penrith Photo-voice group as Alex’s chosen
advocates. It was addressed to Janice only.

- It was not written in a way that was easily understood by the group. It used difficult language such as “systemic issues” and phrases that were vague and confusing such as “provision of Protective Behaviour training, Lifestyle and Environmental Review, Individual Plan.

- It did not identify what “systemic issues” were uncovered.

- It did not say how the “systemic issues” would be addressed.

- It did say that we would not be given a copy of the action plan.

- It did not give a timeframe within which [The Department] would address the problems found with the Photo-voice group in order to discuss what further action should occur.

(Minutes, 1/4/08)

The group was very pleased that the investigation had finally been completed but they found The Department’s letter unsatisfactory, deliberately vague and uninformative. One co-researcher asked Alex how he wanted the group to respond to this letter. Alex said

“I want more information… I want to know what they found… and what they’re going to do about it” (Alex, 1/4/08).

Another group member also stated “We want [The Department] to make a timeline” (Brendan, 1/4/07) so that the group would know when the issues would be resolved. I was very encouraged by these emphatic statements and the clear recognition by the group that this document simply wasn’t good enough! The group decided to, again, endeavour to speak to the Group Home Manager. By this stage a new Group Home Manager had been appointed and so we hoped for an improved relationship with this person. I was given the responsibility of trying to arrange a meeting for the group with the new Group Home Manager at The Department’s local office.

A Meeting!

In April 2008, seven months after first asking to meet with the Group Home Manager, a meeting was finally arranged between our group and the new Group Home Manager. Alex’s mother, Heather, travelled over 200kms to attend the meeting. Each item of concern raised in our original letter to The Department was addressed and a strategy for dealing with the concerns was offered to Alex and
the group for comment.

The group was told that the Group Home staff would be given training. We were told that abusive staff had been moved from the Group Home. Regarding one staff member in particular we were told

“You have my word, he will never work in a group home again, not anywhere in the industry. Never” (Transcript, 24/4/08).

At the conclusion of the meeting the Group Home Manager asked the team if we had any comments to add. Chris asked Alex “What do you think about that Alex? Are you happy with that?” Alex replied “Yes, I’m happy with that” (Transcript, 24/4/08).

The overall success of this meeting will be determined in time. Alex will be able to advise the group if lifestyle changes have provided him with greater freedom, whether strategies to avoid contact with the “inappropriate” resident have been successful in minimising harassment and whether opportunities to improve life skills have been gained.

10.4.6 Literature review

I analysed the Photo-voice research data collected for the Rules that Restrict Us barrier by comparing our findings with the disability literature. This section presents the comparison.

Our research had uncovered a disjuncture between Alex’s experience as an active member of the Photo-voice group and the ruling social practices that occurred in his Group Home. In this subsection of the chapter I argue the Alex we knew as a co-researcher in our Photo-voice group disappeared in the context of his Group Home where a different Alex was constructed. This different Alex was textually constructed by labels imposed upon him years before. It has already been proposed that Alex’s life was textually coordinated and that labels mediated the minutia of Alex’s daily experience. They informed the service provision of staff and his responses to them. They determined and dictated what, when and with whom he may do things, both in the Group Home and outside. When not at Photo-voice we found that Alex’s experience of knowing was subordinated by forces beyond his control. This experience is not unique. By comparing our
research findings with disability literature I was able to identify many similarities between Alex’s situation and service practice elsewhere.

Lessons not learnt from others

Findings on the British social care policy (Parker, 2004) bear striking similarities to issues raised by Alex regarding Group Home rule-based barriers to his self-determination. This indicated to me that the Australia human services industry had not heeded the lessons articulated years ago in the disability literature.

Parker’s analysis highlights that there were inadequate review mechanisms for Group Home residential placements. Similarly, Alex and his mother had informed our group that his IP had not been reviewed for over 12 months and his mother’s call for a managed food program had been ignored (Alex, 31/7/07; Heather, 24/9/07). Even the updated phone program review was inadequate as the new version was not communicated to all Group Home staff. This demonstrates that inadequate review processes existed within Alex’s Group Home environment.

Parker notes that the British social care system is built on concepts of vulnerability, need for care and, increasingly, risk (whether to self or others). A risk-focused service delivery system limits opportunities for independent living and for participation which most other citizens could reasonably expect. As previously described (2.2.2), language is a powerful social construction tool. Within the Australian disability service industry it is striking that the everyday nomenclature for the service system resorts to the term care rather than support – a conceptual position similar to that of Britain in 2004. The NSW State Awards (2003) refer to those working in not-for-profit organisations as carers (Industrial Relations Commission of New South Wales, 2003). While The Department uses position titles such as: Residential Support Worker and Community Support Worker (Correspondence, 1/2/10) this was not the vocabulary of the Group Home. Alex always referred to Group Home staff as carers, for example “She’s one of the carers” (Alex, 26/6/07), “The carers were...” (Alex, 31/7/07).

This language reflects a culture of disablist paternalism, constructing those with whom carers work as needy and requiring care rather than as able but requiring some measure of support or assistance. Conversely, such language constructs the staff as people of power.
Informed by the epistemological position of need and care, the Group Home rules proceeded from a particular way of looking at disability, an ableist and medical model frame of reference. Residents were viewed as disabled not just impaired, and in need of carers. This is a theoretical position that informed the running of the Group Home and the program management of residents and staff. Zarb (2006) notes that the importance of position titles and description is much more than semantic. The way in which the essential purpose of services is defined has a significant practical impact on how those services are organised and delivered. This in turn affects the kind of outcomes people receive. Could it be that when staff are employed by different agencies, under varying awards, with position titles articulating contradictory essential purposes (some as carers, other as support workers) people resort to a familiar and traditional care model? Outcomes based on care tend to maintain and reinforce dependency. On the other hand, outcomes based on support hold an expectation of participation and active citizenship (Zarb, 2006). Alex’s Group Home appeared to be based on a care model.

The Group Home risk management strategies imposed on Alex included movement restrictions within the house if staff were not present, barred kitchen doors to reduce access to food and sharp implements, restricted access to personal items (such as Alex’s mobile phone and his spending money (Appendix 2 and discussed further in 10.4.7)) and not being allowed to leave the premises unaccompanied. Alex told me

“I’m not allowed to go out for a walk without a carer with me. I can’t walk around the shops, or go for a walk up the road, I can’t go up to the phone box and ring my mum” (Alex, 4/7/07).

This surprised me as on previous occasions and of his own volition Alex had volunteered to do some shopping for group supplies. For example

“I’ll go to Franklins and buy some disposable cups if you like. Would you like me to get you a coffee as well, while I’m out?” (Alex, 27/6/07).

I had not questioned his ability to do this task. As I had no prior knowledge of the group when they joined the research project I did not really have any explicit expectations of what the members could or could not do. So when Alex offered to

66 A grocery store 20 metres down the road from our Photo-voice meeting room.
be helpful I handed him $10. Alex demonstrated initiative, thoughtfulness and competency, returning with the cups, coffee, two receipts and the correct change. He demonstrated self-determination and reliability and did not need to be accompanied wherever he went.

Such Group Home restrictions disabled rather than enabled Alex. They limited his living skills development, freedom and autonomy, and they made him dependent upon others for the provision of basic essentials such as food, money and transport. Alex’s mother confirmed that restricted opportunities to use previously acquired living skills, such as travelling on public transport and cooking, has meant “Alex’s been de-skilled since he moved into his current place of residence” (Heather, 24/9/07). While at school and living elsewhere, a different Alex had the confidence and skills to catch public transport to and from school. Our-Alex was able to walk to the shops near our Photo-voice meeting room and independently purchase items, often discerning which product was best value for money, and return safely to our meeting with the items, a receipt and change (Minutes, 13/6/07, 27/6/07). Had I been informed of the Group Home rule restricting his movements it is very likely that I too would have judged it too risky (falling back on the Group Home’s professional knowledge and a duty of care text) to send him on an errand unaccompanied. Slee refers to the “hegemonic appeal and grip” (1997, p. 57) of professional knowledge that sees people set aside their own judgment and defer to that of the professional. Fortunately, having no prior knowledge of the group members I only had to deal with my own assumptions and not those of other people as well. While at Photo-voice, Our-Alex was not encumbered by low expectations or the restrictions placed on him in the Group Home.

Another criticism in common between the disability literature and the Photo-voice group’s findings included assumptions of people’s inability to make decisions for themselves and competently exercise control over their lives, with an over-emphasis placed on risk (this is paternalism overriding autonomy). Alex raised this criticism with regard to his treatment by Group Home staff. For example, refusal to give him his phone because staff claimed “he would not need it” (Minutes, 14/11/07) was contrary to Group Home policy and directly against Alex’s stated wishes. However, the assumption by staff that they knew best meant that Alex was powerless to assert his right to take his phone out with him.
Alex’s Group Home was situated on the outskirts of Sydney’s western suburbs. There was no railway line and no daytime bus service to the closest railway station between 11:15am and 4:20pm Monday to Friday (the last returning bus left the station at 5:22pm) and only two buses on Saturday. The service did not operate on Sundays or public holidays (Westbus, 2009). Alex complained “I can catch taxis but they sometimes get lost” (Transcript, 26/6/07). Furthermore, this isolation meant that there was little for Alex to do during the day. Alex noted “in my life not much happens. I’m just at home and it’s boring” (Alex, 31/7/07) This echoes Parker’s findings that people in residential care were isolated in the community and that service design and/or delivery hindered rather than enhanced independent living.

Lack of advocacy was another finding in common. Goodley and Tregaskis (2005) emphasise that the key ingredient of empowerment for people labelled with learning difficulties is a supporter or advocate. Alex’s lack of efficient grievance processes not only delayed lodgement of his complaints, but meant he was then required to lodge them with people about whom he was complaining. He had no access to an advocate or the police. In fact, Alex advised the Photo-voice group that he was explicitly warned by Group Home staff not to complain to the police because “you’d be laughed out of court” (Alex, 24/10/07). Not only did this remark minimise the nature of John’s ongoing assaults on Alex, staff intimidated Alex by implying others would ridicule him. Group Home management urged him to report staff incidents to them to be dealt with internally (Alex & Heather, 24/10/07).

Alex claimed that his IP had not been reviewed for a very long time (Alex, 31/7/07). His mother confirmed that the last review had been well over 12 months ago before (Heather, 24/9/07). Without review of his IP, Alex had no opportunity to change his weekly activities. Our-Alex, who was a co-researcher and developing interests in new areas and learning, was not reflected in the outdated IP. That text constructed a different Alex. The Alex we knew was an ideas man. He frequently thought of ways to raise money and generated over $1500 in corporate donations (as detailed in the UWS Photo-voice project account), sourced travel options for the Photo-voice trip to Victoria (12.6.1) and always actively contributed to our group brainstorming. In 2009, he wanted to participate in the group excursion to Victoria, to learn more about photography and write his
own travel journal, but none of these activities were part of his IP. When Alex told the Group Home management of his plans to travel to Victoria he discovered that, as a Group Home resident under the care of a NSW State Government Department, he was required to obtain permission from The Department before he could travel interstate – and permission must be sought at least three months beforehand. This was at age 26 years, with the knowledge and support of his family, accompanied by the Photo-voice group, and even though he did not have a legal guardian. The Department claimed that they had a duty of care to know Alex’s movements by way of a daily itinerary which outlined a time schedule, addresses and flight details (Field notes, 12/12/08). This Departmental risk-focused policy constrained his freedom of movement (and hence his self-determination). It constructed him as a dependant ward of the State. Such restrictions disable people in Alex’s situation from accessing cheap flights that are available on standby or advertised as a last-minute discount. They remove a degree of impulsive spontaneity from the experience of travelling which many travellers enjoy (Urry, 2007).

10.4.7 Collaborative analysis through discussion

In this subsection, the analysis that took place through dialogic interaction within the Photo-voice group is considered.

Becoming social interpreters

Through discussion, group members were able to share perspectives, shed new light on Alex’s situation and together become social interpreters. Social interpreters are allies who

“... assist people with intellectual disability to understand what is happening in their environment, assist them to make the decisions they wish to take and assist them to exercise their rights. In this way a social interpreter helps a person with an intellectual disability to interpret the world and correspondingly may assist others to understand the preferences, decisions or aspirations of a person who has an intellectual disability” (National Advisory Committee on Health and Disability 2003, p. 21).

The concept of a social interpreter is tied to that of an ally. Ferguson and O’Brien (2005) recommend this as an appropriate position for disability service providers to take but note that it is a shift in social relations from providing a service to being of
service. It entails a willingness to change power relations and a recognition that the person receiving the service should take the lead.

The Photo-voice research group regularly sought direction from Alex (see 10.3.1 for example). Through group discussion, they assisted Alex to recognise what was happening in his Group Home. Where Alex had accepted John’s inappropriate interference with him as normal in the Group Home and the restriction of access to rooms as annoying, the Photo-voice group alerted him to the fact that these arrangements were not normal and were breaches of his human rights. In this way the group became social interpreters for Alex while his membership of the Photo-voice group assisted Alex to develop his own social interpretation skills.

Inflated social status

While researching Alex’s situation, the Photo-voice group repeatedly came back to the fact that staff in the Group Home appeared to have an inflated status (though in the group discussion it was articulated more as “Who do they think they are?”). For example, on being told that John had been punished by staff for tearing Alex’s jacket it was noted by the group members that it was not the role of staff to punish adult residents, because “They’re not his parents” (Alex, 23/1/08). The Group Home staff appeared to have significant power to speak into residents’ lives on personal issues such as how they could spend their money or if they should have a pet – but the Home was Alex’s home while the staff were paid workers.

Another incident which demonstrated the staff’s apparently inflated position of power occurred when Alex and I were going out together for a coffee one day. When I met Alex at the Group Home he greeted me holding a fruit juice and a banana. As he climbed into my car I could see that he was annoyed. When I asked him what was wrong he said “Just drive”. When we were out of sight from the house I asked Alex again what was wrong. “Look at this” Alex replied with a tone of disgust, holding up the drink and the banana. “They wouldn’t give me my $5 for a coffee” (Field notes, 31/7/07). When I later spoke with Heather about this incident she explained

“The house staff make judgments about how much money he should spend. It’s not their place to do that. If he spends too much he is punished by not being allowed to
take $5 out when going for coffee. Carers have no right to make those judgments. They should be flexible. Alex was mortified. Janice, I wish I could find a stronger word for it. He was more than mortified to not be able to buy you a coffee that day and instead to be given the banana and popper.67” (Heather, 24/9/07).

The Photo-voice team wondered why Group Home staff had the authority to dictate whether Alex could spend his own money. In discussion, we learned that “Most [later determined to be about 75%] of my pension goes into my rent” (Alex, 21/9/07). This meant that Alex, whose pension went each week to cover the cost of living in the Group Home, was in fact someone contributing to Departmental coffers from which staff wages came. He was paying to receive a service, and that service wasn’t very good. Furthermore, those providing the service were not answerable to him, but, quite the reverse, seemed to lord it over him.

Another example of inflated status involved the objections made by staff about Alex having a pet cat, even though the Group Home Manager had approved the pet and Alex was “a responsible pet owner” (Heather, 24/9/07). Alex said that the staff were making life difficult for him. When I asked him why, he replied

“He [Fred] does it to get me in trouble. In the past me and him haven’t been getting along, and [Rowena, also staff] the same... he doesn’t want the cats there and [Rowena] doesn’t want the cats there. They want to get rid of the cats... [Fred] said to me and [Rowena] said to me, they’re going to get rid of our pet cats” (Alex, 31/7/07).

During a discussion with Heather about the cats she confirmed

“The cat fuss is ridiculous and I’m adamant that [Alex] is going to keep his cat. [Fred] has tried to discourage me, claiming it would be too expensive for him [Alex] to own a cat and warning me... ‘Staff will not transport the cats in their vehicles to the vet.’ They don’t have to, we’ve utilised a mobile vet when we needed to. Or they complain that they get paw prints on their cars...” (Heather, 24/9/07).

When discussing these issues, the group decided that whether or not Alex had a pet cat “was not their [staff] business” (Chris, 1/8/07). Neither should they decide what he should spend his own money on.

The following subsection presents the group’s creative analysis of Alex’s situation. Through haiku we were able to pare back data layers and access core issues.

67 A 200ml fruit juice carton.
10.4.8 Inclusive analytical methods

“it is through poetry that we give name to those ideas which are – until the poem – nameless and formless, about to be birthed, but already felt. That distillation of experience from which true poetry springs births thought as dream births concept, as feeling births idea, as knowledge births (precedes) understanding.”

(Lorde, Audre, 1984, p. 36)

In this subsection the Photo-voice group’s reflections on incidents reported to them by Alex are explored. Utilising Heron and Reason’s (2008) notion of presentational knowing (described in 5.4.4) I attempted to encourage the group’s experiential knowing to emerge through the expression of poetry.

Poem 1 - John and the Jacket

Method

The group members shared their thoughts and critiqued the Group Home staff responses to the incident (described below). We then took phrases from the recording and, counting out the syllabic phrases by clapping as we said the phrases aloud, broke them into metered phrases calculated to compose a haiku (5,7,5 syllables) of Alex’s story. The poem captured the essence of Alex’s narrative and reflected the group’s distain of the service provider’s attitudes towards John, their workload and serious breaches of human rights. Through this presentational form of knowing the group was able to succinctly and clearly articulate their experiential knowing, clarifying their thoughts and distilling experience into poetry.

Background

Alex told the Photo-voice group that John tried to lock him out of the house again. He had grabbed Alex by the coat and torn it. As punishment, Group Home staff would not let John buy a drink (one glass of beer at the local pub) that weekend. When the other residents went out for their drink John had to stay at home. So, Alex explained, John took all the washing off the clothes line and threw it in the swimming pool. Alex claimed that “the carers spent all weekend writing Incident Reports” (Alex, 23/1/08) on John’s bad behaviour.

When we heard Alex recount this story Chris was annoyed and said
“That place is weird. They wouldn’t do nothing when that guy touched you, but they get upset about the washing. They can always rewash the washing” (Chris, 23/1/08).

John and the Jacket

John ripped my jacket (5)
So the carers punished him (7)
Stopped from buying drink (5)

“That’s stupid” said One (5)
"It’s a childish punishment” (7)
John is a grown man (5)

“That place is just weird (5)
They worry about the washing (7)
But not his touching” (5)

Group Reflection

John’s bad behaviour was not improved by childish punishments, “it was made worse” (Chris, 23/1/08). Although John responded like a petulant child, at 26 years old it was still inappropriate for paid staff to punish a resident. “They’re not his parents” (Alex, 23/1/08). “They might have got him to pay to have the jacket fixed or bought a new one” (Brendan, 23/1/08). We all thought this idea was a more appropriate response and might have had the beneficial consequence of John learning from his actions.

Why did the incident with the coat trigger numerous incident reports? “Because John was playing up all weekend” (Alex, 23/1/08). The staff response to the coat incident did indeed appear to have made things “worse” (Chris, 23/1/08), sending John’s behaviour into a downwards spiral. Perhaps there were lots of Incident Reports because spoiling the washing directly affected staff workloads. Staff had a vested interest in ensuring that the authorities knew about these things because these incidents increased their workloads. They had to rewash the clothes. However, John’s continued “inappropriate” touching of Alex did not particularly affect the Group Home staff. Perhaps it was minimised and dismissed because it did not inconvenience the staff as much.
The following discusses a poem composed in 2007. It was not collaboratively constructed.

**Poem 2 – Powerlessness**

**Background**

Poem 2, influenced by haiku, was born from a distressing Photo-voice incident. The text is taken directly from statements in the transcript of a telephone conversation with Alex on the afternoon during which he spoke of killing himself to escape the stress of living in the Group Home (10.3.3). Writing this poem was a way for me to deal with the experience, process the information and endeavour to distil the intensity of Alex’s despair.

**Powerlessness**

I want it to stop
they won’t return my mum’s calls
or meet with our group

I want it to stop
John, always trying to touch
Fred, always teasing

I want it to stop
But I don’t think it will stop
They never listen

If I kill myself
then I won’t put up with it
no, not anymore

**Reflection**

As I experienced this stage of the research I found I was caught up in an enormous sense of powerlessness, not unlike that expressed by my colleague in the above poem. Alex’s social barriers to having control of his life (to self-determination) appeared insurmountable and death was a way of escape. My powerlessness came from being unable to change the dreadful situation he was
in. I was powerless to pursue our investigation because of the obstructive responses received from The Department. I was also powerless to stand back from this situation and impose the traditional detachment that exists in other types of research. But the Photo-voice project was not traditional research, my colleague was not the object or even the subject of my study and I the researcher. He was my co-researcher. He was hurting, he was in trouble and I was very worried for him. Tim and Wendy Booth (1998) speak in detail of the difficulties incurred when the lives of researchers become enmeshed with the research participants. They also stress the obligations that researchers have in the context of disability research to go beyond traditional research boundaries. This level of commitment is needed in IPAR, both as part of the principal researcher’s duty of care and in the vision of liberation. It isn’t a nine-to-five kind of commitment.

Although things did eventually improve for Alex, at that stage of the research I felt impotent and fearful that I had caused the stirring of a hornet’s nest and made an awful situation terribly worse.

I was distressed by what appeared to be a dreadful situation in which Alex had to live, day in day out, with repeated abuse and harassment. I certainly wouldn’t want to live like that. As Alex left the group each week to return to the Group Home, to John and to staff that did not appear to appreciate the seriousness of his situation, I was often weighed down by Alex’s circumstances. I wanted to protect Alex - but was this maternalistic? Should I just allow Alex to protect himself? I wanted to ring the police, but Alex had not asked me to, neither had he explicitly asked me personally to get involved. The Photo-voice project was supposed to allow people to have control of their lives but how would that happen if I started taking control? Alex should choose for himself to ring the police. But I also knew Alex could not ring the police as he had no access to phones. Incidents were reported and Incident Reports written. However, his appeals to the carers were apparently dismissed in such a way that Alex sometimes thought the assaults were his fault. Now he had told the group about them. Was he calling out for help? Yes. Would I breach group privacy by going to the police? Yes. Would I compromise his trust? Possibly. Had I sent him home to more abuse and neglect? Very likely! Did I have an ethical duty of care to report these things (and to whom?) or should I uphold our privacy agreement and respect his dignity to be
in control of his life? After much deliberation and having heard Alex’s call for help, my moral duty of care and my responsibility as the principal researcher in the project convinced me that since I knew about these dreadful goings on I would be complicit in covering them up if I did not act. (Some of the resulting actions have been discussed in 10.2.2.)

10.4.9 Busy staff schedules

There were many issues that we were unable to pursue because, as Alex advised us, “the staff have been told not to talk about it” (Alex, 29/10/07). We were unable to explore why internet shopping was preferred, why staff reacted so proactively to the washing-in-the-pool incident (10.4.8 Poem 1), but dismissed John’s repeated sexual advances on Alex.

Jones and Lowe (2005) have recognised that a significant disabling barrier for people living in residential accommodation is the busy work schedule of support staff. Residents are often left with little to do. They refer to the “hotel-model” (p. 121) of service provision, in which staff are rarely trained in positive interaction with residents and are actually discouraged from promoting participation. The hotel-model tends to blame the victim, pointing to challenging behaviour, unhygienic habits, or lack of ability rather than recognising deficiencies in service provision. The Incident Reports on John throwing the washing in the pool may well be an example of blame-the-victim, although it was most likely the staff’s punitive response to the torn-jacket incident that was actually at fault. Jones and Lowe recommend approaching disability service provision from a different paradigm to ensure people can enjoy full and active lives – from “giving service to being of service” (Ferguson & O’Brien, 2005, p. 5). Brendan’s recommendation of paying for repairs also shifts the paradigm by turning the incident into an action-learning opportunity rather than involving punishment.

10.4.10 Thus far

Throughout the Photo-voice research project the team developed a strong commitment to one another. Alex shared much with us concerning his experiences as a Group Home resident and called upon us to support him as his advocates in speaking out on the rules that restricted him.
We utilised an array of research methods to make clear what was happening in the Group Home, to organise and analyse our data and identify gaps, relationships and contradictions, with the purpose of instigating positive social change. These methods included important discussions with Heather and Alex, corporately in group settings and also individually by me with Alex or Heather. We critically reflected upon issues and questioned the status quo. Our dialogic analyses built new levels of understanding and made meaning collaboratively. However, our investigation unsettled circumstances in the Group Home and exposed serious flaws in service provision. A review of disability services literature revealed that the problems we uncovered had already been identified more generally as serious concerns in the disability industry (Gray, 1981; Wiederholt, 1989; Rojewski, 1992; Parker, 2004; National People With Disabilities and Carer Council, 2009). Whilst it might not be expected that Group Home staff had read this literature, the makers of policy and procedures informing practice should be guided by and reflect the disability literature.

Institutional ethnography was employed (mostly by me) in order to trace the textually-mediated social organisation of Alex’s life and discover where barriers arose and how they were maintained. This was particularly helpful in illuminating the ramifications for Alex of having wrongly been given a Prader-Willi syndrome label. It was also the means through which the research exposed administrative errors and communication problems which significantly affected quality of service provision and undermined Alex’s right to dignity and self-determination.

A textual analysis of Departmental correspondence was a helpful consciousness raising exercise, exposing implicit disablism within an uninformative and deliberately vague letter composed using exclusive text. Poetry was then used as an inclusive analytical tool through which experiential knowing emerged.

The Photo-voice team’s endeavours to support Alex to voice his concerns about the Group Home highlighted a proliferation of issues. Many of these appeared to stem from the ableism/disablism dichotomy.

**10.4.11 Ableism / disablism**

Photo-voice investigations suggested that an ableist culture (Campbell, F. K., 2009) underpinned The Department, informing its policies and procedures and
perpetuating disablist paternalism (10.4.2 for example). Grounded in the national medical model definition of disability (Commonwealth of Australia, 1992), the medical Discourse permeated much of The Department’s service practice, placing an emphasis on individual deficit rather than on capacity building. Restrictive practices (such as kitchen/telephone rules and relying on Group Home staff for transportation) were established which actively and passively discouraged residents from developing independence skills such as cooking, managing a mobile phone or travelling on public transport. Labelling of residents, imposed by the medical Discourse, was perpetuated by institutional practices underpinned by seemingly irresistible medical assumptions. Even though Alex’s label of Prader-Willi Syndrome was known to be incorrect, staff continued to refer to it to explain their actions and restrictive practices.

The ableist language of carer cast staff in positions of power and actively disabled residents, who were seen as needing care. It buttressed the construction of residents, already labelled disabled, with assumptions of incompetence and need of programming, counselling, restricting, monitoring and reporting. Ableist Group Home staff assumptions that they knew best actively disempowered Alex from asserting his rights and undermined his credibility with staff.

The apparently ableist and disablist culture within The Department further inhibited the development of independence and self-determination through service practices which denied client choice and placed a higher value on institutional norms than on opportunities for self-advocacy. Ableism was also evident in The Department’s disregard for the Photo-voice group by insisting on addressing all correspondence exclusively to me, even when complaints were jointly signed by the whole team. Ableism was manifested through the use of exclusive and jargonistic language in their correspondence. I interpreted The Department’s willingness to meet with me as ableism, while its refusal to include the other two members of our team in discussions was blatant disablism.

We found this active disablism to be overtly disrespectful. It displayed a disregard for Alex’s dignity and disrespected his rights by refusing him his choice of advocates. This was an overt breach of the minimum requirements of DSS 10.1
Advocacy68 (NSW Ageing and Disability Department, 1998). Disablism was also evident in service practice. Childish punishments imposed upon adult Group Home residents (such as denying a resident access to his money and being sent off with a banana & fruit juice when going out for coffee with a friend, or not permitting residents to go on a social outings because of bad behaviour) were inappropriate. They demonstrated disrespect of residents, poor staff training and an inflated opinion of the staff’s own status. The willingness of staff to deride Alex and speak over the top of him in front of his mother suggested that such disrespect was institutional and an everyday practice. It also indicated a complete unawareness that this behaviour was inappropriate.

The extent of poor service practice and disablism was revealed through Alex’s accounts of vindictive taunting and intimidation by one of the Group Home staff. It was also displayed by the way staff minimised the significance and severity of frequent sexual harassment of Alex by another resident. Heather’s claim that staff deliberately aggravated Alex as a strategy to gain more staff (Heather, 24/9/07) also points to disablism. The Department’s willingness to house a known predator with Alex – despite repeated assaults, complaints and numerous incident reports – in addition to staff’s readiness to dismiss Alex’s accusations as either hear-say or non-consequential, betrayed a worrying lack of care for Alex. Disturbingly, The Department’s attitude perhaps also indicated a disablist assumption that assaults on someone labelled with learning difficulties were somehow acceptable.

### 10.4.12 Outcomes and learning experiences

Many issues arose from Alex’s Rules that Restrict Us barrier to self-determination. In supporting Alex to negotiate the barrier and challenge the rules that restricted him, our small group of social researchers and disability advocates triggered an internal investigation into a State Government Department. The evidence of disabling practices that unfairly and unnecessarily disadvantaged one person over another was difficult for the dominant powers to ignore (McLean, 2005).

Whilst much still needs to be accomplished to address the restrictive culture of

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68 DSS 10.1 “The Agency acknowledges and respects the role of people who act as independent advocates for service users, including their families, guardians and friends when they take on that role” (NSW Ageing and Disability Department, 1998, p. 103) – but note the ambiguity of the plural, apparently interpreted by The Department as “any one of his friends”.

Alex’s Group Home, including a continuing complaints conundrum\textsuperscript{69}, significant changes have occurred. These include the removal of some staff members and the recruiting of new staff as well as staff training. Also, Alex’s IP was reviewed in April 2008 and it appeared that he and his fellow residents were enjoying greater freedoms. By 2009, Alex was permitted to open his mail, keep his phone on him when going out or alone in the Group Home and has a house key so that John cannot lock him outside. He has been successfully travel trained to catch public transport from his home into the local business district as well as to Heather’s house (a task requiring a bus, three trains and travelling over 250km) and is permitted to go for short walks by himself in his local area (Heather, 2/2/09). Changed living conditions for John and the development of procedures to involve residents in meal preparation and shopping have reduced Alex’s exposure to abuse and increased his opportunity to develop life skills. The Photo-voice group hopes that the changes our actions have assisted Alex to make in his life and in his Group Home will positively affect the lives of other residents too.

\textbf{10.5 Conclusion}

Through this experience of advocating alongside Alex, the Photo-voice group has learned a great deal. We have learned that although a complaints flowchart or policy might appear straightforward, in reality the process can be protracted and extremely difficult (especially when there is no alternative than to complain to staff about staff, or when Managers actively discourage residents from speaking to outside authorities like the police). Flowcharts may claim that reprisals will not happen – but Alex and the team found that sometimes they will. We learnt that even though DSS 10.1 states that service users have the right “to choose their own advocates” (plural noted in original, NSW Ageing and Disability Department, 1998, p. 103) and DSS 7.8 stipulates that complaints and disputes procedures must allow “for the participation of the service user’s advocate where requested” (NSW Ageing and Disability Department, 1998, p. 56), a request for three advocates is deemed to be out of the question and non-negotiable.

The Department’s efforts to keep the Photo-voice silent made researching very

\textsuperscript{69} For example, when the (new) Group Home Manager was absent Alex was still constrained by his phone program and was only able to lodge a complaint to the Group Home staff about whom he wanted to complain. Alex was still trapped with no one independent to appeal to.
difficult for us, but we persisted. As a result, we learned how to be advocates and actually supported our colleague to be a self-advocate. We exercised our rights as citizens to seek assistance from our Government representatives. We learned how to access resources such as the Ombudsman’s office and other legal/advocacy services. We also learned that “the squeaky wheel gets the oil”. It is too easy for an institution to dismiss or ignore issues of concern but it may eventually respond to the squeak. We learned that we have the right to voice our findings and insist that our complaints are heard and dealt with.

Alex’s resilience throughout the complaints process was noteworthy and his determination to persevere in having the Photo-voice group as advocates was quite remarkable. Nobel laureate Pearl Buck has claimed that people who have always been free cannot understand the power of the hope of freedom for those who are not free. Perhaps this “terrible fascinating power of the hope of freedom” (Buck quoted in About.com, 2010) from the oppressive conditions of his Group Home has been a motivator for Alex. The possibility that freedom was not achievable certainly seemed to push Alex close to despair. However, he continues, three years on in 2010, to be a member of this (now self-directing) Photo-voice group, whose commitment to each other has forged a strong sense of solidarity within the group.

Although we were a very small group we took on a giant - The Department. As Alex’s advocates we also became agents of positive social change.

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At the conclusion of Chapter 9, Figure 57 illustrated the actions undertaken during Stage 3a of the Photo-voice project where the group explored the Public Transport barrier. In the present chapter I described Stage 3b, exploring our second barrier Rules that Restrict Us. Upon completion of this stage of the project I wondered if the research process had been as inclusive as I had intended it to be. Was it really as collaborative as I had thought? Had I been facilitating or directing, discovering with or depositing into? In the following chapter I discuss a creative analytical tool developed to resolve these questions.
Chapter 11 – Creatively Analysing the IPAR Process

11.1 Introduction

In this chapter I discuss a creative, hermeneutic, analytical tool developed in order to gain an understanding of the degree of collaboration that occurred during the social action stage (Stage 3) of the Photo-voice research project. Why and how the analytical resource was developed is described along with its benefits and application to the research project.
11.2 Postit patchwork

11.2.1 Background

In December 2007, six months after Photo-voice began and as the social action stage of the project appeared to be winding up (Public Transport actions had been completed and Alex’s complaints had met a Departmental brick wall), I reflected on what had occurred since the Photo-voice exhibition in September 2007. I wondered if the Photo-voice research project had been as collaborative as I had intended it to be. Had it really been as collaborative as I thought it was? Throughout the project I had tried to ensure that participants shared the role of undertaking or authorising actions, though many of the responsibilities had fallen to me. This was because I had the literacy skills required to write the letters. I had the internet access and motivation to send emails. As the research group leader, the group felt that my voice had authority. Also, I was a full time student and had the time to chase up the issues and since this was my PhD I had a vested interest in ensuring actions were completed. It was also evident that some of the group lacked the self-regulatory skills and self-confidence to follow through with actions for which they volunteered.

With a mountain of data and still deeply submerged in the practicalities of the Photo-voice project, I wanted to gain a deeper understanding of the Photo-voice research process by representing events and actions that occurred with colours, and then visually tracking its course. It was difficult to be reflective when still engaged in the project. Hermeneutics was seen as a way of taking a step outside the project and looking back into it to gain a deeper understanding of what was actually happening. Hermeneutics is the term given to a philosophical mode of thinking which tries to reconnect with the spirit of a form of expression (linguistic or non-linguistic) when that form of expression itself has become difficult to see (Davey, 2002; Ramberg & Gjesdal, 2009). It is the art of interpretation. I was seeking to interpret the research project, to communicate with the collaborative spirit of the IPAR in an effort to analyse the extent of that collaboration.

Data (issues arising and actions undertaken by the group) recorded in meeting minutes, emails, personal journal notes and field notes, were charted chronologically. Issues and actions were colour-coded on a computer document
to differentiate their origins. Colours were allocated to symbolise each of the various actors involved in the research. By identifying and scrutinising my independent actions from those carried out by me in collaboration with the group, along with actions completed by other group members, I hoped to expose any imbalance in the collaboration process. Colour-coding data also highlighted the various actors with whom we had interacted. My aim was to distinguish one action from another at a glance, free from detail, in order to gain an overall impression of the research process.

What resulted was a colour-coded, two-dimensional timeline showing what had happened and who was involved in the Photo-voice research project from September to December 2007. I had hoped to gain a visual indication of whether or not there was a dominant influence which stood out from the others. However, due to the amount of data, the chart extended over fourteen computer pages making it difficult to gain an overall impression by reading it from a computer screen.

I then decided to transfer the information onto one large surface. Taping together several pages of broadsheet newspaper the date-ordered details were summarised onto colour-coded postit notes. I had purchased a packet of five fluoro-coloured postit notes and coded the actions as follows:

- **Yellow** = Photo-voice group issues and actions (group authorised)
- **Orange** = Janice’s individual issues and actions (not group authorised)
- **½ yellow / ½ orange** = Janice’s representative issues and actions on behalf of the group (potentially authorised)
- **Pink** = Outside influences and agencies/people issues and actions
- **Green** = The Department (responsible for disability services) issues and actions.

### 11.2.2 Postit note patchwork analysis

Starting at the bottom of the sheet and working from left to right, postit notes (7.5cm square reusable labels) were placed chronologically side by side in rows of ten postits. By the end of 14 rows (140 postit notes) I had a good impression of
the dominant colour. Yellow postit notes dominated the display, indicating that the Photo-voice group-authorised actions had dominated the research process and confirming my hope that the project had been demonstrably collaborative.

I displayed this large sheet of analysis for several days in my study at home to enable me to reflect upon it while also allowing the postit note analysis to speak to me. I wanted to see it (up close and from a distance), to think on it (both deliberately and subconsciously) and allow the colours to communicate to me in some way. After a few days I became uneasy with the colour coding, realising that it was too simplistic and required refining. I had included the incidents raised by Alex, which the group had decided to pursue. These were coloured yellow as Alex was a group member. However, they were not the group’s issues as they were barriers or issues external to the group. They therefore needed to be colour-coded differently to distinguish them from the Photo-voice group and to ensure that the visual impression was not overly biased towards the Photo-voice group.

Alex’s issues were reallocated a light pink postit note and the chart updated accordingly. Unfortunately, the similarity of the postit note hues was another design flaw as they did not provide the distinction necessary to clearly differentiate actions. The yellow and lime-green postits were of a similar shade, as were the orange and bright pink postit notes. At a glance the dominance of one colour was not clearly evident as the colours used were not different enough from each other. By limiting myself to the five similar colours (conveniently available in the posits pack) the chart produced an informative but unsatisfactory result. It was practical in that I could count the colours and determine the results. However, I felt that a different type of analysis was possible by engaging with the chart on a purely visual level. It was easy to become lost in the mountain of data collected. I wanted the colours to speak more clearly to me. I therefore needed to consider (listen to) more than five factors.
Figure 59 - Postit note analysis in 5 colours for Photo-voice actions 9-12/07
I had used bright pink to represent outside agencies and people. My supervisor had been included in this pink group. She was not an outside agency. As supervisor, she was ultimately responsible for the research. Although separate from the group she had been closely involved in many of our group actions (for example, proof reading my letters and providing me with counsel and research advice). This level of support required its own colour. I did not anticipate that this would influence the overall impression of the display but it was an important factor to consider for a fuller, more accurate representation of the research process. Adding this new colour would more clearly depict the interaction of various players, demonstrating how often this interaction occurred and thereby mapping peaks and troughs. The aim was to use colour as text, instead of words, to represent the barriers to self-determination social action journey.

Once re-charted, I might have left the analysis there, counting the coloured postits and tallying the results – content with the fact that the yellows had prevailed, the project had been collaborative and I had achieved my aim. But I was not content. The result did not articulate clearly enough the social action journey and I felt that there was more to be said. The postit patchwork analysis had proved useful but the resources I had employed did not adequately convey the whole story or effectively demonstrate the power of this visual analysis tool. I wanted to reconstruct the analysis with more carefully chosen colours in the hope that this would give me a more accurate visual summary of the research process. I decided to move from posits to fabric.

11.3 Creating a patchwork analysis throw

Using patchwork (fabric shapes sewn together) as an analytical tool was effective in making the abstract tangible and the theoretical visual. I wanted to be able to share this analysis with others, particularly the Photo-voice group. I also saw patchwork as a decidedly female occupation. Resourceful women have been patchworking for hundreds of years and, while I am not a sewer, I liked the idea of claiming this historically female activity as an intellectual device. Aware of Smith’s criticisms of patriarchy embedded within sociology (Smith, D., 1990), my patchwork analysis could perhaps be called a feminist method. Patchwork has also traditionally been a community-based activity through which women gained
support and encouragement by meeting in Quilting Bees (Linen Lace Patchwork, 2008). Sharing this analytical method with others within a learning community would expand that tradition.

Another reason for moving from paper to fabric was that even if my first attempt at a colour-coding analysis had been completely satisfactory I was not convinced that coloured posit notes on newspaper would inspire anyone. I decided to turn the postit patchwork into a practical keepsake, a throw, that could be re-used as a teaching tool and shown to others as an analysis strategy to be shared.

11.3.1 Choosing fabric

Choosing fabric to patchwork was a creative activity that required me to think differently about the project. Initially, I thought that purple fabric might symbolise the feminist influence in the research but I was intuitively drawn to a roll of beautiful autumn-coloured fabric. The multi-coloured fabric would metaphorically signify a diverse group of people. With many different colours working so beautifully together, I thought it would be a perfect fabric to represent the collaborative and cooperative nature of our group. The Photo-voice project has been a season of our lives, which was also captured in the autumn fabric. The pattern on the fabric depicted a garden with different coloured flower-pots. I felt that the project had been beneficial to everyone in the group, having all grown a great deal through this experience. Our personal development was symbolised in the fabric.

The fabric used to represent my action was sage green, a favourite colour. My supervisor's fabric was a cloth embossed with gold. I chose this not only because the deep maroon blended with the autumn shades but because she was such a precious resource, rich in research knowledge and experience. The Department was represented by an olive green fabric. I used a strong, deep colour to signify the density or size of this Government Department. Too much of this heavy shade of green would darken the overall appearance of the throw. As it has turned out in practice, the influence on and obstruction of our research project by The Department was a weighty issue and we had uncovered dark topics so the colour was appropriate.

Outside influences were denoted using a bright orange fabric. These had
generally been very positive influences and their suggestions refreshingly helpful (such as the IDRS and John Evernden of the Independent Living Centre), so this too seemed a suitable choice of fabric. Also, splashes of orange were found in the Photo-voice print, thematically tying the fabric colours together. Alex’s colour was a mottled brown and chosen purely for its aesthetic appeal.

11.3.2 Constructing the throw

The patchwork throw was a simple piece comprised of 140 x 10cm squares. For the squares signifying my potentially authorised actions I cut squares of the autumn Photo-voice fabric and of the sage fabric diagonally in half. The two halves were sewn together along the diagonal side to form a bi-coloured 10cm square.

The throw was assembled one row of ten squares at a time. The squares followed the postit note template (with the addition of a new colour for my supervisor’s actions and advice).

11.3.3 Presenting the throw to the group

On 30th January 2008 I took the roughly constructed throw to our regular Photo-voice meeting. I described to the group the various meanings of the coloured patches. I explained that the patchwork throw resulted from my concern about whether or not I had driven the IPAR or allowed it to be genuinely collaborative. These concerns were particularly related to Alex’s issues as I had often needed to act before there was time to call a meeting to obtain group direction (for example, when Alex’s mother rang me (24/10/07) and asked me to intervene in an urgent Group Home matter). I was not sure whether the concept behind this analytical tool would be too complex for the research team to grasp, but hoped it was accessible. Once more, the group unsettled my assumptions by demonstrating great interest in the throw and asking lots of questions about each of the squares.

“Oooh [laughs]. Look at all [The Department]s! What were these ones [pointing to two green squares side by side]?” (Alex, 30/1/08).

“Who are these orange ones?” (Brendan, 30/1/08).

“What about public transport? That was my main issue. I think I should have had a patch as well” (Chris, 30/1/08).
Chris had raised two issues. First, he highlighted the dominance of actions associated with the barrier of Rules that Restrict Us in the throw. This was a valid criticism. We had collaboratively explored two barriers but the patchwork analysis brought out very clearly how much more energy had been spent exploring the Rules that Restrict Us barrier rather than Public Transport. Caught up as we were each week in Alex’s significant issues with the Group Home, which required prompt action, the research project had almost exclusively concentrated on Alex’s issues since the middle of October 2007. The scope for action relating to Alex’s Group Home was broad. In contrast, the social action undertaken on Public Transport was less complicated, more linear. It involved an excursion, letters to transport authorities, participation in the Review of Public Transport Disability Standards and liaison with the Independent Living Centre. On the other hand, Rules that Restrict Us involved a complex web of communications and activities.

Regarding Chris’ second point, “I think I should have had a patch as well”, I explained that everyone had taken their own photos of buses, trains and taxis. Chris had nominated public transport as his main barrier to self-determination but it wasn’t solely his issue (although I did have to agree he had complained almost every week about the poor bus service in his area). I reminded the group that all members had different issues with the public transport system (ticket machines, poor timetables, lack of travel training). The common link they all shared was that these were all public transport problems. That was why they all shared the same coloured patch. In contrast to this, the group was supporting Alex with his issues, it was Alex who brought the issues to the group and these involved incidents that only he had to endure.
Figure 60 - Photo-voice project analysis patchwork throw for Photo-voice actions 9-12/07
11.3.4 Accessible analysis

Alex was particularly interested in finding his squares (those representing issues he had raised) and became quite excited. He said

“Here’s another one. Oh, and look at all these [Department]s” (Alex, 30/1/08).

It was clear to the Photo-voice team that different groups of people (such as Department staff, Alex’s mother, the Ombudsman’s office) were represented by different coloured patches and that I was represented by three different coloured patches (autumn, sage and half-half).

The group counted each of the patches and recorded how many of each colour was found in the throw. By visually representing the Photo-voice actions and then comparing these with other actions and incidents depicted in the throw, the group was able to see, quantify and understand the extent of collaboration in the Photo-voice project. The group members were able to determine visually and quantitatively for themselves that the Photo-voice patches dominated the research process. Alex commented “Janice has 19 green ones and 24 half-half ones”. Another co-research added “but we’ve got more. We’ve got 37” (Chris, 30/1/08).

From their analysis of the throw the group decided that the Photo-voice research project had been collaborative.

Articulating activity

Another interesting outcome of the patchwork throw analysis was the way in which it visually demonstrated increasing group activity. As the project progressed (and the throw grew) the number of autumn patches increased. For October 2007 the group produced only nine patches, I had seven unauthorised patches and two potentially authorised patches, Alex had five patches, The Department had four patches and outside influences had eight patches. However, for February 2008 the group generated 22 new patches whereas The Department only had four (all were in response to our contact with them). As the group members gained skills and confidence they generated more group-initiated actions.
Accessibility of patchwork

It was encouraging that the patchwork was an accessible analytical tool, and one that the group enthusiastically embraced. From early 2008 the group moved into a highly self-determined phase of the project (described in Chapter 12) and produced many group initiated activities. At one meeting, while brainstorming various fundraising initiatives, Bart commented “I hope you’re writing all this down, Janice. We’ll be adding another whole row to the quilt” (Bart, 13/2/08).

There was a sustained interest and identification with the patchwork process and a clear understanding that the group’s actions were abstractedly reflected in the patches of the throw. Over the following months of 2008 the group members would enquire how the throw was developing. On one occasion, commenting on the group’s fundraising activities and how busy everyone had been, Bart said “that throw must be a bedspread by now” (Bart, 11/9/08). This remark demonstrated not only Bart’s understanding of the link between the patches and the group’s actions, but also a recognition of the growing size of our project. The group had moved beyond identifying barriers. Their social actions were taking place across a number of areas including letters to Government agencies, meetings with Government officials and Departmental staff, project presentations to groups, fundraising activities and corporate liaisons seeking sponsorship.

11.4 Conclusion

The patchwork throw was a successful means of creatively and accessibly analysing the collaborative nature of the project with people labelled with learning difficulties. It embodied a research report that could be symbolically read to others by the group. The throw indicated that, overall, the research was genuinely and successfully collaborative. Most actions had been authorised by the research team. Furthermore, as the Photo-voice project progressed, actions were increasingly undertaken by, rather than on behalf of, team members.

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In the following chapter I give an account of how the Photo-voice team became self-determining and what that meant for them.
Chapter 12 – Self-determined Self-funded Research

12.1 Introduction

In this chapter I discuss Stage 4 of the Photo-voice project. This phase was not part of the originally planned IPAR but grew unexpectedly out of Stages 1 to 3. It was characterised by initiative, resourcefulness and collaboration. Beginning with the research team self-determining to become self-directed and self-funded, I discuss the development of the Photo-voice website. Also reviewed is the team members’ decision to actively disseminate their research findings to their audience of choice, commencing with special education students and extending to conference and university presentations. Fundraising activities, corporate sponsorship and an interstate trip are amongst the many activities documented below.
12.2 Stage 4: Photo-voice becomes self-directed

In December 2007 our research activities appeared to be drawing to a close. We had finished working on the Public Transport barrier (Chapter 9). Unfortunately, the concerns about Alex’s Group Home remained unresolved at that time. I was reluctant to wind up the project while Alex’s issues were still up in the air, and none of the team wanted the project to finish either. So, at our final meeting for 2007 we agreed to take a Christmas break and resume in mid-January 2008. We hoped the Departmental investigation would be over by then and we could prepare a research report.

When we next met (16/1/08) I informed the group that I would need to withdraw much of my organisational support in order to concentrate on thesis writing and other commitments. However, there were still plenty of activities to be completed – Bart’s website suggestion (Minutes, 6/6/07) needed following up, William’s schools road-show idea could be explored (Minutes, 19/9/07), the option of conference presentations had to be discussed and a Photo-voice research report written. The team decided to continue meeting fortnightly for a few more months while further information was gathered on these areas.

In February 2008 The Department still had not addressed our issues. However, the team had made progress in several areas. I had gained funding from the UWS Social Justice Social Change Research Unit to develop a Photo-voice project website and train two people to administer it (see 12.3). The group had decided to present its research findings to four schools during the year (Minutes, 30/1/08) (see 12.4). We also discussed presenting at disability conferences as the opportunities arose. The Photo-voice team thought that the school presentations would “be good practise” (William, 30/1/08) for the conferences.

One decision all thought particularly exciting was to attend and present our research at the Having a Say disability conference, to be held in Geelong, Victoria, in February 2009. Achieving this goal would take considerable planning and a lot of money, though none of us was fully aware at that time of the extent of planning or money required. I reminded the group that I would not have the time to commit

70 Efforts were made to produce an audio report that would be accessible to non-readers, to be uploaded to our website, but this eventually proved too difficult for us to complete.
to the fundraising due to my study, travel and family commitments in 2008.

“That's OK, we can do that. We can organise the fundraising and just ask you for advice when we need it” (Bart, 6/2/08).

“We can spend this year raising the money” (William, 6/2/08).

So, in February 2008, the group self-determined to become self-directed, relying on me only as a resource when needed. I was still allocated time-consuming responsibilities (such as negotiating the website project, liaising with the Department of Education in order to gain access to schools, obtaining information about the conference and organising registration and accommodation) but I was acting more as a consultant than facilitator of the group. They were now directing their project. I was absent from the group for June and July 2008 (though I had previously contributed to the planning of activities that unfolded during my absence and was in regular email contact with Bart while I was away) and provided follow-up support on my return.

Becoming self-directed and self-funded was a significant step for the group to take. It was an immensely exciting and unexpected development. Contrary to winding up, the IPAR was transitioning into a self-determined and emancipatory research group.

Meeting time & place

Being self-directed meant that the group could choose where their meetings were held. During the first eight months of the Photo-voice research project the group met weekly (except during school holidays) at a community building in Western Sydney in which I had hired a room. Throughout 2008 meetings were held less regularly at an accessible local library, though on occasions the team chose different locations such as at cafés in Blacktown and Penrith. While I was absent, Bart arranged meetings as needed via the telephone (Correspondence, 19/6/08).

71 Emancipatory Research expects that people with impairments initiate and control all aspects of the research process, including social and material relations (5.3.1)
12.3 Building a website

The idea of a Photo-voice website was first raised by Bart on 6/6/07 during our second Photo-voice meeting. Over the following months the idea was discussed repeatedly. The group (particularly William and Bart) discussed establishing a Photo-voice page on MySpace, but that proved too difficult for them to do independently, and my limited IT skills were of little help. However, through UWS contacts I found Tri Community Exchange (TriComm). TriComm is a non-profit organisation that works collaboratively with community-based groups to increase their participation in processes promoting social justice. TriComm provides “training, resources, information and support to the community services sector in Penrith, Hawkesbury and Blue Mountains and NSW for IT services” (Tri Community Exchange Inc., 2010).

With UWS Social Justice Social Change funding we commissioned TriComm to build a website and provide website maintenance training for Bart and me. TriComm provided an array of templates of what a website might look like and the functions it might include. The Photo-voice group had to consider what was wanted from the website. From a catalogue of various designs they chose a
website program called Joomla. It was basic but appeared suitable for novice administrators such as Bart and me, and could accommodate our need for a photo gallery, news pages, information links and a visitor's book. Anne commented

“I really like Joomla. It is quite an accessible information management system... You can increase the font sizes, that's helpful for the vision impaired... I think the interactive, changeable colour scheme is also a good feature” (Anne, 11/11/09).

On 5/2/08 and 7/2/08 Bart and I received basic website administration training and also support to upload our research photos. At the time, Bart was also undertaking a Certificate ii TAFE course in IT. He commented

“The website training is really helping me with my TAFE. I can practise working at the backend of a website” (Bart, 17/2/08).

The TriComm training and practise with website administration has complemented his TAFE studies and helped consolidate his learning there.

Over the course of the Photo-voice project, Bart and I have experienced difficulties updating the website, mainly due to our inexperience. We received support from Anne, whose IT skills were far superior to ours and whose literacy skills enabled her to update our news page as events occurred. We also received support from William’s TTW disability service provider, Break Thru, who allowed their IT staff to contribute support. Bart’s administrative responsibilities have involved checking emails regularly and alerting me to any that required a reply from me.

The website (www.penrithphoto-voice.net.au, screenshots are shown in Appendix 5) is currently (2010) funded through the Photo-voice project account at UWS. This funding responsibility will fall to the group once our UWS account balance is exhausted. The website served the purpose of informing the global community of the Photo-voice research project and celebrates the team’s achievements. It also demystified social research by demonstrating accessible methods and providing an example of IPAR.

12.4 School presentations

Another way in which the Photo-voice team promoted their research was through school presentations. Prior to the team becoming a self-determining group,
William had raised the idea of conducting a “Photo-voice road-show” (William, 19/9/07), presenting our research to special education students and telling them about Photo-voice. In January 2008 the Photo-voice team planned to visit four high schools. All my colleagues had attended either a special school or been in a special education unit within a mainstream school and they were keen to demonstrate to other special education students what they had achieved.

In order to address special education classes we first had to gain permission from the NSW Department of Education. In February 2008 I contacted Janice Sutton, Transition Support Teacher for the Western Sydney Region, to determine the protocol. Following approval from the NSW Department of Education Regional Students Support Coordinator, a Photo-voice presentation was arranged for 14/9/08 to be held at UWS and attended by TAFE support teachers, secondary school special education teachers and Janice Sutton. Our aim was to showcase our research and gain permission to present in school and TAFE classes. Following our presentation of 14/9/08, permission was granted. We contacted Wyndham College, Quakers Hill. This was William’s old high school and he was thrilled to be able to show his teachers what he had achieved.

On 27 November 2008 the Photo-voice group introduced their research to a class of approximately 20 Wyndham College students. The group fielded questions from the students and their teacher, demonstrating confidence and research knowledge. It was an excellent dry-run for our impending conference presentation. Due to time constraints we only presented to one school during 2008.

12.5 Fund-raising

Fundraising consumed a considerable amount of the group’s time during 2008 and was an action that was only minimally supported by me. Fundraising required planning, organisation, teamwork, competent communication, commitment and considerable effort. In the following section I summarise a range of the research team’s fundraising activities, highlighting the challenges and important lessons learned by the group. Details are provided on a number of their actions to demonstrate the processes and challenges involved. I have documented these to show the resilience and resourcefulness of the team in dealing with and learning
from each situation.

In February 2008 Andrew arrived at a team meeting equipped with a comprehensive handwritten list of fundraising ideas he had thought of. Having extremely limited literacy skills, Andrew’s list had taken him considerable time and effort. Activities included putting on a fashion parade, Tupperware and candle party plans, car washes, sausage sizzles and selling chocolates and Krispy Kreme Donuts. Building on Andrew’s excellent start, William again raised the idea of a sponsor and suggested that Break Thru be approached (12.5.7). William, with the support of his TTW trainer, had also brainstormed fundraiser ideas and suggested screen-printing canvas bags and T-shirts for sale, making and selling calendars depicting Photo-voice photos, framing and selling our photos, as well as catering for TTW functions. William’s TTW trainer suggested that some of these activities could be incorporated into his TTW program as pre-vocational training (Field notes, 23/10/08). Unfortunately, the calendar and screen-printing activities did not occur.

Bart embraced William’s calendar idea with his usual good humour suggesting “Hey, maybe we could use Photo-voice to make a nudie calendar!” (Bart, 18/3/08), at which the group roared with laughter and heartily agreed. Some of the fundraising ideas were labour-intensive (such as car washes), and others yielded little return (selling chocolates). However the group’s enthusiasm to give it a go was evident in their application to brainstorming ideas for actively raising their own funding. Increased control of the project by the group was evident in the Photo-voice Minutes of 2/3/08 where my discomfiture with the unhealthy nature of chocolate and Krispy Kreme fundraisers was noted. However, my objections were overruled by a majority agreement of the other team members, “The group decided that if it brings in a profit we should try all avenues” (Minutes, 2/3/08).
12.5.1 Getting started

![Bart and his cashbox, selling drinks (7/12/08)](image)

**Figure 63 - Bart and his cashbox, selling drinks (7/12/08)**

Appointing a treasurer

Bart volunteered to become our group treasurer. The group felt that Bart qualified as he could count and he owned a lockable cash box in which the money collected would be safe (Minutes, 6/2/08). Although I had set up a spreadsheet on which to record financial transactions during the hot cross buns drive (12.5.3), this was outside Bart’s skill set. He preferred to collect the money and receipts and keep them in his cash box. He would be able to count the money and ensure it tallied with orders and recorded payments. It was agreed that when a sizeable amount of cash was raised (for example $200) the money would be deposited into a Photo-voice project bank account. Bart’s father would support him with banking tasks. Since Bart believed he was capable of the job and the co-researchers were happy for Bart to oversee the money, we agreed on his appointment as treasurer (Minutes, 6/2/08).

William asked

“What will we do with the money we get until we give it to [Bart]?” (William, 6/2/08).
It was decided that both William and Andrew would have money boxes in which to keep funds raised. We went shopping and the team chose and purchased money-tins (which required a can opener to extract the cash). Andrew and William would collect their fundraising money, store it in the tamper-proof tin and then give the tins to Bart when full (Field notes, 13/2/08). This is an example of one of the many small but important collaborative actions the group undertook.

Opening a bank account

We planned to open a Photo-voice bank account. This simple notion required much discussion as we considered many questions. Who would be the account signatories? Who would decide how the money was spent? What was our group goal and what was the money raised for? What would we do with left over money? These were complex questions which the group thoughtfully and collaboratively worked through, coming to a consensus of opinion on each one and documenting the agreements in our meeting minutes on 13/2/08.

We met with the Manager of the local branch of the ANZ bank\(^2\) to discuss how to open a bank account. However, we found that unless we were an incorporated organisation or could prove affiliation with UWS, we could not open a fee-free account in the name of the Penrith Photo-voice Project. I found that UWS would not provide us with a letter of affiliation as they insisted all such funds be held in a UWS administered account. The team agreed that Bart would oversee the group’s money in his cashbox. Amounts over $200 would be deposited into the UWS account we had previously established (Minutes, 18/3/08).

12.5.2 Critical reflections

One of the key components of emancipatory disability research is that people with impairments control the social and material research relations (Barnes, 2001). Entrusting Bart with the responsibility of treasurer was a significant step towards emancipatory research. In the spirit of collaboration, recognising the broader self-determining research environment being created by the Photo-voice project, I agreed with the group’s appointment of Bart as treasurer and accepted Bart’s accounting methods.

\(^2\) Two team members already had accounts with ANZ bank and nominated this as the preferred bank.
“It’s fine by me. You are controlling this group together now. So long as you guys are sure you can account for the money accurately, it’s fine by me” (Janice, 18/3/08).

This was an action on my part that required trust in Bart’s integrity, respect for his skills and a willingness to genuinely relinquish control and expose the project to a level of risk. I was not only risking that accounting mistakes might be made and the integrity of the research project breached through inadvertent mismanagement of funds, but more generally I risked actually walking my Inclusive Research talk. Although the group had talked about managing the project’s fundraising and being self-directed, to actively hand over control of this aspect of the project to Bart took me quite outside my comfort-zone.

Why was I uneasy about this? As I reflected upon my discomfort I realised how protective and possessive I still was of the project. Understandably, I had a strong vested interest in it as my PhD project and it had been a major focus of my life for the previous two years. However, reflexive examination of my response to this small concession exposed unacknowledged maternalism and disablism.

Within a social model of disability framework, to not hand control over to Bart would be to become a social barrier to the group’s self-determination. What was I afraid of? Did I think it was risky because Bart had a learning difficulty? Did I assume Bart might not be able to maintain accurate manual records? Such an assumption was unfounded. He might be much better at it than me.

Did I privilege technology (spreadsheet program) over manual accounting? People were collecting and recording financial transactions long before computers were invented. Did I think it was risky because an error would reflect poorly on me? Did I think that the integrity of the project was more important to me than to the others? This was not just my research project.

Through this self-examination I recognised afresh what I have known clearly at various times throughout our research journey together – the group was just as determined to undertake quality research as I was. We had made mistakes and used them as learning experiences. This was another learning opportunity for each of us.
Bart proved he was a capable and accountable fundraising co-ordinator, as evidenced in the following email update he sent me.

“WE RECEIVE ANOTHER ORDER OF CHOCLATES TO DAY
WE GOT 21 BOX
WE SOLD 15 BOXS IN LAST 3 WEEKS.SO WE BROUGHT SOME MORE
I JUST THOUGHT YOU MIGHT WANT TO KNOW
OK BYE” [sic] (Bart, 19/6/08).

12.5.3 Hot cross buns

I suggested that I begin the fundraising with a small activity (a hot cross bun drive within my own local community (church, workplace and university) to generate a pool of funds. As none of the group controlled their own bank accounts, I could contribute from my personal finances to kick-start a kitty, on which the group could later draw to finance other fundraising activities.

I initiated and controlled the first fundraising activity. Brendan suggested that he assist me in the collection of orders and the distribution of buns at my workplace. No one else was going to participate in this fundraiser and this was agreed to by the whole group.

Difficulties encountered

Unbeknownst to me, Alex started collecting bun orders and recruited his extended family and Group Home staff to collecting orders also. He obtained orders for over 1200 hot-cross buns, to be delivered over a geographical area extending 160km from the Blue Mountains, west of Sydney, to the Hunter region north of Sydney. The logistics of collecting and distributing all the buns were difficult to manage. I also encountered problems balancing Alex’s orders with the money collected. What was initially intended to be a small activity became complicated and stressful. Our profit was only $1 per dozen buns and so the considerable effort of distributing 1200 buns raised only $178 (including donations received and not counting time and petrol invested). However, it was a lesson for me in the need to carefully consider the cost-effectiveness of suggested activities and to keep in contact with all group members. I did applaud Alex’s initiative. He had certainly

73 Brendan attended a disability program run by Break Thru, which was also my employer.
exercised self-determination. However, he lacked the planning skills to carry out this activity without support. Had we been aware of his intended actions, the team may have been better able to plan for and support his desired participation.

Critically reflecting on this activity afterwards, one team member said

“The Hot Cross Bun drive was only going to be Janice's responsibility and now [others] seem to [have] somehow got involved too now” (Chris, 18/3/08).

Without targeting Alex, they pointed out that the original plan had gone astray. The team agreed that their next fundraising activity would be co-ordinated by Bart and everyone would speak with him about how to go about it. We discussed the need to allocate responsibilities and to communicate with one another so that tasks were completed efficiently. It was agreed by consensus that:

- Everyone (except Janice) would be involved in the Chocolate sales.
- William would be primarily responsible for organising the calendar, screen printing T-shirts and car wash fundraisers (organised through his TTW provider).
- Bart would be responsible for ordering the glow sticks, chocolates and for banking the money.
- Andrew was responsible for organising the BBQs, but everyone assist on the day if they could.

(Minutes, 18/3/08)

12.5.4 Glow sticks

Our second fundraiser had limited success. Bart was very enthusiastic about the idea of selling glow sticks to raise money.

“Who wouldn’t want to buy glow sticks? I’ve got six brothers and sisters, they all love glow sticks” (Bart, 13/2/08).

Bart researched and brought information about a supplier to the group meeting. However, before ordering the stock the group discussed the need to investigate current retail prices and decide upon their own price at which to sell the glow sticks. The fundraising brochure advised that the recommended retail price ranged between 50c - $2 each. William found

“They sell them for $3 each at the Easter Show and $2.50 in the clubs” (William, 20/2/08).
“How about we sell them for $1 each then? That’s 60c profit for each glow stick and it makes ours cheaper than the others, so they’ll buy ours” (Bart, 20/2/08).

The group agreed to this. The decision was based on market research and economic sense. However, the group found the glow sticks very difficult to sell. They didn’t want to sell them door-to-door and were “embarrassed” (Bart, 25/3/08) to approach strangers to sell them. After exhausting their contacts, none of the group knew what else to do with 360 tubes of glow sticks (Minutes, 24/4/08).

After exploring various options I followed one of my contacts and sent the glow sticks to a high school in Australia’s Northern Territory where she worked. The students raised $40 for the Photo-voice project as part of their Community Development studies. It was an interesting way for this fundraiser to finish, spreading the word about our Photo-voice project into outback Australia.

Difficulties encountered

Selling the glow sticks was not the only difficulty the group encountered. In April 2008 I received a request from Bart to mediate between William and one of William’s family. His family member had taken it upon themself to sell glow sticks to friends and work colleagues at the reduced price of $1 (instead of $15) a tube74, causing a loss to the group. William advised our group that he had unsuccessfully tried to dispute the price, but the family member had assumed William was mistaken, taken the glow sticks and refused to let William sell anymore (Minutes, 24/4/08). William, aged 19, was powerless to retrieve them and sought Bart’s assistance. Bart asked me if I could speak to William’s family and work things out.

I liaised with the family member and informed them that William’s price information was correct. I stated that the group would review their price in light of the family member’s feedback. The Photo-voice team reviewed the price. Based on the evidence we had gathered and the recommended price from the supplier, the group decided that the original price was fair and did not need to be reduced (Minutes, 15/5/08).

“We’re not being greedy. It’s a good price for someone who wants glow sticks” (Bart, 15/5/08).

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74 $1 per tube equated to 6.6c per glow stick instead of $1 per glow stick.
I wrote to William’s family member on behalf of the Photo-voice group outlining our review process and the team’s decision, requesting reimbursement for the glow sticks. Using the authority of UWS to give our request weight, I asked for (and received) payment by cheque, forwarded to a UWS account established for the project. Although this took the money out of the group’s control, I hoped it might ensure we received payment.

Important lessons were learned from the glow stick experience. The group had not anticipated being embarrassed selling glow sticks. They had not anticipated interference from others. It is one thing to want to be self-determined and quite another thing to achieve this in an environment where others can take control. However, the group developed resourcefulness. William had drawn upon resources available to him for advocacy support. Bart, in turn, had solicited my support. I had utilised UWS resources. As a team we had co-operated and achieved an acceptable outcome, regaining control of the activity and demonstrating competence. In this way, the team utilised power, demonstrated resilience and contributed to the re-construction of the label of learning difficulties.

12.5.5 Chocolate and drink sales

Selling chocolates and drinks were also activities from which lessons were learned. To maintain privacy, in this subsection I will revert to using the pseudonyms Alex, Brendan and Chris.

Chris was responsible for overseeing the fundraising activities, ordering product (such as cans of soft drink and chocolates), arranging the distribution of the goods to other group members, collecting their money and banking the profits. Initially, the group collaboratively decided what flavoured chocolates or soft drinks to sell (Minutes, 2/3/08). The choices were based on team member preference. However, in time the team identified the flavours that sold best, which directly affected their decision-making on purchases. Chris explained

“I buy Coke ’cause everyone likes coke and I think it’s better than Pepsi. And to start we also bought orange, but we got left with lots of orange. They don’t sell good. So I don’t buy anymore orange. It’s mostly Coke and lemonade” (Chris, 21/8/08).

Chris and Alex sourced fundraising information which the team reviewed before
deciding which fundraising company to use. Chris’s fundraising promoted Cadbury chocolate products whilst Alex’s information promoted Crest chocolates. Although some group members were keen to sell Cadbury because they knew the product, the decision basically came down to a matter of who was able to do the ordering and receiving of stock. Alex admitted

“Stealing might be a problem in my home, ’cause of the casuals [staff] and other residents... I’m also not allowed to use the phone to make orders” (Alex, 18/3/08).

This statement demonstrated Alex’s insight, based on his experiential knowledge, of the risks and anticipated difficulties he would face if responsible for ordering and receiving chocolate deliveries. (Alex’s response also ran contrary to claims by Group Home staff that Alex had a food obsession, since he willingly and rationally chose not to be responsible for the chocolates.)

Instead, Chris undertook this responsibility and also decided to choose Cadbury because “everyone buys Cadbury chocolates” (Chris, 12/3/08).

**Difficulty encountered**

In August 2008 Chris contacted me regarding a shortfall in Alex’s money and Alex’s insistence that more chocolates be ordered. Payment for the chocolates was made in arrears, four weeks after delivery. The group had four weeks to sell enough chocolates to break even, finalise the account, then sell the rest of their chocolates and bank the profits. Unfortunately, Alex did not have any profits. He had been receiving orders for chocolates from the Group Home staff who had then been selling them to their families and friends at cost price, without any profit mark up. Chris was unaware of the level of support Alex required to competently fulfil his role in this activity.

Alex stated that he “was being hassled by [Department] staff to get them more chocolates” (Alex, 10/10/08). It appeared that Group Home staff were either unaware of the correct price at which to sell the chocolates, they were deliberately buying/selling chocolates to their family and friends at a reduced rate, or they were selling the chocolates at the correct price but only giving Alex the cost price. We did not know which of these options was correct. Chris noted “They’ve been taking advantage of him” (Chris, 10/10/08). Perhaps they had been, we could not
know. As we discussed the issue, Alex was confused about what the sales price for the chocolates was. Chris pragmatically proposed

“I think we should write that money off and just stop doing the chocolates. They’ll only get angry if we say they took the money, or bought them cheap on purpose” (Chris, 10/10/08).

Rather than pursue the issue, the group agreed to this approach, with Chris philosophically noting “at least we haven’t lost money” (Chris, 10/10/08).

12.5.6 Sausage sizzles

Andrew secured three separate bookings for sausage sizzles during 2008. Sausage sizzles can be excellent revenue generators but they are not straightforward. On the practical side they are labour intensive. Although our first BBQ on 25/5/08 ran at a loss (we had to purchase all our supplies and over-catered), our second sausage sizzle on 7/12/08 was a great success. Fortunately, all our food products (10kg onions, 20 loaves bread and 60kg sausages) for this event were donated. We made over $1000 profit, which offset the losses from the earlier event.

Difficulties encountered

On the administrative side, sausage sizzles are bound by numerous legal and institutional regulations which constrained the group’s opportunities for self-determination. In this section I discuss the difficulty I had remaining inclusive while finding my way through the UWS administrative requirements.

Negotiating our sausage sizzles was complicated. Before we could secure a date to hold our first event, the group had to provide “a certificate of currency” (Bunnings Warehouse, 2008) – evidence that we had insurance cover to the value of $10 million. The cheapest premium for this level of insurance I could find was $700 (Field notes, 15/2/08), an expense far exceeding the reach of my student funding. I approached UWS to see if their insurance would cover our activity, since the research group was affiliated with them. An email conversation ensued that involved up to eight different correspondents from various UWS Departments including Finance, the UWS Foundation, School of Social Science and the Social Justice Social Change Research Centre (Correspondence, 16/4/08). It did not
include my research colleagues. My bureaucratic manoeuvrings with UWS to secure insurance cover were conducted at an institutional level. In doing so I unconsciously participated in the exclusion of my research colleagues. I engaged in an institutional discourse as an individual, not as part of a team. Upon reflection, I later recognised I was promoting my research project and its needs. This evidenced of my own unchallenged ableism.

Due to their limited literacy skills, I doubted that the Photo-voice team could read and understand the correspondence. I assumed my co-researches would not be interested in receiving copies of my correspondence with the UWS Finance Department. I assumed that they would find the content tedious (I certainly did) and that it would just clog up their email inboxes. It was more efficient to email, telephone and meet with various UWS personnel on my own. I was also cautious of unnecessarily circulating UWS email addresses to the team. In this way I demoted their status from co-researchers to participants. As they were not University staff or students I had unquestioningly excluded them from negotiations with UWS. I later recognised this approach as uncollaborative, undemocratic and disablist. It undermined the emancipatory efforts of the team and contradicted my own research goals. Perhaps they would have found the emails tedious or unreadable but the group members had a right to decide for themselves if they wanted to receive copies.

I was informed that monies raised under the protective insurance banner of UWS belonged to UWS and had to be deposited into a UWS account, managed by UWS. This took control of the funds raised by the group out of its hands. I was disappointed that this reduced the group’s ability to be self-determining. But I was also not recognising my own double-standards. By excluding the team from the insurance discourse I too had limited their self-determination through lack of information. Instead, I was disturbed by the more explicit loss of control of the money to the University. I was advised by the UWS accountant that

“Any funds that are deposited into University accounts will be subject to normal University policy & procedures and accordingly the Delegations Policy will apply to any expenditure ie: any expenditure must be approved by a delegated officer...” (Correspondence, 22/4/08).

Access to the money was constrained (or coordinated) by UWS policies.
Accessing money from the delegation officer required the completion of payment requisition forms. Such texts needed to be completed, signed and submitted by me, as the student of UWS. The trade-off of wanting a benefit from UWS was reduced control of the money. None of the group appeared to be disturbed by this. When asked if this was OK they quite willingly said “Sure” (Bart, 22/4/08). On the one hand I was sorry that the University’s processes excluded the team from controlling their funds but on the other, I had also contributed to that exclusion.

However, not all the group’s fundraising was under the auspices of UWS. Bart managed the funds raised from chocolates, glow sticks and drink sales in his role as treasurer.

Our fundraising activities were full of benefits and challenges. Together the team raised over $4000. In addition to the funds generated, important life-lessons were learned by all of us. Teamwork, praxis and resilience are amongst the chief skills gained throughout these activities.

12.5.7 Corporate sponsorship - Break Thru support

William, James and Bart had all been associated with the disability service, Break Thru. In the following section I detail the considerable success the group achieved in establishing a research partnership with this non-profit organisation.

William had a keen desire for the research group to seek support from his TTW service (Break Thru), often suggesting them as a Photo-voice sponsor (Minutes, 13/6/07, 20/6/07, 11/11/07, 23/1/08, 30/1/08). William offered to speak to Break Thru but this suggestion was dismissed with Bart saying

“Who do you think they’ll listen to William, you or Janice?” (Bart, 14/2/08).

However, with the support of his TTW trainer, William did speak to Ross Lewis, Chief Executive Officer (CEO) of Break Thru, about supporting the team to attend the Having a Say conference in Victoria, 4-6/2/09. The CEO agreed to consider the idea. He invited William and Bart to attend a meeting with him in August 2008 to discuss it further. The team met to talk about what they might need to take to

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75 Supporting, co-operating and communicating with each other.
76 Critically reflecting on our practice (how we did things) to improve future actions.
the meeting, such as a budget to cover airfares, accommodation and a meal allowance for five people. I prepared a brief budget estimating costs to be around $4000. I did not attend the meeting. Demonstrating his intention to be well prepared for the meeting, Bart sent me the following email.

“[The TTW Trainer] is having a meeting with Ross [Lewis] on wednesday so me and [William] is going to it and you may come to it it is on this wedensday at 2pm if you cant make it can you send me what we are rasied for how much we need what we are going to do over there and what we are going to spend over there how much we are trying to rasied
i need it by wedensday can email it before then” [sic] (Bart, 4/8/08).

On 6/8/08 Bart, William and the TTW trainer found that the meeting had been changed to a teleconference. Teleconferencing was a new experience for Bart and William. Feedback from the CEO later informed me that he believed they coped well, with William’s confidence and communication skills equipping him to take the lead. This was an interesting change in roles, as Bart’s leadership stood out in the Photo-voice group context. I received the following feedback from the CEO.

“[William] was the most talkative of the two as we have an established relationship through me popping into TTW regularly. I feel this helped him in the situation which was very new to both. [Bart] was fairly quiet” (Correspondence, 8/8/08).

I received an excited phone call the evening of the teleconference from William.

“The boss said your budget wasn’t big enough Janice. He said we’d need $8000. Then he said “better make it $10,000”. And he wants you to put in a proper proposal to the board” (William, 6/8/08).

The Break Thru CEO was willing to present our project’s case before his organisation’s board, suggesting that we be supported under Break Thru’s Unfunded Program Policy which allows funding to be allocated to community activities matching company core values.

The Photo-voice team was thrilled with the notion of receiving corporate sponsorship. At our next meeting I suggested to the team that, since we were planning to visit Geelong, Victoria for three days, we could incorporate a short road trip along the Great Ocean Rd.
Bart: “Mad.”

Andrew: “Yeah!”

William: “We’ll have a Photo-voice holiday… and [the TTW trainers] can come.”

(Field notes, 13/8/08)

It was an exciting prospect. The Victorian Great Ocean Road winds along some of the most magnificent scenery in the world. A road trip provided what I hoped would be an exciting opportunity for the group to extend its photographic compositions to include stunning landscapes. It also presented the prospect of creating pictorial travel journals. The group enthusiastically embraced the idea.

The notion of a travel journal extended the concept of Photo-voice from the original project into a new form of creative writing. The Photo-voice group would be able to capture and record a different aspect of their lives on film. They would not be taking holiday snaps. They would be recording the prestigious experience of travelling to Victoria to present at the disability conference, from their own perspective. It was also an opportunity to describe that part of Australia pictorially and had the potential to develop into a tourism/travel/research report for William and others to present to their disability service providers.

The Photo-voice project had identified societal assumptions of literacy as an issue of concern (Chapter 9). The group recognised that society’s dominant use of written text had an exclusive and disabling effect on the group members which significantly reduced their ability to participate in society with the same level of freedom enjoyed by more literate Australians. Limited written literacy skills in a textually reliant world reinforced unnecessary feelings of inadequacy. However, photography is a different form of literacy. It is a means of creating pictorial texts with wider accessibility. Photographs can be read by non-readers and non-English speakers. The text created through the group’s Travel Journal could provide the Photo-voice group members with a positive sense of achievement and competence as well as a medium through which their voices could be heard.
12.6 Victoria: road trip and conference

12.6.1 Preparation

In April 2008 Alex independently researched flight costs while Chris investigated rail travel costs. Both team members brought these details to our next Photo-voice meeting. I brought Great Ocean Road tourist information and we had a very talkative time of information sharing and planning. We started to plan where we would like to visit, where we should stay and how we might achieve this.

I had not previously prepared a funding proposal and my first attempt at budgeting had been considered insufficient by Break Thru. Approaching the UWS Innovation and Consulting Department for assistance, I received support from its Associate Director, Mark Woodbridge, who invested a significant amount of time guiding me through the process. The proposal included group member profiles, learning objectives, an itinerary at 15 minute intervals over a five day period, a comprehensive budget of $13,000, and detailed the benefits to the group, the community and to Break Thru. The proposal was grounded in the Federal Disability Service Standards as set out in the Commonwealth Disability Services Act, 1986 (Australian Government, 2006). In particular, it drew on the principles of participation and valued status, identifying how these would be promoted through the group’s road trip and conference presentation.

Break Thru accepted the proposal and arrangements were made for the funds to be transferred to our UWS account, thereby establishing a community partnership between Break Thru and the UWS Social Justice Social Change Research Unit. As UWS was overseeing the funds, all travel arrangements, including car hire, flights, conference registration and accommodation bookings were made through the University travel system and utilised their preferred travel agent. I was, again, disappointed that these responsibilities could not be shared by the group, but we were all very grateful for the support received from UWS.

In December 2008 I received an anxious call from Alex. He claimed that the Department demanded a detailed itinerary twelve weeks prior to leaving before approval would be given to travel interstate (Alex, 12/12/08; also see 10.4.6). As our travel was planned for 1/2/09 we did not have the required twelve weeks.
Although we had been discussing and planning the trip since August 2008, I was unaware of this Departmental policy. I phoned Alex’s mother who advised that The Department claimed they had a duty of care to know Alex’s movements by way of a daily itinerary which outlined a time schedule and gave addresses and flight details. I was pleased to have provided Break Thru with such a detailed itinerary to share with The Department. It proved sufficient for their needs and was accepted, even though we had not given the required notice.

**12.6.2 Road trip**

On 1/2/09 the Photo-voice group (Andrew, Bart, William and Janice) embarked on our Victorian adventure. Travelling by taxi to the airport we arrived at Sydney Terminal “totally pumped” (Andrew, 1/2/09). It was an excursion of firsts for many of us. It was my first time supporting an interstate, five-day excursion. For some it was their first time travelling without their parents, to Victoria, or of checking in luggage. Alex’s mother Heather, who has senior first aid training and extensive disability support experience, was employed as a support person. We met Heather at the airport. Gill also came to Victoria but only attended the Having a Say conference.

The following is a brief pictorial account of our trip to Victoria, using the group’s photos to show highlights. The Photo-voice group’s Travel Journal accompanies this thesis (Appendix 6).
12.6.3 Road trip and conference photos

Figure 64 - Our Great Ocean road trip
Our journey began at Sydney airport.

Figure 65 - Andrew, William & Bart checking in luggage at the airport en route to Victoria (1/2/09)

We arrived at Avalon Airport, just outside Geelong, Victoria.

Figure 66 - Disembarking at Avalon Airport
Over the next five days we shared each other’s lives, taking photos of our experiences.

Figure 67 - Andrew & Bart taking photos together in Victoria

Figure 68 - Bart photographing from inside the van
We saw the beautiful Australian coastline and the 12 Apostles.

Figure 69 - The 12 Apostles (Andrew 3/2/09)

Figure 70 - Victorian coastline (Andrew 3/2/09)
The group members took some amazing photographs.

On the third day of our trip we went to the Having a Say conference, held at Deakin University, Geelong, 4-6/2/09.

Figure 71 - Bart setting up our conference presentation on the computer (4/2/09)

Figure 72 - Bart, William & Andrew speaking at the Having A Say conference (4/2/09)
Break Thru supplied shirts to wear to our presentation. The team presented a conference paper (Ollerton, Kirkwood, Boyle, Roberts, et al., 2009) on their research to a group of approximately 50 delegates and answered their questions.

Figure 73 - Andrew on the Open Mic answering a question from the audience (6/2/09)
On the final day of the conference Andrew took the opportunity at the Open Mic session to share with 1000 other delegates why he was attending the conference. He told them very succinctly that “Photo-voice was all about having a say” (Andrew, 6/2/09).

**12.6.4 Travel journals**

On our return from Victoria I worked one to one with group members as they created their own travel journals using Target Photobooks (Target, 2010) software. Each group member’s travel journal was unique as they chose their photos and dictated to me their description of each photo. The group also met together to choose which photos would be used in a group travel journal to be presented to Break Thru and the UWS Social Justice Social Change Research Unit in appreciation for their support.

The travel journals are tangible mementos of the group’s road trip in Victoria. More significantly, they are beautiful and accessible pictorial texts that provide windows into the lives of the Photo-voice group members and that also allow them to communicate their experiences in their own voices to both literate and non-literate audiences.

**12.6.5 Corporate presentation**

On 4/11/09 the team attended the Break Thru board meeting, sharing a meal with board members before the start of the meeting.

William and I prepared a display on the walls of the boardroom of a sample of the framed photos previously exhibited by the team, choosing photos we thought summarised our activities in Stages 1-3 of the Photo-voice project. William and Andrew spoke about the photos, explained what the research had involved and answered questions from the eight member board. The team expressed their gratitude for Break Thru’s support and presented the CEO with a copy of their group travel journal.

Presenting to the board of directors of an organisation was a new experience for the team. It provided an opportunity to speak as experienced social researchers, disability activists and as young men enjoying learning new skills and exploring
Australia. Notably, they did not present as disabled researchers nor as people involved in some form of community-participation program. They had control of what they said and each speaker self-determined how they represented themselves and their team.

**12.7 Recognition of accomplishments**

The Photo-voice team has presented its work at a number of significant events, receiving recognition and praise for their achievements. The following is a list of the research group’s conference presentations and some of the commendations received.

**12.7.1 Conferences and university lecture**

**Having a Say Disability Conference** – Deakin University, Geelong Vic, 4-6/2/09

*Rights, Camera, Action!: The Penrith Photo-voice Project* (Ollerton, Kirkwood, Boyle, Roberts, et al., 2009)

This peer-reviewed conference, the largest of its kind in the southern hemisphere, provided the group with an opportunity to share their research story with people from across Australia. Our PowerPoint presentation was included in the Conference DVD, available for purchase from the conference organisers (VALID, 2009). Comments included “Well done, what you guys have done is awesome!” – Conference delegate (Journal, 4/2/09).

**Disability Studies Conference** – UNSW, Kensington NSW, 26-27/6/09

*Rights, Camera, Action: The Penrith Photo-voice Inclusive Participatory Action Research* (Ollerton, Kirkwood, Boyle, & Roberts, 2009c)

A Trans-Tasman peer-reviewed academic conference, this forum provided the group with an opportunity to join the scholarly community and demonstrate the effectiveness of Inclusive Participatory Action Research. Comments included

“This pioneering and creative project not only opens up new possibilities in collaborative research and activism - it is an artistic and political tour-de-force that shows how real change can be achieved” – Professor Gerard Goggin, Journalism and Media Research Centre, University of NSW (Correspondence, 6/7/09).
Photovoice Conference – UWS, Richmond NSW, 24-25/9/09

Photo-voice: A Tool for Finding a Voice
(Ollerton, Kirkwood, Boyle, & Roberts, 2009a)

Photo-voice: A Tool for Voicing the Findings
(Ollerton, Kirkwood, Boyle, & Roberts, 2009b)

The group presented at two sessions, attended primarily by community development workers, academics and Photo-voice practitioners. As Photo-voice participant-researchers the research team brought a different and significant perspective to the conference. Comments received included

“I loved having your group here with us at the conference. They've made a vital contribution” – Dr Claudia Baldwin, University of Sunshine Coast, Qld (Correspondence, 25/9/09).

University lecture

In March 2010 the Photo-voice team gave a lecture to UWS students studying human rights. They shared practical knowledge of how human rights are breached in Australia. Student feedback from our lecture expressed surprise that rights abuses occur in the suburbs of Sydney (Correspondence, 10/3/10).

I also presented the group’s research at a number of international conferences (see Appendix 4).

12.7.2 Recognition as Photo-voice practitioners

Our website also received positive feedback and commendations from around the world. I was contacted by Associate Professor Patricia Struthers, University of the Western Cape, South Africa, seeking advice on “using photo voice as a research method with learners with Down’s syndrome” (Correspondence, 6/2/08). A summary of our methods was provided as a helpful tool for research students. This was later commended as “wonderful, useful and practical ideas” – Professor Geert Van Hove, Ghent University, Belgium (Correspondence, 7/2/08).
12.8 Conclusion

Stage 4 of the research was an unexpected but very interesting journey. Watching the group become self-determined was exciting, challenging and unanticipated. The lessons learned and strategies improved upon through progressive fundraising activities saw the group secure corporate funding for $13,000.

Travelling to Victoria and speaking on stage before a crowd of over 1000 conference delegates was unimagined when we began in 2007. The group’s subsequent conference presentations at a Disability Studies conference (June 2009) and the Photovoices conference (September 2009), at which the team was received and recognised as experienced Photo-voice researchers, dispels the stereotype of people labelled with learning difficulties as incompetent.

Feedback from my co-researchers, their families and disability service providers indicates that involvement in this research has been life-changing for my colleagues.

"Photo-voice has helped me improve communication skills, self-confidence and my camera skills. Travelling independently to Photo-voice has improved my travelling skills. I have also improved my understanding of my citizen rights and responsibilities" (Brendan, 11/8/08).

"[Alex]... really enjoys being with the Photo-voice group. I can't tell you how beneficial this has been for him. We've tried so hard to have changes implemented. What the team have achieved is remarkable. It has changed [Alex's] life and taught him invaluable life skills" (Heather, 7/12/08).

"All I can say is that, Photo-voice has made a big different in [Chris'] life, it gave him the confidence to deal with all problems and take them head on. Truly, he has grown from a boy to a man in the time he was with Photo-voice. Photo-voice made him stand up for people with disabilities, made him see the problem, research the problem, and seek a way to fix the problem. PV gave [Chris] leadership & community awareness, where at one stage there was only Chris" (TTW Consultant 7/9/10).

It has contributed to increased confidence, pride and self-worth for everyone involved. Opportunity to plan, budget, make decisions, learn from mistakes and support one another in that learning process has contributed to their (and my) human flourishing. Drawing upon one another as advocates and friends has increased opportunities for self-determination and personal control. These
achievements are highly significant since none of the group was assessed as “work ready” or “open employable” by their disability service providers when the project began in 2007.

Support has been required. Andrew, William and Bart drew upon support as needed to fulfil actions and retain control of their lives (as I did too). We had the opportunity and ability to support one another. The emancipatory outcomes achieved during Stage 4 of the project were not “trivial” or “professionally stage managed” (Riddell, et al., 1998, pp. 81-82). This thesis has demonstrated that undertaking IPAR within an emancipatory paradigm is achievable. I hope it has also shown that, while often demanding, time consuming, discouraging and exhausting, it can also be successful, rigorous, liberating and society changing – and really good fun.
Chapter 13 – Conclusion

“To make an end is to make a beginning. The end is where we start from.”

T. S. Elliot (Four Quartets)

13.1 Introduction

What if everything about you was investigated and written by someone else?

In response to this question the foregoing chapters have presented the results of a collaborative exploration of social barriers to self-determination with people labelled with learning difficulties. This thesis has demonstrated that people so labelled are unacceptably disadvantaged by ableist social structures and disablist practices. Grounded in disability rights, the research challenged the social construct of learning difficulties and ableism/disablism in society by use of the social model of disability. It claimed the right to self-determination, the right to participate in research concerning oneself, the right to inclusive research methodologies and accessible research methods. As a result Inclusive Participatory Action Research (IPAR) was developed.

Two barriers to self-determination for a group of five people labelled with learning difficulties were identified, Public Transport and Rules that Restrict Us, and explored with the IPAR methodology creatively implemented using a variety of methods including the camera-based approach Photo-voice.

Naming these barriers (in a Freirean sense) has led to action! The world has been changed at personal, local, national and international levels as a result.

13.2 Reflections and results

13.2.1 Reflections on the social model

The social model of disability has had an enormous impact on disability policy across the world. It informs the policies of various Governments, including the United Kingdom and New Zealand disability strategies (Department of Health, 2001; New Zealand Office of Disability Issues, 2001). It underpins the Convention on the Rights of Persons with Disabilities (United Nations, 2006) and the WHO’s
redefinition of disability in the International Classification of Disability Functioning and Health (WHO, 2002). The social model informs much of the research in Disability Studies (Barnes, 2003). However, it can be argued that the social model approach has largely ignored people labelled with mental health or learning difficulties (Williams, V. & Heslop, 2005). I sought to address this issue and found the social model to be a very practical model to implement in IPAR.

However, the paradox of doing IPAR informed by the social model of disability is that while endeavouring to support empowerment through inclusive research strategies there is a tacit assumption of incompetence of the co-researchers because they are labelled with learning difficulties. Walmsley (2004) has noted the difficulty of a binary divide between labelled and non-labelled researchers. She raises terminological difficulties, pointing out that “only the excluded need inclusive research” (p. 69). There is also an assumption that people labelled with learning difficulties will begin the research from the position of the disempowered. Although Disability Studies literature (Goodley, 1999, for example) claims that the social model begins from the perspective of capacity not deficiency, the social model can position the labelled person as a victim. For people labelled with learning difficulties, their label frequently renders them victims of disempowerment due to constrained lifestyles controlled by others (see for example Roets, Adams, & Van Hove, 2006). Limited opportunities for the development of self-determination skills further impede the flourishing of their potential self-determination and can reinforce the appearance of impairment (Wehmeyer & Garner, 2003).

I struggled with the question of how to facilitate research that promoted the development of self-determination if I did not first start with the assumption of need. I have not overcome this difficulty and actually perpetuate it through the acronym IPAR. It is not easy to avoid the unequal social position that the learning difficulties construct holds. IPAR therefore begins with unequal power relations that must be acknowledged from the start – it is dishonest to pretend that they do not exist. I started from the position of assuming potential of my co-researchers but recognise that this necessarily also assumes deficiency, though with room for improvement.

Based on the literature of self-determination (frequently informed by a medical,
and therefore deficit, model of disability\textsuperscript{77} I assumed my colleagues would have under-developed self-determination skills as a result of deprived opportunities and social barriers (Baker, D., et al., 1999; Field, S., 2005). As a result, my original research plan was paved with capacity building strategies\textsuperscript{78} and opportunities to practise self-determination skills, aimed at building the skill-set of my collaborators and supporting them to take on increased control of the research process. Although such strategies may be appropriate learning opportunities for any novice researcher, in this context they were explicitly designed to build the four basic characteristics of self-determination in the research team\textsuperscript{79}. I now recognise this as disablism and contradictory to the social model. Rather than inexperience, it presumed incompetence.

Throughout the Photo-voice research project my assumptions regarding my colleagues’ inabilities were challenged and repeatedly proved incorrect\textsuperscript{80}. The social model and IPAR reflective cycles required me to be reflexive, critically examining my practice to identify disablism\textsuperscript{81}, and to interrogate my assumptions and question their validity. These were helpful pedagogical exercises. Working within the social model of disability contributed to my increased knowledge of the construct of learning difficulties and its flaws. At the same time it exposed unchallenged ableism and disablism in my own practices, transforming my understanding of myself and others around me. In the spirit of Freirean pedagogy I learned from my co-researchers and my own reflections, and my colleagues were willing to be my teachers (Sleeter & McLaren, 1995).

“Don’t worry about that. We’ll tell you” (Bart, 20/6/07).

“Heck, yeah” (James, 20/6/07).

The social model was an accessible social theory for the research team to grasp and apply analytically using accessible research methods such as Photo-voice. It was effective in consciousness-raising for all research team members, including myself. Using the social model of disability, the Photo-voice research has

\textsuperscript{77} See 4.4 Shifting the paradigm.
\textsuperscript{78} For example, 8.2.2 Getting started.
\textsuperscript{79} See 4.3.3 Models of self-determination.
\textsuperscript{80} For example, William’s use of metaphor (6.5), Kathy’s travel-training initiative (8.2.3) and Bart’s website suggestion (8.2.4).
\textsuperscript{81} For example, my dismissal of William’s suggestion of immediate action (8.2.4) and my reservations about relinquishing complete control of the research (12.5.2).
contributed new knowledge to the fields of Disability Studies, self-determination, human rights and to my own professional practice as an adult educator.

13.2.2 Applying the social model

The social model of disability provided a reference by which to critique disabling barriers – their necessity, how they came to be, their purpose and their benefits. Introducing the social model of disability to my Photo-voice co-researchers was also anticipated to raise their consciousness to their constructed status. It provided a vehicle by which to demonstrate ways in which disability was not their fault, or anything to do with them, but was a consequence of an ableist society unaccommodating of difference.

The Photo-voice research team chose to explore two research problems, Public Transport and Rules that Restrict Us barriers to self-determination. In the following subsections I discuss how the social model was applied, the effects this had and what we learned from the research. I also indicate research limitations and suggest areas for future investigation.

Public Transport

The Public Transport barrier was explored and critiqued within the IPAR methodology by using Photo-voice in concert with textual analysis, critical dialogue and problematisation, the Convention and institutional ethnography.82

As a result of the Photo-voice research project a clearer awareness of ableism was raised for everyone in the group. The team revealed the public transport system’s reliance on text-based technologies which disabled people, such as those “who can’t read, and visitors and that,... And that's not fair” (Bart, 3/10/07). The ability to expose ableist assumptions and their disabling consequences on the public transport system transferred the problem of disability from commuters to the public transport system. This knowledge assists in reconstructing learning difficulties by offering an alternative view of a social issue, interrogating ableism not incompetence.

The Photo-voice research team also exposed institutional tools of power by

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82 9.3 Actively exploring the barrier.
Rights, Camera, Action!

identifying examples including public transport signage designed “to cover their [public transport authority] butts” (Bart, 3/10/07) or make “excuses” (Bart, 3/10/07) for poor services. Through institutional ethnography and critical dialogue the team gained an understanding of how the everyday lives of the travelling public are socially co-ordinated by institutional forces and texts\(^83\), for the benefit of the organisation.

The Photo-voice team’s application of institutional ethnography methods to the Public Transport research could be described as an introductory exploration of the trans-local ruling relations with which commuters invisibly and unknowingly interact every time they travel on public transport. A more thorough IPAR exploration of these invisible actors who determine when, where and at what cost public transport is available would enable researchers to gain a deeper level of understanding of the way technologies of power are used to co-ordinate commuter behaviour. With an awareness of how the tools of power are used to organise society, citizens are better able to respond to that knowledge and implement social change.

We gained a greater knowledge of our human rights and learned how the Convention could be used to illuminate and claim these rights. Knowledge that the transport authorities have an obligation under international law to remove access barriers contributed to the team’s power-knowledge (Article 9, United Nations, 2006). We had knowledge upon which we could (and did) take social action\(^84\).

In undertaking research on the social barrier of Public Transport and claiming the team’s disability right to accessible public transport and public information we contributed to social change by:

notifying transport authorities and the Human Rights Commissioner of breaches of human rights\(^85\);

contributing to the national and international debate on human rights, on the public record through our submission made to the review of the Disability

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\(^{83}\) For example, 9.3.2 Textual analysis (Social organisation).

\(^{84}\) For example, Bart’s email to the bus company in 9.4.5 Acting individually.

\(^{85}\) 9.4.1 Contacting the authorities and 9.4.3 Writing to the Australian Human Rights Commissioner.
Standards For Accessible Public Transport\textsuperscript{86}. This submission, which provided photographically illustrated data on areas of concern and suggestions for improvement, will inform public policy;

liaising with the Independent Living Centre\textsuperscript{87} which informed the development of their access awareness program (Evernden, 2008a) and conference publication (Evernden, 2008b).

Such contributions challenge the construct of people labelled with learning difficulties by re-constructing my colleagues as competent, knowledgeable, politically aware, social researchers. It enabled them to speak out for themselves on matters concerning them. My co-researchers did not need someone Speaking For The Voiceless (Southern Connecticut State University, 2010). They used their own photo-voices.

With a heightened awareness of rights and of ways of exercising citizenship the Photo-voice team now has strategies for challenging ableism and disablism. The team members demonstrated confidence to approach utilities and elected representatives to voice their discontent\textsuperscript{88}.

The social barriers explored in this research were the concerns of a small research team consisting of six (maximum) but generally only three, young people labelled with learning difficulties. From such a small group it was never expected that the research findings would be generalised or seen as representative of barriers experienced by others in the community with a similar label. Further research is required to explore the extent to which text-based technologies restrict access to public information. In addition, IPAR incorporating transport users in the development of more accessible signage and technologies could be undertaken to build a more inclusive transport system.

Rules that Restrict Us

The Rules that Restrict Us barrier specifically pertained to Alex’s situation in a Government-run Group Home. The Photo-voice research team explored and critiqued this barrier within the IPAR methodology using Photo-voice along with a

\textsuperscript{86} 9.4.4 Reviewing the Disability Standards for Accessible Public Transport.
\textsuperscript{87} 9.4.2 Liaising with the Independent Living Centre of NSW.
\textsuperscript{88} The team did this via letter, email, and by speaking to the local MP, see 9.4 Addressing the barrier.
range of other methods. These included institutional ethnography and textual analysis\textsuperscript{89}, critical dialogue and problematisation\textsuperscript{90}, the Convention and DSS\textsuperscript{91}, a literature review and poetry\textsuperscript{92}.

Applying the social model to our critique challenged the status quo in Alex’s Group Home and revealed the disabling nature of its service practices. We identified textually-mediated systems which actively constructed disabled identities\textsuperscript{93} and established disablist practices\textsuperscript{94}, thereby robbing residents of previously acquired skills\textsuperscript{95}. This perpetuated the notion of people labelled with learning difficulties as incompetent and needy. The Photo-voice research group questioned these assumptions\textsuperscript{96} and found that they were often unfounded and benefited Group Home staff rather than residents\textsuperscript{97}.

Through our efforts to support Alex’s self-advocacy we became social interpreters\textsuperscript{98}, advocates\textsuperscript{99} and, more generally, disability activists. My colleagues and I gained experiential knowledge of disablism as we supported Alex to name his barriers. Dark issues such as sexual abuse and restrictive practices, which were minimised and disguised with Group Home rules, were brought to light. Through the application of human rights instruments such as the Convention, the Universal Declaration and the DSS, the research team exposed poor service practice and overt human rights breaches, giving Alex grounds for complaint\textsuperscript{100}. Our research revealed to Alex that the situation in his Group Home was dysfunctional and unacceptable, and he did not have to put up with it. Knowledge that The Department had an obligation under State, Federal and international laws to address these barriers and stop the human rights abuses contributed to Alex’s power-knowledge. With the support of his IPAR colleagues and his family, Alex had knowledge and authority with which to take social action – and he did.

\textsuperscript{89} 10.4.1-4.
\textsuperscript{90} Throughout 10.4.
\textsuperscript{91} 10.2.4 Following up incidents.
\textsuperscript{92} 10.4.6 Literature review and 10.4.8 Inclusive analytical methods used.
\textsuperscript{93} 10.4.1 - Vignette 4.
\textsuperscript{94} For example, phone rules (10.4.1- Vignette 1), kitchen rules (10.4.1 - Vignette 4) and no access to money (10.4.7 - Inflated social status).
\textsuperscript{95} 10.4.1 - Vignette 4.
\textsuperscript{96} 10.3.1 Advocacy actions.
\textsuperscript{97} For example, the use of “incident reports” (10.4.1 - Vignette 2) and a “safe room” (10.4.1 - Vignette 4).
\textsuperscript{98} 10.4.7 - Becoming social interpreters.
\textsuperscript{99} 10.3.1 Advocacy actions.
\textsuperscript{100} For example, 10.2.4 Following up incidents and 10.3.1 Advocacy actions.
The Photo-voice research team found evidence of an ableist culture underpinning The Department and informing policies and procedures that perpetuated disablism\textsuperscript{101}. Our social model-based research challenged the medical model-based practices of The Department. As we explicated the implications of Alex’s misdiagnosis of Prader-Willi Syndrome, we were confronted with the constructing power of labels, which we challenged\textsuperscript{102}. By critiquing the Rules that Restrict Us barrier to self-determination and by taking advocacy actions, our IPAR generated an internal investigation into Alex’s Government-run Group Home. The successful complaint outcome for Alex contributed to practical knowledge for his family, who had struggled for many years to have their suggestions for improved service taken seriously. Our approach was more than a matter of the squeaky wheel getting the oil (though we certainly did some squeaking). The IPAR trialled numerous strategies\textsuperscript{103} and, in consultation with Alex’s mother, we found practical ways of exposing disablism and instigating action that worked for positive social change\textsuperscript{104}.

Disability literature notes that people labelled with learning difficulties or impairments are primarily “thought of in terms of their disability” (Davis, L. J., 1995, p. 10). Participating in an IPAR project narrowed the gap between how my colleagues were viewed by others (for example, Group Home staff, disability service board members or conference delegates) and how we viewed one another. Our IPAR worked to dismantle a stereotypical identity characterised as incapable and reconstructed the team as capable social researchers, activity planners, fund-raisers, conference presenters, treasurers, web site designers and administrators, photographic exhibitors, human rights campaigners and disability activists\textsuperscript{105}.

Our research also taught us that social action can have distressing ramifications when others are resistant to criticism and change. However, armed with rigorous research data, sound analytical tools and supported by allies, change can occur. Confirming the findings of Goodley and Tregaskis (2005), we demonstrated that self-advocacy can be more effective when undertaken with support than

\begin{itemize}
\item \textsuperscript{101} 10.4.11 Ableism/disablism.
\item \textsuperscript{102} Powerfully exemplified by Alex’s successful oversight of the sausage sizzle (12.5.6).
\item \textsuperscript{103} Including trying to meet with The Department, writing letters of complaint, seeking legal advice and complaining to the Ombudsman, the local MP and the Minister responsible for Disabilities (Chapter 10).
\item \textsuperscript{104} 10.4.12 Outcomes and learning experiences.
\item \textsuperscript{105} As evidenced in Chapters 8, 9, 10 and 12.
\end{itemize}
without\textsuperscript{106}. Our IPAR actions provided this support, resulting in important quality of life improvements for Alex\textsuperscript{107}.

The Department’s unwillingness to enter into dialogue was a significant restriction. The Photo-voice research team’s preliminary findings, submitted in our letter of complaint, were followed up by a Departmental investigation. Our research on the Rules that Restrict Us barrier was largely undertaken by adopting Diamond’s (2006) covert research strategy of observation – insider information through Alex and his mother, analysis of our own interactions with staff\textsuperscript{108} and textual analyses of Departmental documents as they were made available to us\textsuperscript{109}. Our complaint was justified and Alex vindicated when The Department replied that the

“investigator's report identified a number of systemic issues at the group home which require attention” (Correspondence, 19/3/08)\textsuperscript{110}.

This is not to say that all is now sweetness and light and IPAR has been completely successful in transforming the world, or even Alex’s corner of it, or even all of his Rules that Restrict Us barriers.

I recommend that an independent IPAR institutional ethnography be conducted in collaboration with disability service users from outside The Department to explicate how the “systemic issues” came about and to identify the structures that perpetuate them, including disablist service practices. This would further respond to the Convention’s call to “promote awareness of the capabilities and contributions of persons with disabilities” (Article 8, United Nations, 2006) and demonstrate the value of disability service users’ participation to correctly identify specific needs.

Our limited research identified a raft of human rights breaches within just one Group Home in Western Sydney. Although this research does not assume that Alex’s Group Home is representative of all Government-run Group Homes, it raises similar concerns to those identified by Janette Welsby (2010) concerning

\begin{footnotesize}
\begin{itemize}
  \item \textsuperscript{106} Alex’s mother advised that she had tried for years to have a “restrained food program” (Heather, 24/9/07) implemented (see 10.4.1 - Vignette 4).
  \item \textsuperscript{107} For example, 10.4.12 Outcomes and learning experiences.
  \item \textsuperscript{108} For example, reflecting on the language used during phone conversations or emails from Departmental staff.
  \item \textsuperscript{109} For example, 10.4.1 - Vignette 1 Alex’s mobile phone rule and 10.4.4 A textual analysis of The Department’s reply.
  \item \textsuperscript{110} 10.4.3 Dissed by The Department.
\end{itemize}
\end{footnotesize}
restrictive practices. It also raises serious questions regarding the extent of the problem within disability residential services, especially concerning Group Home staff. Disability literature identifies the necessity of good disability support staff to assist people labelled with learning difficulties to develop self-determination (Williams, V., et al., 2009).

As a signatory to the Convention, Australia has an obligation

> “to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:…
> to ensure that public authorities and institutions act in conformity with the present Convention” (Article 4.1.d).

The Photo-voice IPAR has revealed examples of service practices of public authorities which are inconsistent with the Convention\textsuperscript{111}. Furthermore, there is an express obligation

> “to undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention” (Article 4.1.f).

As a public authority, The Department has a legal obligation to undertake or promote research that develops service practice in keeping with the Convention. Having trialled the application of the Convention as an IPAR analysis tool, and in light of its educative benefits and proven accessibility for people labelled with learning difficulties, further research into how Government–run residential services measure up to the Convention is recommended.

### 13.2.3 Emancipatory IPAR

The Photo-voice IPAR project took an exciting turn in 2008 when the group self-determined to take its research findings to the nation and present them at the 2009 Having a Say conference in Geelong, Victoria\textsuperscript{112}. This decision included becoming self-directed and self-funded. This decision transferred the IPAR model into the emancipatory-research paradigm as the Photo-voice group took control of the material and social relations of the Photo-voice project. This step

\textsuperscript{111} 10.2.4 Following up incidents.

\textsuperscript{112} 12.2 Stage 4: Photo-voice becomes self-directed and 12.7.1 Conferences and university lecture.
introduced a new set of learning experiences and responsibilities. But most excitingly for this research project, it presented many new opportunities for self-determination which the team embraced enthusiastically. My colleagues did so with the confidence that they had the ability and resources to meet such opportunities.

“... we can do that. We can organise the fundraising and just ask you for advice when we need it” (Bart, 6/2/08).

Chapter 12 detailed the ups and downs of self-funding a project and of taking (and handing over) control. It celebrated the Photo-voice group’s many achievements. Each of these, including presenting to NSW Department of Education officials, organising and running sausage sizzles, teleconferencing with corporate executives and presenting at national and trans-national conferences, contributed to the reconstruction of the label of learning difficulties by dismantling negative connotations of incompetence. My co-researchers’ achievements demonstrated that they were not disabled in and of themselves. Their achievements have demonstrated that they are very able when given opportunity and support.

13.3 Contributions to knowledge

In addition to the positive personal and social outcomes achieved through the barriers to self-determination research, significant contributions have been made to a number of fields of knowledge including research methodology, self-determination research, the construct of learning difficulties, disability rights and human rights education.

13.3.1 Methodology

The research presented in this thesis has contributed to research methodology knowledge through the development of IPAR. IPAR is a fabric of Inclusive Research (Walmsley & Johnson, 2003) and Participatory Action Research.

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113 12.4 School presentations.
114 12.5.6 Sausage sizzles.
115 12.5.7 Corporate sponsorship.
116 12.7.1 Conferences and university lecture.
117 5.5 Inclusive Participatory Action Research.
(McTaggart, 1994) with liberatory pedagogy (Freire, 1996).

IPAR necessarily calls for inclusive and accessible methods. It requires the research facilitator to be flexible and innovative and to learn, through critically reflective cycles, how to adapt traditional research tools to enhance the participation of the IPAR team. Exercising praxis in this way develops methodological theory grounded in practice. The Photo-voice research project adapted multiple methods to ensure accessibility\textsuperscript{118}.

The implementation of Photo-voice and conscientization to the complex research strategy of institutional ethnography was innovative. Using a camera and critical dialogue, abstract concepts were reduced to concrete photos and deconstructed by the research group to problematise everyday situations and reveal social organisation\textsuperscript{119}. By reducing exclusive printed text to an accessible pictorial text, my co-researchers developed and conducted a new style of textual analysis (as non-readers) to uncover meaning\textsuperscript{120}.

The application of multiple methods (particularly Photo-voice) within a dialogic methodology was beneficial in ensuring the voice of the group was heard by their audience of choice (such as parliamentarians, service providers, Government Departments, the Human Rights Commissioner, as well as family, friends, academics and others labelled disabled) and not overridden by mine. It responded to Anne Chappell’s concerns,

“If people with learning difficulties need nondisabled allies in the research process… how can the integrity of their accounts be maintained? How do we prevent nondisabled researchers… from assuming a dominant role in the research process?” (Chappell, 2000, p. 41).

Furthermore, the Photo-voice IPAR successfully demystified social action research and made it accessible to people with different abilities. It was also as much political action as it was research, through its consciousness-raising activities and the challenging of social structures (Walmsley, 2001).

IPAR is risky. It invites researchers to share control and to “push methodological

\textsuperscript{118} Chapter 6 Opening the Camera Bag.
\textsuperscript{119} Chapters 9 & 10, in particular 9.3.2 Textual analysis and 10.4.1 Four vignettes.
\textsuperscript{120} 9.3.2 Textual analysis - discussion on Figure 52.
boundaries in order to [inclusively] address research questions that cannot be explored with traditional methods” (Taber, 2010, p. 6). By sharing control of the research, the research process can flourish and progress to an emancipatory outcome. By examining my reactions to the IPAR risks I was able to expose disablism in my own life and improve my research practice.

This thesis has demonstrated the potential of IPAR. IPAR offers hope of empowerment through research participation and by incorporating the voices of those labelled with mild to moderate learning difficulties. Very little published research has attempted to include people labelled with severe or profound learning difficulties as co-researchers. Creative research strategies will need to be developed so that these people can also participate in matters concerning them. Photo-voice within an IPAR model may meet some of their accessibility needs and provide means through which they too can participate in research concerning themselves. Without their contribution to knowledge our understanding of a sociology of people labelled disabled is significantly lacking.

13.3.2 Self-determination research

Although much self-determination research strives to build knowledge that will enhance self-determination for people labelled with learning difficulties (for example Powers, et al., 2006) I found none that was underpinned by Freirean liberatory pedagogy (Freire, 1996, 2004) encouraging critical dialogue and conscientization. None challenged the disability label or cast people as change agents with the capacity to re-mould the construct of learning difficulties or to name, apprehend and remove barriers to their self-determination. The IPAR strategy introduces a new approach to how self-determination research can be done:

Critiquing social barriers to self-determination through the social model of disability challenges the epistemological assumptions of traditional self-determination research and introduces new pathways to self-determination knowledge.

Responding to the imperative nothing about us without us the Photo-voice research was with not on people labelled with learning difficulties and from their standpoint.
Developing IPAR was an innovation to self-determination research because it is participant-driven rather than professional-driven research.

Through the application of Photo-voice we explored participant issues not professional issues.

The success of utilising IPAR in self-determination research has also contributed knowledge to the construct of learning difficulties.

13.3.3 The construct of learning difficulties

The Photo-voice research project was undertaken with young people assessed as having mild to moderate learning difficulties. It did not include people labelled with severe or profound learning difficulties. It has therefore contributed to knowledge in the mild to moderate category of the construct of learning difficulties. Our research challenged the construct of learning difficulties in the following ways:

This thesis contributes to disability literature concerning people labelled with learning difficulties. It differs from much of the literature, see for example Emerson, Hatton, Thompson & Parmenter (2004), in that a significant proportion of this document is the voice of my research colleagues, conveyed graphically and by direct quotes on issues of importance to and identified by them.

While some have questioned the efficacy of critical dialogue with those perceived to be “intellectually ill-equipped to participate in the deliberative public sphere” (Weinberg, 2007, p. 71) on political issues such as civil rights (for example, access on public transport\textsuperscript{121}) and human rights (for example, freedom from abuse\textsuperscript{122}), the Photo-voice research has demonstrated that people labelled with learning difficulties are insightful and well able, with support, to think critically in the public sphere.

Recognising and naming the social barriers described in this thesis were powerful acts. Critiquing and documenting the social injustices, oppression and disablism were powerful acts. Re-evaluating disability and transferring it from the research team to the disabling society was another powerful act.

\textsuperscript{121} Chapter 9 Public Transport.
\textsuperscript{122} Chapter 10 Rules that Restrict Us.
Taking political action through self-advocacy and lobbying local members of parliament were also acts of power. These actions contribute to the re-construction of learning difficulties by demonstrating empowerment and self-determined actions.

My colleagues’ successful organisation of fundraising and their presentation of our findings to a broad cross-section of the community (school groups\textsuperscript{123}, disability services\textsuperscript{124}, the disability service users community, conferences, academics and university students\textsuperscript{125}) further challenges the label of learning difficulties and makes a positive contribution to new knowledge. Control of the research material resources (funding, equipment, website) and product (our findings) was successfully transferred to the team (now using me as a consultant). Managing the material relations of the research was also an act of research power. It demonstrates that emancipatory research is possible by people labelled with learning difficulties, showcasing ability rather than disability.

13.3.4 Disability rights and human rights education

The Convention calls on the international community to recognise the value of participation of people with impairments to correctly identify specific needs and for individual empowerment. I responded by inviting people labelled with learning difficulties to actively collaborate in IPAR as co-researchers. Their contribution through this research has added to existing knowledge on disability and human rights. Our IPAR serves as an example in practical rights education and application. It has produced knowledge based on real-life experiences of the IPAR team that can assist others:

The Photo-voice research project operationalised the Convention, the Universal Declaration and the DSS, to determine whether those things perceived as social barriers to self-determination were justifiable or not. This thesis has provided many examples of situations where civil rights to public information were ignored on the public transport system\textsuperscript{126} and where human

\textsuperscript{123} 12.4 School presentations.  
\textsuperscript{124} 12.5.7 Corporate sponsorship.  
\textsuperscript{125} 12.7.1 Conferences and university lecture.  
\textsuperscript{126} Chapter 10 Public Transport.
Rights were routinely breached in a Government-run Group Home\textsuperscript{127}. Under the Convention we identified these rights as disability rights.

Together, the Photo-voice team learned through our research and educated through our conference presentations (Ollerton, Kirkwood, et al., 2009a, 2009c, 2009b; Ollerton, Kirkwood, Boyle, Roberts, et al., 2009) and university lecture on human rights. Such knowledge raised community consciousness, exposed disablism and undermined unchallenged ableist practices. It also responded to the Convention’s imperative to raise human rights awareness in the community (Article 8 – Awareness Raising).

It was timely that Australia became a signatory to the Convention in March 2007 (Australian Federation of Aid Organisations, 2008) and our Photo-voice research began in May 2007. The Photo-voice group was among the first in the world to operationalise the Convention. It was made accessible to the people for whom it was written. The strategy to use human rights instruments as analytical tools exemplifies how they can be used in the field of disability and human rights research and education.

\subsection*{13.4 Final focussing}

Much has come from this research and there is much more that can be explored. There is a temptation to tell the story without pausing to add that it wasn’t always easy. Personalities had to be negotiated and tolerated, sometimes actions were remonstrated against but most often celebrated. My original aim was to empower people to recognise, name and challenge social barriers and to generate positive social change. I did not realise at the time that I could not empower people. Empowerment is a reflexive concept and not something that can be done to others (Starkey, 2003). The research presented in this thesis has shown me that people empower themselves (Oliver, 2002) when given the support and opportunity to do so. This is their right and something to be further promoted through inclusive research strategies. The Photo-voice IPAR acknowledges the right of people labelled with learning difficulties to self-determination, their right to be included in research concerning themselves and their right to inclusive methodologies and

\textsuperscript{127} Chapter 11 Rules that Restrict Us.
accessible methods. It facilitated a means of exploring and asserting those rights for the purpose of positive social change.

Very clearly, the Photo-voice research project has shown that disability research can be conducted inclusively using creative research methodologies and achieve emancipatory outcomes. Various research methods were used and adapted to make the research process accessible and creatively utilise the skill set of the Photo-voice research team. One highly versatile tool used was the camera. The camera was employed for data collection, consciousness-raising, problematisation and critical dialogue, analysis and the dissemination of findings, and to re-construct the label of learning difficulties by enabling people to control how they represent themselves in research.

In this thesis I have endeavoured to present self-determination research which powerfully demonstrates the abilities of people labelled with learning difficulties when unfettered by ableist assumptions and given support. These fetters included my own disableist practices and unfounded fears. However, when assumptions are critically challenged and prejudices cast aside, positive outcomes can occur. Social change was successfully achieved through collaborative action!
13.5 Conclusion

The dignity of research

What if you were labelled with learning difficulties?

What if you conducted your own collaborative research?
What if you identified your own social barriers to self-determination?
What if you took action to address those barriers?
What if you used your photo-voice to exhibit those barriers to a wide audience?
What if you raised those barriers with ruling authorities?
What if you met with politicians, liaised with organisations, negotiated your own project funding and formed your own group?
What if you used your Photo-voice skills to create an accessible and beautiful photographic text?
What if you lectured on human rights at university and presented your research to academics at national and international conferences?
What if you were able to share your research with the disability community?

What if public transport was made more accessible because of you?
What if rules were made less restrictive because of you?
What if you named your world and changed it?

What if it was your rights, your camera, your action!
References


Health Research, 16(10), 1405-1413.


Optima Press.


Darder, A. (1995). Buscando America: The contribution of critical Latino educators to the academic development and empowerment of Latino students in the


Emerson, E., Madden, R., Robertson, J., Graham, H., Hatton, C., & Llewellyn, G. (2009). Intellectual and Physical Disability, Social Mobility, Social Inclusion
& Health. Retrieved from http://eprints.lancs.ac.uk/26403/1/Disability_Social_Mobility_Social_Inclusio
n.pdf.


in.pdf.


Rights, Camera, Action!


Hearn, K. (1991). Disabled lesbians and gays are here to stay. In T. Kaufmann & P. Lincoln (Eds.), High Risk Lives: Lesbian and Gay Politics After the
Rights, Camera, Action!


404


McIntyre, A. (2003). Throught the eyes of women: Photo-voice and participatory research as tools for reimagining place. Gender, Place and Culture, 10(1), 47-66.


Rights, Camera, Action!

Aggressive Behavior, 24(2), 135-146.


Oliver, M. (1996a). A sociology of disability or a disablist sociology. In L. Barton


Rights, Camera, Action!


Ware, L. (2001). Writing, identity, and the other: Dare we do disability studies? Journal of Teacher Education, 52(2), 107-123.


Sydney, Australia.


Appendices

Appendix 1 - Photographic Participant Consent Form

Appendix 2 - Initial letter of concern to Group Home Manager

Appendix 3 - Alex’s Phone Program and Departmental email

Appendix 4 - Conference presentations

Appendix 5 – Penrith Photo-voice CD (back cover pocket)
  5.1 - Penrith Photo-voice Project – website screenshots
  5.2 - Penrith Photo-voice Project – Having a Say conference 2009

Appendix 6 - Travel Journal (accompanies the thesis)
Appendix 1 - Photographic Participant Consent Form

Photographic Participant Consent Form

My name is………………………………………………..

It is OK for you to take my photo and use it in the Photo-voice research project. I know that the project is looking at what people with learning difficulties think are the things in life that stop them having more control and a say in their lives.

The reason why people from the project want to take my photo has been explained to me. I was given the chance to ask questions about the project. The way the photos will be used has been explained to me. I know that if I want to, I can ask to have my photo taken out at any time (prior to the exhibition/publication). To do this I will ring the Photo-voice contact number given to me.

Please circle yes or no.

It is OK to use my photo in a Photo-voice exhibition……………………………yes / no

It is OK to use my photo as part of a report on the project………………………yes / no

It is OK to use my photo in a thesis for the University of Western Sydney and other places as well (such as journal articles and newsletters)……………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………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Appendix 2 - Initial letter of concern to Group Home Manager

House Manager
[The Department] Office
[address] 21/9/07

Dear [Group Home Manager],
This letter concerns social barriers to self-determination highlighted during the Photo-voice Project by [The Department] Group home resident, [Alex]. [Alex] has identified the following home rules or lifestyle restrictions as things that he believes unnecessarily restrict his ability to exercise and develop his self-determination skills. Also detailed in this letter are recent events recounted to the group by [Alex], demonstrating the frustration he experiences when the rules are inflexibly managed by staff.

1. [Alex] enjoys food and loves to cook. However, he is not allowed in the home kitchen. It has a security door preventing access. [Alex]'s mother allows him to experience cooking when he visits her but he is not permitted to cook or enter the kitchen of the home in which he lives. This does not accord with the principles of normalization.

2. [Alex] is not permitted to use the House phone at any time.

3. [Alex] owns a mobile phone but is not permitted to use it. He is not permitted to keep the phone. It is kept in the Carers' office. (Another resident, [Sean], is permitted to have his phone with him. [Alex] thinks this is unfair). When [Alex]'s mother wants to speak with [Alex] she must call the home, ask staff to give [Alex] his phone, and then ring [Alex] again on his mobile. [Alex] recognizes that he has gone through too much credit on his mobile but is not happy with the current arrangement. [Alex] is only permitted to ring his family on set days. It is really silly that he cannot access his mobile. Mum has asked that he be allowed to be on his own in the house but he can't access phone to ring or answer.

4. [Alex] has said that he thinks the isolated location of the group home is a social barrier for him. Although he attends Photo-voice weekly, his employment service monthly and recreational activities with NADO on occasions, he has said that he feels he lives an isolated life in which not much happens. This does not accord with the principles of normalization.

5. [Alex]'s home is not close to public transport, public phone access or shops. It is few kilometres to the local shops, phone, post office, bus stop etc. [Alex] is not allowed to go for a walk to the shops and is not permitted to use a public phone or public transport even if it was available. This does not accord with the principles of normalization.

6. [Alex] has never been travel-trained and is not permitted to catch public transport unaccompanied. [Alex] claims he is not permitted to go anywhere unaccompanied. This does not accord with the principles of normalization. It is disempowering to be always reliant on others for transportation. After Photo-voice this week [Alex]'s carers were late in collecting him. We waited 30 minutes before I suggested that he go to Nova Employment and ask them to ring the Carers for him. As he is not allowed to use telephones and had been recently reprimanded for using a phone (see recent incident below) I suggested that [Alex] get the Nova staff to ring on his behalf. However, requiring others to phone on his behalf is also disempowering, patronizing and does not accord with the principles of normalization. I felt my principles were compromised by these rules! ([Alex] had already told the group the story below and so he was anxious about telephoning the carers). I waited with [Alex] for him to be collected for over an hour.

7. [Alex] is not permitted into rooms of the house unaccompanied if [John] is in the room, as [John] touches [Alex] inappropriately. This rule indicates that [Alex] is living in a [The Department] home with a predator, exposing him to risk and is in
breach of NSW Disability Service Standard 10: Protection of Human Rights And Freedom From Abuse. Rather than removing the predator, [The Department] imposes lifestyle restrictions/social barriers upon [Alex] to reduce his risk of abuse. This is unacceptable.

8. [Alex] has said that a lack of privacy in the home is a social barrier. When [Alex] receives a call and takes it in his room for privacy. He claims that the Carers listen to his conversations through the door. They then raise issues with [Alex] that he has spoken to his Mother about in confidence, in breach of NSW Disability Service Standard 4 Privacy, Dignity and Confidentiality.

9. [Alex] has said that the carers make threats which are social barriers limiting his personal control. The Carers make threats such as “If your mother rings I'll tell her not to speak to you”. This kind of comment appears to be provocative and a breach of power. It could be viewed as a breach of both the respect principle of Disability Service Standard 4 and Disability Service Standard 10 (freedom from abuse).

10. [Alex] thinks the Carers tell lies about him and do not believe him when he is telling the truth. [Alex] said he went without his supplementary rental assistance payment for approximately 6 months because no one would believe him when he said that his pension payment was short. [Alex] raised the pension concern with the Photo-voice group in April 2007 and advised us in September 2007 that he had finally received a significant back payment from unpaid rent assistance. Six months wait is unacceptable.

11. [Alex] claims that some of the carers tell lies about him and “stir him up” until he “loses it” to deliberately provoke him because they do not want him to have a cat. He has told the group that he thinks they are making life difficult for him until he gets rid of his pet cat. [Alex]’s mother has confirmed that [Alex]’s cat is causing tension with some of the carers in the house, although she claims that [Alex] is being very responsible cat owner. As the Group Home is [Alex]’s home and the carers are merely [The Department] employees in that home, their resentment of a resident’s pet is unreasonable and does not accord with the principles of normalization. This would appear to be in breach of Disability Service Standard 4 (Dignity) as [Alex]’s desire to have a pet is not being respected.

12. [Alex] is not allowed to open his own mail. He does not know why this is so. This seems to breach the privacy and the dignity principles of Disability Service Standard 4.

13. If [Alex] has a complaint against a staff member he must ask another member of staff to write his letter of complaint for him. If he has a complaint against all staff he must report this to [the Group Home Manager], when she visits (which is not every day). [Alex] is not permitted to ring [the Group Home Manager] with his complaint and is not allowed to know her phone number. [Alex] must wait until the day he is allowed to ring his mother and then tell her that he wants to make a complaint to [the Group Home Manager]. There is a significant lack of immediacy with this grievance plan.

14. The home rules are inflexible. If [Alex] requires spending money throughout the week he must remember to mention this during his one-to-one sessions on Mondays. If something comes up later in the week and [Alex] needs eg. $5 he is unable to access his money if he has not previously mentioned this need at his Monday one-to-one session.

Recent incident
I recently picked [Alex] up to take him out for a coffee. He greeted me holding a banana and a fruit juice popper. He expressed considerable frustration that he was expected to go out for coffee without money and was instead sent off, like a child, with “play-lunch”. I discussed this issue at length with [Alex] to determine if it was a dietary matter or possibly lack of finances. He was under the impression that it was because the rules are inflexible and he had not forewarned the carers of his need for $5.

Another recent incident:
[Alex] had an appointment with Nova Employment after the Photo-voice session last week. He had been advised by the group home to ring the carers when he was ready to be collected. He telephoned the home from Nova but there was no reply. Nova also phoned the home for [Alex], but there was no reply. [Alex] said he assumed that the carers were out in the car and so phoned his mother from Nova to get the carers’ mobile phone number. He did this so that he could let them know he was ready to be collected. [Alex]’s mother also tried to contact the carers at home to let them know he was ready to be collected.

When the carers arrived [Alex] got into trouble for ringing his mother on a Wednesday as he is only allowed to ring her on Tues, Thurs and Sundays. An incident report was lodged against [Alex] for breaking the rules. This, again, reflects the inflexibility of staff in applying the rules. It does not seem reasonable for [Alex] to be “put on report” for using initiative (seeking the carers’ mobile number) rather than sit helplessly in the Nova Employment office.

The above information has been reported to the group by [Alex]. It may contain misunderstandings. Many of the issues raised may appear petty. However, their accumulative affect is one of frustration, disempowerment and reduced opportunity for self-determination. I trust we will be able to clarify things when you meet with the Photo-voice group on Wednesday 26/9/07.

I look forward to meeting you,

Regards,

Janice Ollerton
Photo-voice Facilitator
Appendix 3 - Alex’s Phone Program and Departmental email

(Pseudonyms have been used as appropriate.)

**ALEX’S PHONE PROGRAM**

This program covers all calls Alex makes on his mobile phone or the house phone.

Alex is to adhere to this program and is NOT permitted to use phones at ANY TIME outside these calls, without the express permission of his Key Worker or Network Manager.

**Tuesday, Thursday & Sunday**

- Alex’s mum will phone on the house phone when she is able due to her work schedule.
- Alex’s mum will inform staff, what time to give Alex his mobile or house phone at that time.

**Tuesday**

- Alex will phone his sister around 6:45 every second Tuesday and she will phone on alternate Tuesday.

**Wednesday**

- Alex will phone his dad at 8:00pm.
- Please give Alex his mobile 15-30 mins prior.

**Friday**

- Alex will phone his brother on every alternate Friday at 7:00pm with his mobile.

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From: [Redacted]
Sent: Friday, 23 November 2007 5:16 PM
To: [Redacted]

Subject: Phone Procedures with Alex

Importance: High

All staff are to ensure that Alex has his mobile phone on him at all times when not in the Unit or alone in the Unit.

This is not reliant on whether he is being driven in a Dept van or not.

This has been agreed to by Alex, his mother and Dept as per message in the communication book for staff previously.

There is no reason Alex cannot take his item with him as per instruction.

Any confusion about this staff can contact me, do not enter into a conversation regarding this matter with Alex.

Thanks for your assistance in this.
Appendix 4 - Conference presentations

The following are relevant peer-reviewed international conference presentations given by Janice Ollerton:


Ollerton, J. (2008). Rights, Camera, Action! – The Penrith Photo-voice Project. Canadian Disability Studies Association Conference (CDSA-ACEI), 4-5/6/08, University of British Columbia, Vancouver, British Columbia. (As a result of this presentation I was invited to discuss inclusive disability research methods as the keynote speaker at the conference below.)


Appendix 5 – Penrith Photo-voice CD (back cover pocket)

5.1 - Penrith Photo-voice Project – website screenshots

5.2 - Penrith Photo-voice Project – Having a Say conference 2009

Appendix 6 - Travel Journal (accompanies the thesis)
The Penrith Photo-voice Project began in April 2007. The aim of the project was to support people with learning difficulties to explore what they thought were the social barriers to their self-determination – in other words – to look at what they thought were the things that stopped them from living life their way and stopped them from having control of their lives.

It was facilitated by Janice Ottlton, a PhD student from the University of Western Sydney. Bart is our website administrator. All the participants on the Penrith Photo-voice Project had mild learning difficulties and all of them contributed in a creative and meaningful way to not only the project but also this website.

Using disposable and digital cameras the group looked at many different areas in their lives where they felt there were unnecessary barriers. We talked about common issues and how things might be different. We worked out a plan and then implemented that plan to change the way things are so that things could be better for people with learning difficulties.

Enjoy this website and learn about how the Penrith Photo-voice Group have been undertaking social action for positive social change.

Latest News Update: April 01 2010 (For items in March 2010)
March 2010

Human Rights Address

Today, 10/3/09, the Penrith Photo Voice Project spoke to a group of Human Rights students at the University of Western Sydney. The Penrith Photo Voice Project have now addressed Department of Education officials, secondary school students and university students, telling them about our research project. This opportunity to share their story with tertiary students represented a new forum and audience with which they have now communicated.

May 2009

Fundraising Update.

The Penrith Photo voice project were able to raise over $3000 from donations and a lot of hard work from the team selling chocolates, glow sticks, hot cross buns and lots and lots of sausages! On top of that they received a very generous donation from Break Thru People Solutions, who supported the group in their efforts to expose disabling social barriers and share their findings with the broader Australian community.

The group’s fundraising efforts will also finance the conference fees when they present their work to the Academic community at this years Australian Disability Studies Conference on 26/4/09 at the University of New South Wales.

Now the group are planning to expand and are in discussions with a consumer-run advocacy service to grow their group and start a new project. Watch this space!

Following the group’s presentation Professor Gerard Goggin stated “This pioneering and creative project not only opens up new possibilities in collaborative research and activism — it is an artistic and political tour de force that shows how real change can be achieved” — Professor Gerard Goggin, Journalism and Media Research Centre, University of NSW

December 2007

Rights Camera Action: a Photographic Exhibition.

3rd December – 17th December 2007 Erina Centre, Erina Fair, Terrigal Drive, Erina, Central Coast NSW. This exhibition is part of the International Day of People with Disabilities celebrations.

November 2007

Rights Camera Action! A discussion on creative social research methods.

Social Research Methods Colloquium, UWS, Parramatta Campus, 13th November 2007. This presentation will discuss how the Penrith Photo-voice research project made manifest new methods in disability research which embraced social justice in both research process and outcomes, using democratic processes to work with people to illuminate and take action on the barriers they identified.

November 2007


20th – 22nd November 2007, Deakin University, Geelong, VIC. Presentation entitled: Rights, Camera, Action! A collaborative exploration of social barriers to self-determination for people with learning difficulties. This presentation sketched an outline of a collaborative research project undertaken. Grounded in a social model of disability and Dorothy Smith’s theory of social organization the presentation discussed how the research incorporated inclusive methodologies and institutional ethnography to explore what the group considered to be the social barriers to their self-determination.

September 2007

Rights Camera Action: a Photographic Exhibition.

Commencing 14th-26th September, 2007 at Penrith City Library, 601 High Street Penrith. This exhibition presented an insight into what people with learning difficulties see as the social barriers that limit the control they have over their lives.
FAQs

1. What is the Penrith Photo-voice Project about?
   Sometimes things get in the way and stop us from living life our way. Things stop us from making our own decisions, setting our own goals and having our say. We call these things “barriers to life”. We wanted to find out what were the common “barriers to life” that stop people with learning difficulties from living the way they wanted to. Using disposable and digital cameras the group took photos of what they thought these “barriers” were. We developed the photos and talked about the stories behind them and what they meant. Together we found the common barriers and talked about why the barriers were there. Then we worked out a plan and set out to get the unnecessary barriers removed.

2. Who was involved and who could join the Photo-voice group?
   Janice lead the group with the assistance of Gil (an experienced Photo-voice practitioner). The group was made up of people with mild learning difficulties, aged over 18yrs, from Western Sydney. Everyone was eligible to receive support from disability services for people with mild learning difficulties. Dr Debbie Horsfall, from the University of Western Sydney Social Justice Social Change Research Centre, was overseeing the project.

3. Why people with learning difficulties?
   Because they are the experts in what goes on in their lives and what they have to say is important.

4. When did the project take place?
   The project commenced in April 2007. We meet regularly to discuss issues and plan activities.

5. Who else has used Photo-voice?
   Photo-voice is a terrific community development and research tool that has been used by others all around the world. Click here to go to our links section to find out more about Photo-voice.

6. What social barriers did you find?
   The group identified a number of different barriers. These are all displayed in our picture gallery. However, there were some barriers that we found we had in common. These were “rules that restrict us” and “public transport”. These were the two barriers that we decided to explore.

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FUNDRAISING

Fundraising

The Penrith Photo-voice group is currently raising money so that we can go and speak at the Disability Conference "Having a Say" in Victoria in 2009. We have planned lots of fund raising activities including:

- A hot cross bun drive
- Car wash
- Bunnings BBQ at North Penrith
- Chocolate sale
- Glow-stick sale

Update!

The Penrith Photo-voice project were able to raise over $3000 from donations and a lot of hard work from the team selling chocolates, glow sticks, hot cross buns and lots and lots of sausages! On top of that they received a very generous donation from Break Thru People Solutions, who supported the group in their efforts to expose disabling social barriers and share their findings with the broader Australian community.

The group’s fundraising efforts will also finance the conference fees when they present their work to the academic community at this year’s Australian Disability Studies Conference on 29/6/09 at the University of New South Wales.

Now the group are planning to expand and are in discussions with a consumer-run advocacy service to grow their group and start a new project. Watch this space!
### Guestbook

Displaying 1-10 of 10 results

<table>
<thead>
<tr>
<th>Name</th>
<th>Message</th>
</tr>
</thead>
<tbody>
<tr>
<td>Josie Cavellia</td>
<td>This project is really exciting. Thank you. I love the captions that go with the photos. Congratulations to all of you.</td>
</tr>
<tr>
<td>Hello</td>
<td>hello</td>
</tr>
<tr>
<td>Tony Weks</td>
<td>A great start to a fantastic process - like an earlier posting in the guestbook! I'd really like to know more about the advocacy stage so it develops. Some questions: what do the group think needs to be done? Could be done about the issues and concerns they have raised? By whom? What would they like to do? What's the way forward? Where would they start and what help would they need to get started? How do they propose to get this help? At some stage I'd like to explore the group presenting to students at the University (UNSW) their exhibition photos/videos and what they learnt from the process... Tony</td>
</tr>
<tr>
<td>Jaspe</td>
<td>This sounds really good. You should think of exhibiting your photos in other parts of Australia. I'd love to know what the outcome of your advocacy stage is. Just one tip: suggestion, it might be good to organise the photos into different categories rather than have them listed as Poster 2 etc. Good luck! Jaspe</td>
</tr>
<tr>
<td>Danielle Bright</td>
<td>show some graphics (e.g. pie charts) WORK</td>
</tr>
<tr>
<td>Danielle Bright</td>
<td>GOOD WORK GUYS AND GIRLS KEEP UP AT THE GOOD WORK</td>
</tr>
<tr>
<td>Elwyn</td>
<td>wonderful! love the photos up the top of the page</td>
</tr>
<tr>
<td>secret admin</td>
<td>great layout and design. Here's the photo scroll across the top... good job, keep up the good work</td>
</tr>
<tr>
<td>dette hontsi</td>
<td>well done - this is fantastic!</td>
</tr>
<tr>
<td>SNs</td>
<td>Great looking site, well done!</td>
</tr>
</tbody>
</table>

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LINKS

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- FAQs
- Fundraising
- Downloads
- Guestbook
- Links
- Search
- Contact Us

Gallery
- Introduction
- What we did
- What we photographed
- Our Exhibition

Links

Web Link
- Photovoice Wikipedia Entry
  - Wikipedia information on this research method.
- Australian Huntington's Disease Association (NSW) Inc
  - Example of other photo-voice project.
- Colchester Borough Council (UK)
  - Example of other photo-voice project.

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Contact Us

To contact the Penrith Photo-voice team, please email info@penrithphoto-voice.net

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RULES THAT RESTRICT US ARE BARRIERS
COMMUNICATION BARRIERS
THE GOVERNMENT PRESENTS BARRIERS
HAVING NO MONEY IS A BARRIER
Having a Say Conference

The Penrith Photo-voice Project

- Janice Ollerton
- Jeremy Roberts
- Matthew Kirkwood
- Ryan Boyle
- Katy Oxley
- Gillian Oxley
Rights, Camera, Action!
The Penrith Photo-voice Project

Looking at the barriers that stop us controlling our own lives.
Rights, Camera, Action!

- **Rights** – to have control over our lives and be involved in disability research
Rights, Camera, Action!

- **Rights** – to have control over our lives and be involved in disability research
- **Camera** – to photograph and explore the problems
Rights, Camera, Action!

- Rights – to have control over our lives and be involved in disability research
- Camera – to photograph and explore the problems
- Action – to change things for the better
We photographed barriers

This trolley is like a barrier blocking our way. We’re like a seedling
Removing Barriers

So we can grow up to our full potential
The photo-voice team
The project involved
Meeting together
Going out into the community
Some of the things we learned

- Advocacy
- Communication
- Organisation
- Doing things ourselves
- Team work
- Leadership
- Decision making
- Reflection
- Computer skills
Things we thought about when taking photos

- Privacy
- Respect
- Safety
Talking about the stories behind the photos
Exhibiting our work

To the public, academics, politicians and service providers
Barriers

Public transport
Barriers

Public transport

Not everyone can read
Barriers

Public transport

There are better ways to assist people who do not read
Barriers

Public transport

Not everyone can use the machines
Barriers

Public transport

We asked “Is this notice meant to be read?”
Barriers

Public transport

Not everyone can read signs
Public transport barriers

What was the most important message here?
Barriers

Public transport

Not everyone can read the safety notices

PASSengers must keep clear of gangway areas whilst vessel is arriving or departing from wharf
Barriers

Rules
Barriers

Rules

- Some house rules treat us like children
Barriers

Rules

Some of the rules were not explained to us
Social action & results

1. Public transport

- We wrote to Human Rights Commissioner
- We wrote to Sydney Ferries
- We wrote to Busways
- We wrote to Ministers for transport
- We wrote to CityRail
- We took part in public transport disability access review
- We offered suggestions for improvement
Social action & results

2. Rules that restrict

- Minister for disabilities
- Group home manager
- Dept disabilities
- Local Member parliament
- NSW Ombudsman
- NSW Council for intellectual disability
- Sought legal advice
Social action & results

- DADHC found many problems
- Staffing reviewed 4 sacked
Social action & results

- DADHC found many problems
- Staff training given
Social action & results

- House rules reviewed changed
- New Individual Plan increased freedom
Stage three – control of the project

We are telling people about our research
Stage three – control of the project

- We are controlling the money we raise
Stage three – control of the project

- We have our own website
Stage three – control of the project

- We are speaking at a Disability Conference
Doing research is really good fun!
APPENDIX 6

Unavailable – please contact author for access.