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Voices for Change: Exploring aspects of Social
Citizenship alongside Young Adults who have
Down syndrome

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AUTHOR'S DECLARATION

This is to certify that:

- I. this thesis comprises only my original work towards the PhD
- II. due acknowledgement has been made in the text to all other material used
- III. the thesis does not exceed the word length for this degree.
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- V. this thesis meets the *University of Sydney's Human Research Ethics Committee (HREC)* requirements for the conduct of research.

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Abstract

This thesis describes a journey in which young people with Down syndrome engaged with a non-disabled researcher in a participatory action research process. The aim was to discover what aspects of a Circle of Support Project could assist them in working towards and achieving some of their life goals as citizens.

The research is conducted within a theoretical framework underpinned by human rights and guided by the principles of Emancipatory Disability Research (Barnes, 2001) which embraces the social model of disability (UPIAS 1976; Finkelstein, 1980; Oliver, 1983, 1990, 1996) as a cornerstone of ethical disability research practice. A flexible and responsive approach is taken to the engagement of the young people throughout the project.

Revealed are some of the benefits and challenges of the participatory research process. The research interprets some key processes of social citizenship as defined by the young people. These findings are located within a theory of human rights emanating from the work of philosopher Alan Gewirth (1981, 1996). Disablement as experienced in the context of the family is examined. Concepts and processes which developed in the course of the Circle of Support Project which proved to be enabling for the young people and families are identified. Subsequently, a refined practice model for a 'Citizen Engagement Project' is proposed.

The study demonstrates that a flexible and responsive approach to research alongside people with a learning difficulty can facilitate high levels of engagement in research production. This has traditionally been regarded as the domain of university-based academics. The fruits of this research reveal that people with a learning difficulty, their families, and staff who work closely with them have a strong contribution to make to the development of disability service models and, correspondingly, to the theory and practice of social citizenship.

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Throughout this project I have received the patience, love and support of my two wonderful sons Will and Tom, and my long-suffering husband and best friend Chris. Thank you all.

Much love to Alice and Keith Dalby and others who have provided warmth and friendship to us and formed part of our family 'circle of support' here in Australia.

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No acknowledgement would be complete without mentioning my family and close friends in England including Karen and Viduet all of whom I love and miss dearly. I would like to remember my beloved grandparents, Lily and Arthur Twigg, and my Uncle Willis. My father Ron Stevenson, upholsterer, steel worker, artist and community activist died in 2008 and so was unable to see this thesis through to its completion. My father taught me never to give up trying to make the world a more just and happy place. My mother, Val Stevenson, has dedicated her life to the family and continues to do so. I dedicate this thesis to my parents.

Prologue

This research concerns itself with young people with Down syndrome, their personal aspirations and their rights and entitlements as citizens. The following quotations are offered to the reader as a source of reflection around each of these points.

It is important that society develop attitudes that will permit people with Down syndrome to participate in community life and be accepted. They should be offered a status that observes their rights and privileges as citizens and, in a real sense, preserves their dignity. When accorded their rights and treated with dignity, people with Down syndrome will, in turn, provide society with a most valuable humanising influence.

Prof. Siegfried Pueschel (2001).

I can't get rid of my Down's syndrome, but you can't get rid of my happiness. You can't get rid of the happiness I give others either. Its doctors like you that want to test pregnant women and stop people like me being born. Together with my family and friends I have fought to prevent my separation from normal society. I have fought for my rights... I may have Down's syndrome but I am a person first.

Anya Souza, protest speech at Down Syndrome Screening Conference, London, 2003 (cited in Reynolds, 2003).

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community.

Article 19, Convention on the Rights of Persons with Disabilities, (United Nations, May 2008).

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Preface

My reasons for undertaking this thesis were a culmination of personal and professional beliefs, experiences and opportunities.

I grew up in a family which was working class, politically 'left wing' and humanitarian, within a household awash with regular discussion of social justice issues. It never occurred to me that I would do anything other than make some contribution to society that would attempt to make it more egalitarian. In so doing I recognised that I would need to empower myself through getting a higher education (as many of the working class do) but not simply become 'middle class'. I did not wish to be absorbed into an oppressive system and help perpetuate its existence. I wanted to make a tangible difference.

A strong influence upon me was my father. He was a self-educated man. He worked as an upholsterer, in the steel industry and in his spare time as a community activist and artist. He had an acquired physical impairment due to a road traffic accident at the age of 21 years, before I was born. The spinal injury he sustained permanently impaired his gait and the movement in his right arm and hand. My father's favourite topics of conversation were philosophy and class politics. He was also constantly trying to encourage community participation and, amongst his other achievements, was instrumental in the creation of a resource house on the housing estate (where he lived) where tenants could learn literacy and IT skills. He rarely alluded to his disability. Because my father's disability was intrinsic to my early life and was a natural part of my world, I did not question the matter and, as a child, did not even know the name of his impairment. I cannot honestly say that my perceptions of him as a person featured the fact that he lived with disability much at all until I reached adulthood. Of course this work has led me to ponder much more deeply on the effect that an acquired impairment would have had upon him.

My undergraduate course in Applied Social Studies (1982-86) furnished me with a degree and social work qualification. The course was inspiring in terms of its emphasis on the structural, economic and political forces within society which

produce poverty, oppression, alienation and 'mystification' of citizens within its midst. I moved into social work practice motivated by structural analysis, full of optimism, energy and ideals about how the world could be changed.

I realised very early on in my professional life that the theoretical ideas of my childhood and social work education were not commensurate with most social work practice opportunities. I worked in a therapeutic community, a surgical hospital and extensively in children and families services. In each of these settings the emphasis has been on individual 'socio/psycho-pathology' or, more basically, a social 'maladjustment' which needs to be addressed and corrected. Problems were interpreted as stemming from factors largely identified within the individual or the individual 'family system'. It seemed that my structural theories had little to offer.

By 1996, I was employed as a social worker in the 'child protection' field. I found myself working with a young mother called Jane (pseudonyms used). Jane had a son Jake, of pre-school age, whom she adored. Jane was a single mother and had no support from Jake's father or her own extended family. She had few friends and was subsequently very isolated. Jane had no job and lived in a poorly furnished council flat. Jane was assessed as having 'moderate learning difficulty'. During the course of my involvement she gave birth to a second child, her daughter Sarah.

I really enjoyed working with Jane. She was a loving, gentle and caring mother, funny and a great listener. Jane was well aware of her learning difficulty label. She showed no antagonism to me as a social worker but was hesitant to discuss any problems with me. I always knew she was afraid that 'the authorities' might take the children away if she exposed any 'inadequacy'. This saddened me greatly.

I do not plan to detail my involvement with Jane. Sufficient to say that at the time, as an agent of the Local Authority, I did not remove her children and worked to increase support for Jane in the community. I am not aware of whether Jane's children remained with her for the duration of their childhood.

Jane, her devotion to her children and fear of a state system that might remove them from her care rather than support her was the inspiration for me to undertake an MA primary research project in the area of the UK child protection system and how it deals with families headed by parents with a learning difficulty. My findings were that many parents (and their children) were often victims of systemic inadequacies as opposed to any deliberate misuse of power by agency personnel (Stevenson, 1998). The MA was conducted at Sheffield University Faculty of Law. In this discipline I gained a stronger understanding of, and interest in, human rights philosophy and its relevance to social work practice.

My later role as a reviewing officer for children in the public care system in the UK increased my interest in the disability field. This role entailed reviewing the placements of children and young people. I became concerned with how we consulted with children and young people with learning difficulty (some of whom employed unconventional forms of communication) about plans for their future. Again, I perceived an oppressive systemic apathy which seemed to lead to a dearth of excitement and aspiration for the adult lifestyles of these young people. The considerable government/agency focus on 'needs assessment' of individuals and their families did not often appear to be matched with a corresponding zeal for ideas, engagement and action geared towards including them in the community. Social workers generally did the best they could but were given insufficient resources and time to really get to know the young people as individuals and advocate for them effectively.

In an effort to better understand issues for young people with a learning difficulty I decided to immerse myself in the disability field further to learn as much as I could. In 2003 I took up a post as a senior practitioner in a local authority 'Transitions' team. As I worked with disabled young people in their late adolescence and early twenties at this crucial stage in their lives, it became apparent that, despite the best efforts of social care staff, the usual rites of passage into adulthood available to non-disabled young people such as moving out of the family home, associating informally with

peers, having sexual/romantic relationships, getting jobs and so forth were regularly ignored or denied to young people with learning difficulty. These issues rarely featured in discussions about their future 'support needs'. Moreover *their voices* rarely featured in discussions about their own future within the wider community. At this time it became obvious to me that state funded provision alone cannot cater for the diverse needs of this (if any) group of people.

Moving to NSW Australia in 2005 and my role (from February 2006) as coordinator of a Circles of Support Project hosted by a NSW Non-Government disability Organisation (NGO) gave me a fresh perspective and clear 'activist' position in social work which I had not previously enjoyed (Healy, 1996; Leonard, 1994). The majority of my work in the UK had been in the statutory social work field. The Circles of Support Project featured in this thesis had been planned in close consultation with young adults who have Down syndrome. This project presented the chance to work alongside people in an ethical, yet less 'procedural', more creative fashion. I was able to coordinate a process where we had freedom to operate (and co-operate) much more flexibly and work towards the kind of support model that participants and their families would wish for. A unique opportunity for participatory research presented itself. This thesis represents a study of some aspects of our journey together, our 'Voices for Change'.

Confidentiality: De-identification of organisations and participants

The ethical parameters of this research are dealt with in depth within the body of this thesis. However, the following discussion clarifies some important matters for the reader at the outset.

In line with the requirements of my application to the Human Research Ethics Committee at Sydney University, the names of the Circle of Support Project, the Non-Government Organisation (NGO) which 'hosted' the project and the research participants will not be identified herein. The working title of the research, 'Voices for Change', is used to describe the doctoral research. The project within which the research took place will be called the 'Circles of Support Project'. The organisation which hosted the Circles of Support Project will be referred to as the 'Host Disability

NGO'. The research participants and any other persons alluded within the Host Disability NGO are given pseudonyms.

As the Voices for Change research was of a highly participatory nature, and was strongly supported by the Host Disability NGO, articles ensuing from this research are subject to negotiation on an individual basis in terms of levels of confidentiality. All personal interview data however will remain de-identified.

The national charity which funded the Circle of Support Project also provided the bulk of the funding for an accessible manual and DVD about the Circle of Support Project. These materials were fully reviewed and approved by the Host Disability NGO and participants and were publicly launched in NSW in 2009. These will not be included in this thesis in order to preserve confidentiality. They can, however, be made available on request.

Language and terminology

The language of disability

The language of disability is controversial, complex and constantly evolving, engendering a host of global and cultural preferences. Even in the context of one profession in the same country the terms used can vary greatly. Although terms will be clarified throughout this thesis, the rationale for basic nomenclature used here warrants discussion from the outset.

This research was guided by the principles of the Emancipatory Disability Research (EDR) paradigm which is underpinned by the social model of disability (UPIAS, 1976; Finkelstein, 1980; Oliver 1983, 1990, 1996) developed in the UK. The research occurred within an Australian setting. Both EDR and the social model will be fully explored in the body of this thesis. However, central to the political project of the social model is its claim that the term 'disability' describes the mechanisms of social oppression that all disabled people face, rather than their specific impairment/s. This assertion impacts upon both how we perceive and discuss disability.

The social model recommends that in terms of disabled people as a group, irrespective of impairment, we should use the term 'disabled people' (Morris, 1993; Carson & Davies, 1999). Self-advocacy groups, however, tend to prefer people-first language. In some (but not all) settings in the UK, self-advocacy groups currently use the term 'people with a learning difficulty' (e.g. People First and Values into Action), hence reserving the term 'disability' (or sometimes 'disablement') to describe social oppression. People First also explain that the term is used to describe a group of people who carry a *label* of 'learning difficulty' and hold that the label itself does not describe the person. They also feel that the term 'learning difficulty' is more flexible and realistic. This thesis endorses their perspective which is as follows:

At People First (Self Advocacy) we believe that people labelled as having a learning difficulty are disabled by society. We choose to use the term 'learning difficulty' instead of 'learning disability' to get across the idea that our learning support needs change over time (<http://www.peoplefirstltd.com/self-advocacy.php> accessed 11th March 2010).

In Australia, 'people with an intellectual disability' is a categorical definition based on a psycho-medical 'diagnosis'. This means that it is a category which is fixed and which one cannot move outside of (Rapley, 2004, pp. 210-211; 'Definition of Intellectual Disability', American Association of Intellectual and Developmental Disabilities website, accessed, 1st July, 2011). It is also now the most commonly used term in the global scientific community. 'Learning difficulty' in Australia often refers to a non-categorical definition including all those people who have difficulty learning one or more academic skills. For example, people labelled with dyslexia, ADHD and Asbergers syndrome are placed in this category in Australia though sometimes other language is used. This same group are often referred to as having 'specific learning difficulty' in the UK.

The problem with this language from the point of view of the social model is that the descriptive phrase 'people with an intellectual *disability*' simply translates as 'people with an intellectual *impairment*'. Hence impairment and disability, once again, can become synonymous and the social model definition of 'disability' can be lost.

Because this thesis is concerned with the social model and embraces the notion of disability as social oppression I will use the terms 'people with learning difficulty' and 'disabled people' for clarity and consistency unless directly quoting the work of authors who use other terms. Additionally, this study involves young people who carry learning difficulty labels and who have Down syndrome. Although some groups (such as People First) eschew the use of medicalised labels altogether, the term 'Down syndrome' is used in this thesis as significant areas of discussion are broached and research citations used which are particular to this diagnostic label. Any articles published from the thesis will use the term 'people with an intellectual disability' whenever possible in accordance with, and respect for, the customary language used by participating Australians.

Another major challenge in writing about people with learning difficulty is that they are an extremely diverse group of people. Each of them is, of course, unique although they may choose to express their collective voice in relation to certain topics. Whilst academics and professionals talk about social groups a great deal, generalising about people with learning difficulty is especially problematic as they are a particularly categorised and 'homogenised' population historically. This issue will be raised in the body of the thesis but it is worth mentioning at this point that sometimes, paradoxically, generalised terms need to be used in order to address certain issues.

There will be ongoing discussion and theoretical integration of language and terminology throughout the thesis.

Accessible language - plain English

Most people value clear, 'non-jargonistic' language both in written and verbal form. This does not mean, however, that complex matters cannot be broached. Whilst Shakespeare (1996) rightly cautions against a simplistic and reductive attitude to research and disability issues in general, knowledge which is not accessible tends to be, in the words of Steinem, 'aerialised' (Denes, 2005), difficult to apply and often ignored altogether outside of academia. I have therefore written as plainly as possible without compromising the depth and quality of this work.

Use of the first person in this thesis

Generally academic writers are discouraged from the use of the first person singular and plural (e.g. 'I', 'we', 'us', 'our' etc.) in their writing and this edict will be followed as far as possible in this thesis. However, this work documents a personal and dynamic participatory action research journey within which I am positioned as a practitioner-researcher alongside co-researchers. In this context the use of the first person in some chapters is appropriate and brings the process to life somewhat for the reader. I will therefore use first person singular and plural at times and avoid converting these into unwieldy and de-personalised third-person expressions.

1. Introduction

1.1 The aims of this thesis

The aims of this thesis are threefold: firstly, to make a contribution to the theory of social citizenship for people with learning difficulties; secondly, to demonstrate how participatory action research within a Circle of Support Project can meaningfully involve young adults who have Down syndrome in research practice towards determining a number of social citizenship processes which are applicable to themselves; and thirdly, the thesis explicates an evidence informed and modified practice model geared towards promoting inclusive social citizenship for young adults who have Down syndrome.

1.2 The significance of this research

This research makes a significant contribution to disability research methodology in developing the principles of Emancipatory Disability Research (Barnes, 2001; Stevenson, 2010) and the practice of participatory action research (Freire, 1970). It offers innovative and fresh empirical material to inform anti-oppressive social work practice. In devising an overarching model of practice for a Citizen Engagement Project, the research provided an evidence base for the application of a human rights and social citizenship perspective in working alongside young adults with Down syndrome and their families. The resulting practice model is more theoretically grounded than the current rhetorical level at which many service programs operate.

1.3 The research questions

As stated above, the research constituted participatory action research (PAR) guided by the principles of Emancipatory Disability Research (EDR). EDR stipulates that research must reflect the interests and wishes of disabled people (Barnes, 2001). The outline of the Circle of Support Project had been crafted in close consultation with young people who have Down syndrome. Their collective ‘summarising statement’ in 2005 was very clear:

[We want] To do stuff in our life like everybody else, -like getting a job, moving out, seeing friends, going out, having a relationship and helping others.

This statement could also be interpreted as a plea for the enjoyment of citizenship rights, the citizen being a 'rights bearing agent' (Marshall, 1950; Gewirth, 1996), or an argument for their full 'social inclusion'. From this statement by the young people, it was fairly easy to deduce a straightforward primary research question which was compatible with the more practical aims of the Circle of Support Project and the Voices for Change research therein:

What aspects of the Circles of Support project can assist young people in working towards fulfilment of their personal goals as citizens?

PAR is a process which is iterative and non-linear. Often research questions develop and become refined in the course of a PAR project (Freire, 1970; Mok & Hughes, 2004). Accordingly, as the review of literature progressed and both the Circles of Support Project and PAR unfolded, secondary research questions were identified:

- 2a Bearing in mind issues of human rights, the young people's status as 'rights bearing agents' and social citizenship; what personal and social activities were of high importance to the young people? How might the young people define some aspects of active social citizenship for themselves?
- 2b Which processes, concepts and practices within the Circles of Support Project as a whole did the families and staff find positive, enabling or facilitatory within the course of their involvement with the project?
- 2c What could the families and staff in the project tell us about disablement (social oppression) as defined through the lens of the social model?

The development of the secondary research questions is fully explicated at the end of Chapter 5.

1.4 Summary of chapters

The scope of literature relevant to this thesis is extensive and therefore spans two chapters.

Chapter 2 Down syndrome, oppression and human rights

The introduction to the review of literature is followed by the identification and contemporary description of Down syndrome which functions to provide the reader with enough basic information to elucidate the implications of Down syndrome as a diagnostic label attached to the young people who participate in the study. The next section outlines the dimensions of oppression of people with learning difficulty labels in the 20th and early 21st-century western European societies. The need for emancipatory activity is evidenced. Towards this end, human rights discourses in relation to people with a learning difficulty and some of the problems inherent in operationalising these rights are explored.

Chapter 3 Theories and voices

This chapter examines 'theories of practical intent': the primary purpose will be to examine what elements of theories and models are relevant and useful and may specifically assist people with learning difficulties and their supporters in operationalising their human rights. Alongside activists and academics, the work of self-advocates and families has been critical in eliciting progress in social justice for people with learning difficulties. 'Listening to the experts' explores the voices of people with learning difficulties and their families, drawing out the contemporary challenges to their status as equal citizens as experienced and articulated by them.

Chapter 4 The context of the study

The context of this study is described in this chapter. An overview of the development of legislation and services for disabled people in Australia and NSW in particular is provided. The shifts and changes in service provision are linked to the ongoing process of de-institutionalisation which has occurred somewhat later in Australia than in other developed countries. Australia has also been slower to wholly embrace the social model of disability and to access its language and political power as a conceptual tool for social development in the field of disability. Post-school services for young people with learning difficulty in NSW are explored as particularly

relevant to the population of young people and families involved in the research. The Host Disability Non-Government Organisation (NGO) within which the Circles of Support Project was implemented is described. The story of the Circles of Support Project is told in order to contextualise the 'Voices for Change' doctoral research therein.

Chapter 5 Research methodology

Firstly the theoretical framework of the research is established. Linkages are made with the social oppression of people with learning difficulty, human rights frameworks, the social model and activist social work and social research in the field. The Emancipatory Disability Research (EDR) paradigm is described and critiqued, and issues of 'control' faced by 'non-disabled researchers' seeking to involve participants/co-researchers who have learning difficulty in EDR are debated. This chapter also discusses and grounds the role and positioning of the non-disabled practitioner-researcher as human rights advocate and activist. Examples of 'inclusive research' with people with learning difficulty are cited and explored. Links are made between EDR and Participatory Action Research (PAR). In this thesis EDR was used as a set of principles to guide ethical research within the disability field. EDR can therefore embrace different research methods and approaches. PAR was seen as an appropriate process via which to establish the field of study and generate data. Whilst the Voices for Change research was evolutionary and flexible in nature, ethical considerations are identified as paramount, as are appropriate criteria for the validity and trustworthiness of the research.

Finally, all the questions which guided the research are posed.

Chapter 6 Findings on the participatory research process

The research process is described with emphasis on the participation of young people in key research processes such as formulating their own research questions, self-advocating as co-researchers, co-presentation, data collection and analysis and dissemination of findings. The process of identification of thematic networks (Attride-Stirling, 2001) as a tool with which to analyse the data is explained in the course of this chapter. This discussion leads into the data analysis itself which was initiated with the participation of co-researchers with Down syndrome. The work is highly diagrammatic yielding both transparency of the analytic process and a clear

exposition of the way in which co-researchers contributed to this phase, both of which are commensurate with EDR principles. The chapter contains critical reflection upon the participatory research process.

Chapter 7 Findings from young people with Down syndrome

Chapter 7 lays out analysis of all the data from the young person informants. Bearing in mind questions of social citizenship, it seeks to identify what their concerns are and what issues they articulate as being important to them as young citizens. Again, global themes are produced which connect and explain the web of data. The text is purposefully rich in quotations which enable their voices to be heard. Young people articulated the importance of engaging with the issues involved in human connection; continuing personal development; contribution to community; and the dignity of risk.

Chapter 8 Findings from parents and project staff

Data from parents and project staff informants is analysed using the lens of the social model and findings are presented in three emergent global themes. Parent data evidences some aspects of the experience of learning difficulty within the family. This global theme is contextualised by the 'Dimensions of Disablement' which describes socially constructed stressors and barriers which families have encountered (and still encounter) as evidenced in the data set. Finally enabling concepts and practices describes the visions, concepts and processes implemented and generated within the Circles of Support Project which parents and Team Coaches perceived as enabling and useful to themselves and the young people in assisting young people to identify and work towards their life goals. There are aspects of this theme that indicate a need for focus upon the enablement of the family as a whole.

Chapter 9 Discussion

Chapter 9 moves on to answer some of the research questions which have evolved in the course of the research journey. In relation to citizenship theory, key processes of social citizenship as defined by the young people are located within a model of social citizenship emanating from the work of other authors (Gewirth, 1981, 1996; Ward & Birgden, 2007; Ward & Stewart, 2008).

Findings around 'disablement' as experienced in the context of the family are held to pose a challenge to wholly psycho-medical interpretations placed upon parental responses to raising and supporting a child or adult with a learning difficulty.

In relation to practice recommendations, a revised model for a 'Citizen Engagement Project' is explained, based on the findings from the research. The research process itself is reviewed in relation to Emancipatory Disability Research principles.

At the heart of this research and the wider Circles of Support Project was a flexible and responsive approach to both research and practice with young adults with Down syndrome and their families. It is therefore inappropriate and self-contradictory to prescribe a 'new dogma', a theory which can be applied to all people with learning difficulty. In PAR the research methodology, findings and their application are largely context-specific. The research does however contain some constructive *messages* to policy makers when considering service design.

The limitations of this research are fully acknowledged.

Chapter 10 Conclusion

This chapter brings together the concluding arguments and findings from the research.

2. Down syndrome, oppression and human rights

2.1 Introduction to the literature review

The area of disability studies is still a growing discipline and the reality for the immersed researcher is fascinating, vast and complex, bringing many issues affecting all of humanity into sharper focus. Although the area of disability evades simplification (Shakespeare & Watson, 2001) the thesis is located within four intersecting areas of inquiry. Firstly, the history of people with learning difficulties is usually couched in terms of their oppression (Williams, 2002; Stevenson 2010). Secondly, how can we ground, respect and promote their human rights and community participation? Thirdly, from a practice perspective, what theories can assist social workers in this process and, fourthly, what do individuals with learning difficulties and their families themselves raise as pertinent issues in their lives? How do they perceive oppression and what do they see as the way forward? To guide the review of relevant background literature within limits most pertinent to the research project herein I focus upon the following domains of inquiry which are arranged over two chapters:

- The identification and contemporary description of Down syndrome. This thesis is not about the medical model of Down syndrome. This information is purely to provide the reader with enough basic information to elucidate the implications of Down syndrome as a diagnostic label attached to the young people who participated in the study.
- In an outline of the dimensions of oppression of people with learning difficulty labels in 20th and early 21st-century Western European societies. Exploring the social oppression of people with learning difficulty is important to this thesis for three major reasons. Firstly, the author embraces the social model of disability (UPIAS 1976; Finkelstein, 1980; Oliver, 1983, 1990, 1996) which reconceptualised disability as the social oppression of people with impairments and is discussed in Chapter 2. Secondly, such a narrative

evidences the human rights violations of people with learning difficulties and the corresponding need for theoretically robust rights frameworks and practice models to defend, and assist them to enjoy, their human rights. Thirdly, Sherwin (2010) argued that an understanding of history is also important for those proposing to work with people with learning difficulties for the reason that services systems often purport to produce new ideas and new, more inclusive living and support arrangements for people with learning difficulties which in essence are merely re-branded old ideas.

- Human rights discourses in relation to people with learning difficulties. The United Nations Convention on the Rights of Persons with Disabilities (2008) was a 'clarion call' to nations to embrace social inclusion for disabled people. This section includes a discussion of some of the problems around the concept of social inclusion and identifies the need for definitions of social citizenship which are grounded at the level of community.
- 'Theories of practical intent': Theories and models of disability which illuminate our understanding of disability. The primary purpose here is to examine what elements of theories and models are relevant and useful and may specifically assist people with learning difficulties and their advocates in operationalising their human rights.
- Listening to the experts. This explores the voices of people with learning difficulties and their families drawing out the contemporary challenges to their status as citizens with equal human rights.

Although I have already undertaken some discussion of language in the preface, language, history and theory are intimately connected. In my journey through this thesis I will clarify and interrogate the use of terms in order to contextualise terminology within relevant discussion.

2.2 Down syndrome: Past and present

Trisomy 21 (Down's syndrome) is observed with a frequency of 1 in 650 live births regardless of geography or ethnic background. This should be reduced with widespread screening (Kumar & Clark, 2005, p. 173).

Dr. John Langdon Down was superintendent of the Earlswood Asylum for the 'mentally defective' in Surrey, England from 1858-1868. Down's career as a physician was in its ascendance at the time of his appointment, he was interested in research, continued his observations at Earlswood and cared for many children throughout this time there. Down was held to be, for his time, a humanitarian and philanthropist. He was eager to differentiate mental illness from learning disability and also show that physical and mental "defectiveness" did not equate with "moral darkness" (Yong, 2007 p.49.). Down published a paper describing the Down syndrome 'phenotype' observing a "Mongolian type of idiocy" (Down, 1866, p.260).

We now know that Down syndrome is a genetic variation that is typically caused by an extra copy of the 21st chromosome. There are three forms of Down syndrome: Trisomy 21 or T21, Translocation and Mosaic. Trisomy 21 is present in 95% of the population who have Down syndrome. The latter two forms are less common.

It is extremely difficult to obtain exact statistics regarding the numbers of people with Down syndrome within Australia as most federal government statistics group all disabilities together. In Victoria, Australia for example, Down syndrome is diagnosed in approximately one in every 350 pregnancies but only in 1 in every 1150 live births worldwide

Although the chance of having a child with Down syndrome increases statistically with maternal age, most babies are born to mothers under 35 years who have not had diagnostic screening. Detection of Down syndrome usually follows the 'Triple screen' (also known as the Bart's or Kettering test) performed during the second trimester of pregnancy upon most expectant mothers in the developed world. This

test can indicate a 'high risk' or 'low risk' of chromosomal 'abnormality'. Where such abnormality is suspected, Chorionic Villus Sampling (CVS) or Amniocentesis can confirm whether Down syndrome is present or not. Currently over 95% of fetuses that are diagnosed with Down syndrome are terminated prior to birth (Barlow-Stewart & Saleh, 2007). At the time of writing, 'MaterniT21' a prenatal blood test intended for women who are at "high risk" of carrying a fetus with Down syndrome has been introduced. The company, Sequenom, holds that the test can detect the chromosomal "anomaly" that causes Down syndrome as early as 10 weeks of pregnancy. It is intended to be less invasive than amniocentesis and hormone testing.

The most up-to-date information about Down syndrome from the US medical community, endorsed by the Down Syndrome Congress 2009, was published in 2010. A diagnostic information leaflet for parents includes the following observation:

Every person born with Down syndrome has a unique combination of strengths and weaknesses that are impossible to predict prenatally or at birth. In general, people with Down syndrome have mild to moderate cognitive delays, low muscle tone and a higher risk than the general population for a variety of health problems, most notably heart defects (Skotko, 2010, p. 2).

Down syndrome is often described as one of the most common forms of learning difficulty (this is confirmed by Down Syndrome NSW and Down Syndrome Victoria) and hence they are positioned here within discourses of learning difficulty. Pueschel (1992), an eminent physician, stated that some people with Down syndrome are not "mentally retarded" at all, which reflects the contested nature of disability, even in one of the most taken-for-granted categories/labels of learning difficulty.

As a social work practitioner and researcher, my own perspective in relation to Down syndrome is that espoused by the Canadian Down Syndrome Society. It is stressed that Down syndrome is "not a disease, defect, disorder or medical condition". Rather, a naturally occurring chromosomal arrangement. Down syndrome has always existed. It happens in all races, geographic areas, socio-economic groups, communities and genders (Canadian Down Syndrome Society website, 10th June, 2011).

2.3 The social oppression of people who have a learning difficulty

The historical narrative of people with Down syndrome is usually told as part of that of all people with learning difficulty labels (Yong, 2007) which in turn intersects with the history of mental illness and shares strong links with the study of physical disability. Their oppression takes many forms and is experienced differently by each person. Whilst it is impossible to generalise about the individual 'experience of having a learning difficulty', this discussion interrogates some of the major historical and social forces which have generated and continue to perpetuate oppression upon this social group.

2.3.1 People with learning difficulties: A marginalised group or oppressed group?

It is important to clarify why the term 'oppression' has been reclaimed for the title of this section of the thesis. The term 'marginalised group' is often used in discourses associated with social inclusion/exclusion. 'Marginalised' is another term which visually illuminates the 'othering' processes of stigma and exclusion and is therefore helpful in many ways. There are two problems inherent in the use of this term however. Firstly, not all marginalised (or indeed stigmatised) groups are marginalised for the same reasons. For example, members of the Klu Klux Klan and PIE (Paedophile Information Exchange, disbanded in the UK in 1984) can be said to be marginalised by many. Their marginalisation in this sense is due to the fact that their intentional practices have violated the rights of Black people and children respectively. Other marginalised groups such as people with learning difficulties are marginalised because of assumptions made about them as people. These differences, in the context of discussions about human rights at least, are significant. 'Oppression' on the other hand is more directly associated with a restriction or violation of human rights. Synonyms include terms such as 'domination', 'coercion', 'cruelty' and 'subjugation'. All these are evident in an excavation of the oppression of people with learning difficulties.

Secondly and following on from this latter point, it is apparent that the oppression of people with learning difficulties is deep and vast. It is *not just* marginalisation which has constituted their past and present oppression. Eugenics, normalisation of selective abortion and control of the sexuality of people with learning difficulties

conspire towards their *elimination*, not marginalisation. This observation also provides us with the important caveat that oppression is a complex, hydra-headed creature and community participation/inclusion alone cannot be held up as a panacea for all issues facing people with a learning difficulty.

Whilst even the term 'oppression' struggles to convey the full impact of these processes, the antithesis of oppression is the notion of liberty which embodies processes of social liberation and emancipation, themes which are further discussed and embraced later in this thesis.

2.3.2 The tyranny of the IQ test: defining who people are

Anya Souza, a self-advocate who has Down syndrome, defined empowerment as the "fight against people who have the power to define who you are" (Souza, 1997, p. 4). This is a potent statement. Who does have the power to define who people are and what mechanisms do they use to do this? Learning difficulty labels are usually assigned by clinical, educational or child psychologists. Many, if not most, of those people now carrying the 'learning difficulty' label have been subject to a range of psychological assessment tests prior to the age of 18 years. The most common of these is the IQ test. This test has consistently formed a criterion via which professionals can determine whether an individual has an intellectual disability ('definition of intellectual disability' AAIDD, 2011 website. retrieved 11th July, 2011; Rapley, 2004, pp. 212-218; Yong, 2007, p. 6) and hence is integral to the apparatus via which people are constructed and categorised as having 'low intelligence'. The story of the IQ test is therefore well worth some probing.

In 1905 Alfred Binet developed the first IQ test which became known as the Simon-Binet Scale. This IQ test had the express purpose of identifying pupils who required more support to learn and hence needed to be decanted into 'special schools', avoiding the disruption of 'normal' pupils (Yong, 2005, p. 51). Whilst we would clearly question this practice today, Binet at the time cautioned against the misuse of the scale and the misunderstanding of its implications:

...the scale, properly speaking, does not permit the measure of intelligence, because intellectual qualities are not superposable, and therefore cannot be measured as linear surfaces are measured (Binet, cited in Gould, 1981, pp. 151-152).

Binet's comments about the limitations of the test were not heeded and in 1916 Terman produced a reworked version of Binet's test known as the Stanford-Binet test which became the standard intelligence test in the US (Strydom & Du Plessis, 2003). By the 1920s the belief, promulgated by Terman (1924), that IQ was an innate and static phenomenon prompted widespread use of the Stanford-Binet test (Osgood 1984). The IQ test has been widely discredited on the basis that it is not clear what it actually measures and is unreliable, often giving discrepant scores for the same person (Gould, 1981; Ysseldyke & Algozzine, 1983; Smith, 1991). High-profile critiques of IQ theory emerged as a result of the racial arguments evident in the work of Eysenck (1971) and his acolytes but it is not until fairly recently that the flaws within IQ theory have been taken seriously in relation to people labelled with learning difficulties (Siegel, 1999). There is enduring support for psychometric testing across many social groups. For example, today in Australia most people with learning difficulties who make claims for a disability support pension need to produce evidence of a school report with a recognised IQ test result or undergo an IQ test with a Centrelink assessor (Centrelink, 2011). This practice links the need for support (or the need for financial help to build in support) to an ascribed 'low intelligence' and the construction of a person who is deficient and 'sub-normal'.

2.3.3 Eugenics

The application of science and social science to the oppression of people with learning difficulties has not been a random process. Neither has it necessarily, as some have suggested, arisen purely from cultural conceptions of normalcy (Gerodetti, 2006). Many of the founding fathers of the testing industry including psychologists such as Goddard and Terman, advocated eugenics (Armstrong, 1987, p. 27). Eugenics involves the selective breeding of humans in favour of, not just a 'normal' but a *superior* race and the purposeful elimination of those perceived as substandard. Economically powerful interests support eugenics (Lombardo, 2002) including the US Carnegie Institute and the Rockefeller Foundation (Black, 2003). The controversial Pioneer Fund (established in 1937) is devoted to researching

heredity and human difference. Miller (1994) noted that the fund issued grants of approximately US\$1,000,000 per year to academics most of whom engage in research geared in favour of the establishment of a genetic basis for racial differences in intelligence and personality. In 2001, Richard Lynn, a scientist who sits on the board of the Pioneer Fund, argued that embryo selection as a form of standard reproductive therapy would raise the average IQ of the population by 15 points in a single generation (Lynn, 2001, p. 300). Lynn predicted that China will be the first nation to practice embryo selection on the basis of IQ.

US funded eugenics research both informed and inspired the World War II Nazi programme of euthanasia (Black, 2003) where hundreds of thousands of ‘mentally defective’ people were murdered after being condemned as “useless eaters” (Mellanby, 1947 p.149). Unlike the murder of Jewish people, no person was ever expressly brought to trial for this atrocity (Gallagher, 1990, p.63). Psychometric testing was instrumental in the legitimization of forced sterilisation of some people with learning difficulties (Gould, 1981). Scandinavia and North America ran such programmes with Sweden sterilising over 60,000 women with learning difficulties between the 1930s and the 1970s (Kevles, 1999). Shakespeare (2006a, p. 87) argued that coercive eugenics has been replaced by ‘individual choice’ and is therefore a ‘value neutral’ activity. Saxton (2006) and Hubbard (2006) have disputed this and held that eugenics lies at the heart of contemporary pre-natal genetic testing and selective abortion. They draw our attention to the manner in which these practices have been ‘normalised’ within communities globally. Research has elucidated the paucity and inaccuracy of information often given to parents about Down syndrome at the time of diagnosis (Skotko, Capone & Kishnani, 2009), the assumptions that genetics counsellors can make (Cooley, Graham, Moeschler & Graham, 1990) and the general lack of public understanding about Down syndrome. These (socially constructed) phenomena all endorse the view advanced by Koch (2008, p. 20) that “the deck is stacked for prospective parents who face the daunting task of raising a child of difference in a society that does not provide adequate assistance to those with ‘special needs’”.

2.3.4 The testing industry

Global capitalism and the considerable profits which can be made from testing provide significant motivation for formulating, promoting and hence 'normalising' the administration of certain tests upon human beings. IQ testing is a multi-million dollar industry (Osgood, 1984), as is the market for pre-natal tests to detect congenital 'defects' (Buckley & Buckley, 2008). For example, the potential profit which might be made from a 'non-invasive test' which can confirm Down syndrome during the first trimester of pregnancy is vast. Sequenom and, Illumina have worked to produce the test. Harry Styli the (now ex) Sequenom CEO boasted that the estimated market for such a test in the US alone "runs to about \$1.5 to \$3 billion US dollars a year". Worldwide, the potential could be between \$6-8 billion profits per annum (Marcial, 2008). The test is currently now available in more than twenty large metropolitan areas in the United States (Graham, 2012).

2.3.5 Labelling and stigma

In his seminal work on stigma, Goffman (1963) proposed that 'a stigma' is a tarnished or spoiled identity, the stigmatised person "is thus reduced in our minds from a whole and usual person to a tainted, discounted one" (Goffman, 2006, p. 131). Stigma is a culturally and historically fluid concept (as are notions of normalcy) in that any perceived human difference is susceptible to stigmatisation. Individuals can be stigmatised according to how they look, speak, act and even on the basis of their ideas and belief systems. Stigma is intimately associated with labelling (Link & Phelan, 2001). Labelling and stigma are subsequently interconnected with IQ testing and the eugenics movement. One type of stigma can be manipulated to reinforce another. For example, Langdon Down initially promulgated a new hypothesis, that such children were 'Mongoloids', a spontaneous reversion by Caucasian children to an earlier 'less developed' race (Borsay, 2005). By the late 1870s Down himself had abandoned this theory, prompted by his political antagonism to slavery and the eugenicist arguments that were part of the oratory of the anti-abolitionists. The term 'Mongoloid' however survived well into the later 20th century as it supported ethnic and racial theories of intelligence (Booth, 1987). Labelling via IQ testing, for example, can lead to stigma and stigma can precede labelling. This is contested by some people with certain types of learning difficulties (for example, Riddick, 2000)

such as dyslexia whose difficulty is not widely perceived to holistically impair their ability to learn. This therefore presumably limits the level of stigma they feel. The impact of stigma upon people with learning difficulties can be profound both in terms of their emotional wellbeing and in the widespread 'assumption of incompetency' that such a label breeds (Richardson, 2000). This can lead to a curtailing of choices and freedoms which most of the population take for granted and the gradual 'internalisation of oppression' by people with learning difficulties. Self-advocate Aspis (1997) succinctly summarised the situation:

People with learning difficulties do not like being called names nor do they like the thought of not being able to learn. As a consequence people with learning difficulties have had a poor self-image of themselves. Through the labelling process people with learning difficulties have had their expectations of life limited by other people. They are told to accept what is 'realistic' rather than having the challenge to go for something that is not available (Aspis, 1997, p.653).

The emotionally painful effects of labelling were also evidenced in the work of Sinason (1992). In an act of resistance some self-advocacy groups who realise its impact refuse to bear 'the label' altogether (Williams, 2002).

Reflecting on the nature of stigma, Coleman (2006) suggested that the challenge for social scientists will be to better understand "the need to stigmatise; the need for people to reject rather than accept others; the need for people to denigrate rather than uplift others" (p. 151). In stating this, however, Coleman presupposed that we all have an innate 'need' to stigmatise. The above discussion suggests that social scientists also need to be as precise as possible in identifying and naming the powerbrokers and social institutions who serve to perpetuate stigma and constructively challenge their culture, motivations and practices.

2.3.6 A culture of segregation

Socially segregated living arrangements

I was three when my parents left me at Willowbrook. My father later explained that he and my mother took me to a doctor because I wasn't developing normally. I was two and could not walk or talk. "There's no hope for her," the doctor said. "She is not going to progress any

further. I'm sorry Mr. and Mrs. Bernard but your daughter will not amount to anything. It would be better to put her away." Then my parents moved back to Oklahoma... I never saw my mother again (Debello, 2006)

Segregated living arrangements for people with learning difficulties became prevalent with the advent of the Industrial Revolution which occurred in the UK from about 1760 onwards. Race (1995) suggested that the Industrial Revolution brought with it challenges in respect of the capacity that people had to cope with technology and commercialism and their subsequent abilities to generate income and profits. A perceived lack of economic usefulness created a stigma which evolved into a belief that social ills such as criminality and alcoholism were also associated with learning difficulty. Almost simultaneously, eugenicist thought began to take hold. Tredgold (1909) wrote about the dangers of "degenerates" having children with non-disabled people which provided further impetus for social segregation. This philosophy seemed to become more embedded in tandem with the notion that mental incapacity was a static and fixed condition, irrespective of any education and care given to the person (Yong, 2007). The UK government's Wood Committee (1929) advocated institutionalisation and the creation of 'colonies' to cater for all groups of people with 'mental defects'. March (1930, p.197) stated that "In England the Mental Deficiency Act of 1913 provides for the care and detention of some of these feeble-minded persons, and when this Act is fully administered the future of the race may be safeguarded." Huge institutions proliferated in the form of 'long-stay hospitals', constructing the residents as patients, offering strict regimes to control daily activity, often enforced by punishment (Martin, 2006; Orme, 2002). With the rise of the institutions and the 'overreach' of medicine came a growth in the disability industry: nurses, psychologists, therapists and social workers who increasingly specialised in the classification and 'treatment' of people with disabilities (Foucault, 1980, p. 62).

Whilst the closure of many of the larger institutions started to gather momentum in most western European countries by the 1990s, the DECLOC project (Beadle-Brown, Mansell, Knapp & Beecham, 2009) revealed that more than 1.45 million disabled people in Europe still live in residential care with 70% of these living in units with over 30 places. Many 'Global Willowbrooks' are still in existence (Winerip, 2000) where mentally ill people and people with learning difficulties experience inhumane living conditions. Richards (2005), a volunteer for 'Mental Disability Rights

International (www.disabilityrightsintl.org), photographed ongoing appalling conditions in public hospitals in Paraguay (Figure 1), Kosovo, Hungary, Argentina and Mexico.



Figure 1. Photographs taken at Asunci in Paraguay by Eugene Richards, 2005

The use of cage beds in institutions in the Czech Republic, Hungary, Slovakia and Slovenia has also been highlighted (Bowis, 2004). In some Romanian and Bulgarian institutions, mortality rates exceed one in five residents (Lewis, 2002). Even today, certain types of residential accommodation for people with learning difficulty may be palatably termed a village or intentional community but, arguably, all forms of segregated living arrangements are problematic for people with learning difficulties. These models are vulnerable and can revert to the ethos of institutionalised contexts (and attendant excluded lifestyles) which have been in evidence for decades.

Socially segregated education

...that's the most important thing, to keep people a part of their own society and not an artificial one made up by others (Souza, 1997, p. 13).

The social exclusion created by the ripple effects of segregated education is well documented (Barton & Armstrong, 2007). As a concept, inclusive education first emerged as the goal of equal access to mainstream education for students with disabilities. Mainstreaming has been embedded in legislation in the USA since 1975 and in the UK Education Act 1981. Australia, to date, does not mandate inclusive education. The Salamanca Statement and Framework for Action (UNESCO, 1994, Article 2) is based on the 1948 United Nations Declaration of Human Rights (UDHR) and states that: "regular schools with inclusive orientation are the most effective

means of combating discrimination". However, the contradictions present in Western European style mainstream school systems have been problematised by many. Can school inclusion policies sit comfortably alongside the forceful differentiation policies endemic in most schools? Roulstone (2008) cites the deliberate identification of a 'gifted and talented' category of schoolchildren as an example of this "Orwellian doublethink" in the UK.

Another issue rarely mentioned is the ritual exclusion of people with learning difficulties from higher education environments although recently innovative and inclusive projects have been initiated such as the "Up the Hill Project" at Flinders University, South Australia (www.adcet.edu.au, 2011).

The inclusion agenda in education is an important one. It appears though that the complexity and difficulty of achieving this without a sea change in what we perceive as 'achievement' in the development of 'inclusive' societies is profound.

2.3.7 Forms of oppression by professionals

The medical model of disability - the role of pathology and statistics in defining what is 'normal'

...the medical model views mental retardation as a disease, and has an emphasis on labelling and determining aetiology; and once one has viewed mental retardation as a disease and affixed the label to an individual, one has a built in, self-fulfilling prophesy (Dunn, 1969, p. 214).

As indicated by Dunn (1969), this discussion is linked to discussions of IQ, labelling and stigma. As noted, disability labels are generally conferred with the assistance of professionals. Danforth (2002, p. 53) stated that the IQ test was the primary vehicle for the rise of the psychological profession, a profession which derives much of its credibility and prestige from positivist inquiry and medicine resulting in a propensity for typological thinking (Rapley, 2004, p. 16). Writing in 1973, Mercer identified two clinical concepts relevant to learning difficulty. Both were adopted by the American Association for Mental Disability in 1961 (Mercer, 1973, pp. 2-3). The 'pathological model' was developed within medicine as a theoretical tool for understanding

disease and bodily malfunctioning. It is a conceptual continuum. At one pole is 'normal', which is equated with health and the absence of pathological symptoms and at the other pole is 'abnormal' which is associated with ill health and disease. We are all arranged upon this continuum. Because the pathological model focuses on symptoms, persons viewed from this perspective are likely to be described in terms of 'what is wrong with them', their perceived deficits. The 'statistical model' for 'normal' describes the 'bell curve' created when a population or group is measured using a tool or set of tools. Hence, degrees of normality or abnormality are perceived in terms of how far someone deviates from the statistical mean calculated. Importantly, when such clinical models are used, the impairment or abnormality of a person is attributed entirely to the individual and exists whether a 'condition' has been diagnosed or not. One can deduce from this perhaps that the bell curve often says more about instruments of measurement themselves (and their creators) than the population. Mercer's description of the normalising processes of scientific measurement links clearly to Foucault's thesis about the process of normalisation which was developed throughout one of his major works *Discipline and Punish: The Birth of the Prison* (1977) to be discussed in the next chapter.

Forms of legal oppression

The famous US *Buck v Bell* case (1927) is still seen as a landmark ruling which heralded the compulsory sterilisation of the 'unfit'. It had a profound impact upon the human rights of both people with learning difficulties and their families and set a precedent for the sterilisation of thousands. Once again proponents of eugenics were heavily involved with this case (for example, Laughlin, 1922) and it is said to have been propelled through the US court system in order to establish a 'model law' giving greater licence to sterilise people deemed 'mentally defective'. This proposed plan was contrary to the 5th and 14th Amendments of the US Constitution giving all adults the right to procreate. Carrie Buck's appointed lawyer, Whitehead, poorly argued her case and failed to call upon important witnesses. Whitehead was a governor on the board of the institution in which Buck was placed and was in favour of eugenics oriented sterilisation (Lombardo, 1985). *Buck v Bell* is a powerful example of how robust legal frameworks and highly developed human rights theories are required to withstand the 'politicisation' of the law. Ironically, Laughlin himself

was an epileptic and therefore eligible for sterilisation under his own criteria as a “socially inadequate person” (Laughlin, 1922, s 2. b).

Mechanisms of professional ‘distance’ and disconnection

With the advent of segregatory practices and the growth of the disability ‘industry’, the ways in which the web of professionals, agencies and organisations can, unwittingly or otherwise, stereotype, categorise and de-humanise people with learning difficulties also grew. Gillman, Swain & Heyman (1997) observed how case history information (in the form of case records) relating to people with learning difficulties for example generally tends to focus on issues such as IQ, medical diagnosis and support needs, ignoring the lived experience of the people themselves. They conclude that ignoring the distinct life history of an individual allows professionals to psychologically detach themselves and apply professional theories and practices to an objectified ‘client’. Again, one consequence of stigma is that it allows an ‘othering’ process to be initiated and maintained, which entails a distancing and dehumanising effect upon the subject. Gillman et al (1997) hence illuminated a pivotal issue for this thesis: when such a disconnection occurs this virtual ‘space’ effectively enables others, wittingly or otherwise, to relate to people with learning difficulties as being less than human: quite simply, their status as humans can disappear.

It is not always apparent that intellectual assessment, diagnosis and surveillance have assisted people with learning difficulties to access the benefits available to non-disabled people. Despite the proliferation of ‘specialists’ in the learning difficulty field stemming from as far back as the late 19th century (Yong, 2007, p. 50), in many areas such as health, outcomes for people with learning difficulties remain poor compared to the non-disabled population. A large-scale study conducted by the UK Disability Rights Commission found that people with long-term mental health problems or learning disabilities were more likely than other citizens to contract some of the major killer diseases of our time, for example, heart disease, stroke, diabetes and some cancers. Sowney (2004) identified a range of barriers to equity of access including a lack of knowledge about people with learning difficulties and their health needs, poor communication and negative stereotypes.

Exploitation and subjectification in research practice

The Willowbrook Studies were carried out by Saul Krugman and his team at the Willowbrook School on Staten Island, New York in the 1950s. This institution housed some 5,000 children with learning difficulties. In the course of the studies, children with learning difficulties were deliberately infected with strains of hepatitis from 1956 until 1971. Funded by the US military establishment, the experiments were justified on the basis (later disputed) that most of the children at Willowbrook would become infected with hepatitis in any event (Krugman, 1986). The experiments were criticised by many, including other scientists, as ethically indefensible (Goldby, Papworth and Edsall's letters to the *Lancet*, 1971). Krugman, however, continued to maintain that his research was justifiable and was repeatedly honoured for his work by the US medical establishment until he died.

Although a trend for inclusive and participatory forms of research is now growing (Williams, 1999, 2002; Walmsley, 2004; Stevenson, 2010) people with learning difficulties have, historically, been consistently subjectified in research and still are. Annison (1999) conducted a survey of five major journals in the learning difficulty field between 1992 and 1996, where 211 articles were identified as focusing on people with an intellectual disability. In 43% of the studies participants were asked to comply with tests or provide answers to formal questionnaires. In 21% of the studies, participants were physically assessed and, in 32% of the studies, 'significant others' were the main source of information relating to them. In 11% of studies, people were questioned using a Yes/No forced choice format or structured interview. With the caveat that certain types of research require specific data collection methods, it is interesting to note that in only 6.6% of studies were open-ended questions asked of intellectually disabled people (Annison, 1999). As a research participant in these studies, one is more likely to be physically assessed and perform a test than have one's views and experiences sought on an issue. Finkelstein (2001) and Oliver, (1998) argued that many academics have drawn career benefits from disability research without a corresponding improvement in the position of disabled people in society. For this reason, theorists endorsing the social model disability introduced the principles of Emancipatory Disability Research in 1991 (Barnes, 2001) to improve the ethics of research practice.

2.3.8 Oppressive media imagery

Barnes (1992) elucidates the ways in which media images can both misrepresent people with learning difficulties and reinforce their oppression. For example, in the film *Of Mice and Men* (1992), Lenny (who has a learning difficulty) is portrayed as being both naive and a risk to public safety. A surprising number of movies tend to allow their segregated disabled protagonists out into the wide world for a short while. In *Rain Man* (1988) Raymond, who has Autism, is allowed into the community for a short time but returns to an institution by the end of the film emancipated neither by his personal gifts nor his improved relationship with his brother.

Not all film-makers have negative impacts however. Jacobs (2009), a disabled doctoral research student, comments that work such as that by Reiff, Gerber & Ginsberg (1997) involving individuals with learning difficulties focused on the considerable skills and strategies that participants used to 'maximise their potential' and lead 'successful' lives. Jacobs argued that although the portrayal of the disabled 'hero' is seen as oppressive by some, disabled people have a right to strive to achieve their full potential and their achievements need to be recognised. In more recent times disabled people have produced media by and for themselves (or worked collaboratively with non-disabled artists) which has led to a thriving disability arts movement. How this movement will eventually impact on popular images of disabled people remains to be seen (Barnes & Mercer, 2003 pp. 89-109).

People with learning difficulties are rarely portrayed in the media as leading 'ordinary lives', for example, going to school, getting jobs, getting married or having children. Reading the above sections, this comes as no surprise. For example, the sexuality of people with learning difficulties has been subject to exploitation and abuse (Crossmaker, 1991; Sobsey & Doe, 1991; Reiter, Bryen & Shachar, 2007) but is also socio-medicalised and subject to extra-ordinary levels of control and regulation (Brown, 1996; McCarthy, 1998) with concerns about the former often being used to justify the latter (Hubbard, 2006; Kempton & Khan, 2005).

How do we begin to address the oppression of people with learning difficulties? How do we work alongside them towards their emancipation and their enjoyment of their

citizenship rights? A recent response to the continued oppression of all disabled people was the UN Declaration of the Rights of Persons with Disabilities 2008. In the next section, therefore, I propose to examine the issue of human rights in relation to people with learning difficulties.

2.4 Human rights, learning difficulty, citizenship and ‘social inclusion’

Kittay (2001) observes that people with learning difficulties have at times been objects of sympathy, charity or mistreatment by their caregivers and the wider community but they have seldom been perceived as persons with human rights and entitlement to citizenship. The following discussion considers human rights, citizenship and the concept of inclusion which is currently being applied to improve the status of people with learning difficulty in society.

2.4.1 Human rights - an overview

Human rights are currently subject to diverse ‘understandings’. It has been suggested that rights do not actually exist, that if they do exist they are in a process of ‘unravelling’ (Wright, 2010) and that they are culturally relative, being the result of a dominant discourse of the Western elite (Ife, 2001). Moral philosophers such as Perry (1997) took a spiritual stance on the subject and argued that to be human is to possess qualities which make us sacrosanct. We are human and therefore have inherent human rights.

Features of human rights principles such as free expression, personal liberty and protection from the arbitrary exercise of authority can be traced back to ancient times and to ancient texts and cultures such as the Bible, the Qur’an, the Torah and Buddhist and Hindu texts (Ishay, 2004). However, it was only with the late eighteenth-century French and American Revolutions that efforts were made to constitutionally entrench them within rationally designed and democratic systems of government. According to Ishay, the intellectual legacies of Marxist thought and the Enlightenment have also contributed to understandings of human rights.

2.4.2 Human rights - what are they?

Hohfeld (1919) defined the concept of a right as a claim for specific human goods made against another person or state who thereby has a duty to provide the good claimed. Following from this assertion, Ward and Stewart (2008) explained the following key concepts within rights theory:

- a *rights-holder* (meaning the rights-bearing agent who makes the claim)
- the assertion of a *claim*
- the *object* of a claim (e.g. free speech or liberty)
- a *recipient* called upon to provide the object in question (meaning the duty bearer); and
- the *grounds* or justification for the claim

Rights involve both *duties* and *obligations*; the recipient of the claim subsequently has a duty to provide the claimant with the object in question (Gewirth, 1981; Orend, 2002). Moral agents have both *negative rights*, which are rights which impose an obligation on the duty bearer not to act such as freedom from torture. Also *positive rights* which require the duty bearer to act to ensure that the rights-holder's claim is met, for example the duty of the state to provide subsistence levels of health, food water and education (Ward and Stewart, 2008).

2.4.3 Grounding human rights - the contribution of Gewirth

Probably the most controversial of all the above key concepts is the justification or grounding of human rights. This is a vital discourse and, as such, has been the locus of hundreds of years of academic contemplation. Interestingly, whilst there are many postmodern critics of Foundationalist thought who question objective norms of morality and place emphasis upon culture and context, human rights philosopher Perry (1997) makes the point that people have always existed within a culture but are not necessarily exhaustively defined by that culture. One also wonders whether cultural relativists would argue that *their* ascribed human rights *did not exist* were they ever to be challenged.

Many writers note that that the Enlightenment project itself was a rebellion *against* dominant discourses, with philosophers striving to find universal truths which would

underpin social justice as opposed to the arbitrary and self-interested decision-making of the powerful social groups such as the aristocracy, government and church, hence making social justice 'accessible' to every person regardless of their capacity or social position. Ife (2001) questions whether human rights can actually be morally grounded but notes the work of Gough & Doyal (1991 cited in Ife, 2002, p. 65) who counsel against the 'deconstruction' of existing human rights frameworks and abandonment of a universalist position for precisely this reason, that the people who decide on rights arbitrarily will be the powerful and not the powerless.

In respect of the grounding of human rights, the work of post-Kantian philosopher Allan Gewirth has inspired many and is particularly worth exploration. In various publications Gewirth attempts to reinforce the universalism of human rights and the responsibilities of the state to act in order to safeguard and promote the well-being of those people whose 'rights-bearing agency' may be compromised. This makes his work particularly relevant to people with learning difficulties. Drawing inspiration from the work of Kant, Gewirth (1981, 1996, 1998) used deductive logic to persuasively argue that certain 'absolute rights' exist. Gewirth argued that all Prospective Purposive Agents (PPA) must lay a claim to the generic preconditions of purposeful action, namely, 'freedom and well-being'. Freedom and well-being are necessary for human agency, cannot be culturally 'relative' and are non-negotiable. Because the justification for this claim is to be found adequately in agency, every agent is unavoidably bound to accepting a duty to respect the rights of all who are agents (Brown, 2004). As such, all agents are committed to the same moral principle, one which Gewirth called the Principle of Generic Consistency (PGC): one must act in accordance with the generic rights of the recipients of one's actions.

A key feature of this argument is what Gewirth called the 'dialectically necessary method' (Gewirth, 1996). Gewirth does not try to assert the objective truth of the PGC; rather, he tries to show that all agents are unavoidably committed to holding it to be true. This rational necessity is central to his argument.

Once this is admitted, one must, as a matter of necessity, value and defend these essentials for oneself and others. To deny them would be to deny one's existence as a prospective purposive agent, which essentially is impossible. Fundamentally, one

must claim one's rights to freedom and well-being. Phillips (1986) argued that Gewirth succeeded in providing rational proof for the generic features of action. In 1991, Beyleveld devoted an entire book to refuting most of the major arguments against this thesis. Toddington (1993) analysed the interdependencies of philosophy, sociology and law and demonstrated that the PGC could be used foundationally by social scientists who must make scientifically determinable moral judgements when expounding theory. Gewirth's work has been used to inform arguments for natural law theory (Beyleveld & Brownsword, 1986) and decision making in controversial areas such as bioethics and the prioritisation of welfare support (Montana, 2009) as well as arguments for autonomy and choice in respect of direct payments to disabled people (Stainton, 2002).

Gewirth's theory forms a prime target for moral sceptics and moral relativists to attack as he is arguing that to be deemed rational, one needs to act morally. The agents must grant the rights they hold for themselves to others and no-one can guarantee this will be the case (Rorty, 1993). My view is that this criticism misses the point somewhat and is only problematic if one refuses to acknowledge another person as a human being. Whilst it is not possible to engage in the florid philosophical debate which is required to answer all critics of Gewirth here, arguably, a well-grounded perspective can lead to social policies being re-designed to respect the freedom and well-being of agents.

In 1996, Gewirth sought to resolve the often opposing concepts of individual rights with a concept of community as way of describing a social context within which the Principle of Generic Consistency (PGC) would flourish (Brown, 2004). He dealt with systems of social and economic rights, rights to private property and economic democracy. In Gewirth's final work, 'Self-fulfilment' (1998), he postulated that different people within different cultures at different times will have differing ideas on what constitutes self-fulfilment (hence embracing cultural and historical diversity) but we will all have concepts of what self-fulfilment is (Brown 2004). Gewirth linked self-fulfilment to purposive action and thereby ties his argument to the PGC. Gewirth endeavours to unite love with reason and self-interest with progressive unity within the community. Although the 1948 UDHR was not guided by any one supreme principle of morality, Ward and Stewart (2008) make strong connections between

Gewirth's justificatory position, its concept of intrinsic human dignity, and the provisions of the UDHR.

2.4.4 Human rights and social work

The Australian Association of Social Workers (AASW) Code of Ethics is commensurate with the definition of Social Work agreed upon in 2001 by the International Federation of Social Workers and the International Association of Schools of Social Work:

The social work profession promotes social change, problem solving in human relationships and the empowerment and liberation of people to enhance wellbeing. Utilising theories of behaviour and social systems, social work intervenes at the point where people interact with their environments. Principles of human rights and social justice are fundamental to social work (AASW, Code of Ethics, 2010, p.7).

The Universal Declaration of Human Rights (United Nations, 1948) is readily acknowledged by the AASW as are all the various UN statutory instruments.

2.4.5 Human rights and 'social inclusion'

The Universal Declaration of Human Rights (1948) and its rights 'progeny' in terms of various UN declarations, whilst not unproblematic, do provide a platform which transcends class, culture, colour and other discourses of difference from which to argue against human rights violations. The work of Ward and Stewart (2008) in applying Gewirth's theory in relation to people with learning difficulties and to the United Nations Declaration of Human Right (UDHR) represents an attempt to give a cogent and grounded structure to social justice in the face of extreme oppression. The Convention on the Rights of Persons with Disabilities (United Nations, 2008), however, stresses the right of people with disabilities to 'full participation in the community', which means their 'social inclusion'. It is at this point that some consideration needs to be given to this term.

What is 'social inclusion'?

Human beings would not even begin to be interested in questions of social exclusion, oppression and disablement (in relation to either ourselves or others) if we did not have some sense that all human beings have human rights on some level which render us worthy of an 'inclusion' agenda.

Social inclusion can be seen as either a technical term (for example, as a policy framework) or an ordinary term. Here it is explored within its ordinary meaning. The term 'social exclusion' gained popularity in France in the 1900s (Sherwin, 2010). As an expression, 'inclusion' forms a useful rallying point for those who wish to promote participation and respect for oppressed social groups. It is easily comprehended (Walmsley, 2001) and allows one to visualise the notion of being inside and engaged with the mainstream instead of being 'othered' (Saloojee, 2001). It has, however, become quite a "buzz" word both in academic and in non-academic circles (Beckett, 2006, p.14). All buzz words over time tend to become amorphous and lose their authority. Inclusive educationalists Armstrong, Armstrong and Spandagou (2010 pp. 31-32) noted that in locating a discussion about inclusion, there are necessary interconnections to be considered that require critical engagement with a broader range of issues about the purpose of social and economic policy frameworks and the nature and meaning of citizenship. They argued that we should proceed from a starting point of "inclusion for whom, into what and for what purpose?" (Armstrong et al 2010, p. 32). From this question different concepts of inclusion will eventuate. This is particularly pertinent in the light of the comments earlier in this chapter by, for example, Roulstone (2008) concerning inclusive education. Incisive criticism however was posed by Buckmaster & Thomas (2009) who, in a paper commissioned by the Australian Parliament, identified significant flaws in the notion of social inclusion arguing that it lacks a clear definition and coherent theoretical foundation. In essence, social inclusion is under-theorised.

Authors such as Sherwin (2010) have assisted in defining what inclusion means in terms of what good 'inclusive' leadership practices are in relation to disabled people. There remains however, much more work to be done in relation to defining and locating social inclusion within a human rights discourse in ways that are theoretically coherent and have richer meaning, particularly in terms of what disabled people see for themselves as their own 'social inclusion'.

2.4.6 Citizenship

Similarly, the concept of citizenship has been imparted by political theorists and practitioners alike with a range of diverse and sometimes incongruous meanings. Its

development, however, is inseparable from both the expansion of human rights and discussions of democracy (Enslin & White, 2003, pp.112, 115; Marshall, 1950).

Saloojee (2001) opined that, unexplicated, citizenship is an exclusive status. Jordan (1996) dismissed citizenship on the grounds that it has become associated with individualism and distanced from notions of collective action and interdependency. The same can be said of human rights in the past in various historical contexts. Klug (2000), for example, observes that within the early industrial epoch of Western Europe, human rights were advanced with an emphasis upon 'negative freedoms' which were concerned with the unbridled acquisition of wealth by the rising middle class under industrial capitalism. They excluded positive social rights which might engender interference with such freedoms as well as a duty to provide for others. This points to the need for unassailable foundational values on which to argue human rights (Gewirth, 1981; 1996).

The most influential post-war writing on citizenship is Marshall's theory of 'citizenship as rights' (Kymlika & Norman, 1994). Underpinning Marshall's theory are inherent human rights. According to Marshall (1950) we advance citizenship by ensuring that everyone is treated as a full and equal member of society and we ensure this membership through according people an increasing number of citizenship rights: civil rights, political rights and social rights. Much like Ishay (2004), Marshall explained these rights in terms of their emergence throughout British history. Kymlika and Norman provide a rigorous critique of Marshall's theory on the basis of its overemphasis on rights and growing globalisation and social differentiation within countries. Rather than espouse a new definition, they conclude that it remains unclear what we can anticipate from a new theory of citizenship. This raises questions as to whether we truly need a totalising new theory of citizenship.

2.4.7 Human rights, citizenship and disability

Human rights and disability

The United Nations' Declaration of Human Rights (UDHR) came into force in 1948 and was historically the first international agreement to promote a concept of human rights. The declaration was seen by some as a response to the catastrophes of the World War II in which many people with disabilities were killed, as discussed in the

previous section. The UDHR has inspired some landmark legislation for people with learning difficulties including the Salamanca Statement and Framework for Action (1994) to promote the appropriate inclusive (as opposed to 'integrated') education for children with special educational needs (Harman, 2010). 1971 saw the United Nations pass the Declaration on the Rights of Mentally Retarded Persons (UN Enable website, accessed 20th March, 2011). In 1975 the Declaration on the Rights of Disabled Persons was passed (UN Enable website, accessed 20th March, 2011) but overall these instruments have been slow to achieve substantial change for disabled people in general. For this reason the UN Convention on the Rights of Persons with Disabilities (CRPD, 2008) was drafted and came into force in May 2008. The CRPD confers *no new rights* for people with disabilities but was passed due to the substantial delay in recognising the human rights of people with disabilities relative to other disadvantaged groups. The 'guiding principles' of the Convention emphasise respect for dignity, autonomy, independence of persons, non-discrimination, full participation and inclusion in society, respect for difference and acceptance of human diversity, equality of opportunity, accessibility, gender equality, respect for the right of children with disabilities to preserve their identities and for their 'evolving capacities' to be respected (UN Enable website, accessed 20th March, 2011) .

Citizenship and disability

Beckett (2006) discussed citizenship in relation to disabled people and notes a revival of interest in the idea of citizenship in the 1990s as "a way of explaining and mediating the changing relationships between the state and its population" (p. 15). She also cautioned that the study of citizenship could be maintained at a purely abstract and academic level rather than seeking simultaneously to discover more accessible 'working models' which might be informed by, and work alongside, oppressed groups to address their practical concerns. She cites the work of Dwyer (2000) as an example of this. Reflecting on her research involving disabled people and citizenship, Beckett (2006, pp. 192-195) discussed postmodernist ideas which stress a concern with human fragility and human rights and suggest citizenship is obsolete. Beckett, however, helpfully suggests that notions of citizenship are intrinsic to governance and, rather, we could view citizenship as a *process* and an umbrella for human rights.

2.5 Concluding remarks

The solution to Down syndrome is not the technology of selective abortion but early interventions, educational programs, and environmental modification. Yet even though we have implemented many programs in response to Down syndrome along these lines, science and technology remain omnipresent not only in terms of the possibilities they introduce to better the lives of people with Down syndrome but also in terms of the threats they continue to pose (Yong, 2007, p. 66).

The discussion in this chapter demonstrates that in the history of human rights violations, there are few social groups who have endured discrimination and abuse as have people with learning difficulty. There is a tendency to simply blame medicine and science *per se* for the oppression of people with learning difficulties with little regard for the social, cultural and ideological forces which define and direct its action (or inaction as the case may be). Indeed, there have been many medical advances which have been of benefit to many people with learning difficulties. In the 1950s the life expectancy for people with Down syndrome was sometimes as low as 15 years of age. Now many people live longer and healthier lives due, in part, to medical treatment and procedures (www.downsyndromevictoria.org.au, accessed 26th August 2010). There have been some shifts in the *manner* in which people with learning difficulty are perceived and supported. It is evident however that eugenics, segregationism and stigma can 'shape-shift' into different forms and exercise a pervasive influence as mechanisms which justify and perpetuate the oppression and social exclusion of people with learning difficulties. What is also evident is the manner in which scientific theories and findings, even when caveats are issued or they are eschewed by their originators, can become oversimplified, reductive, rigid and promulgated by others (as in the case of Binet and Langdon Down) to achieve specific political and economic purposes. This insight alone underlines the case for the continuing interrogation of history and the fact that we need to treat accepted scientific and social knowledge with caution.

Strong human rights instruments are required to support ongoing resistance to the oppression and devaluation of people with a learning difficulty, and in advocating for their social inclusion and equality. The United Nations Convention on the Rights of Persons with Disabilities (2008) stresses participation and inclusion in society as full

and equal citizens. The more robust and well-argued this position is, the stronger such frameworks become. This leads to questions around how this can be achieved and what theories can support human rights activism, particularly in the arena of social work.

On a deeper level it is important to acknowledge that the previous discussion is a privileged discourse arising from academia and one from which the voices of people with learning difficulties themselves have been largely excluded (Williams, 2002). How do people with learning difficulties themselves and those close to them articulate their oppression? What are their aspirations for inclusion? What processes do they see as upholding their social citizenship?

The following chapter explores relevant literature in the area.

3. Theories and Voices

The review of literature continues in this chapter. I explore a 'toolbox' of theories of practical intent and what they have to offer in terms of discussing and promoting human rights in relation to people with learning difficulties. It then moves on to consider the 'voices' of people with learning difficulty, their families and advocates in relation to how they articulate their oppression and in order to glean some insight into how they might respond to questions around inclusion and social citizenship.

3.1 Theories of practical intent and disability

Theory with practical intent seeks not only to understand the world but also to transform it. The practical intent of such theory-its orientation to changing the world-is the expression of an emancipatory interest (Alway, 1995, p.1).

There are many models and constructions of disability which influence our understanding of impairment, and, both implicitly and explicitly, set the parameters for our response to disabled people (Clapton & Fitzgerald, 2007). But what theories inform the direction that people with learning difficulties and their advocates should take in the face of the continued exclusions and human rights violations that they face?

The following section explores some of the theoretical perspectives which have emerged over the last century and considers their application to the field of learning difficulty. The theories discussed are considered broadly in order of their chronological emergence but as theory development is generally a non-historically linear and iterative process there will be some significant interconnectedness to consider.

3.1.1 Normalisation and Social Role Valorisation (SRV)

The term 'Normalisation' was initially advanced by Bank-Mikkelsen and incorporated into the Danish Mental Retardation Act of 1959 (Flynn and Nitsch, 1980). This was later reformulated and conceptually developed by social work theorist Nirje (1969) in Sweden and refined by Wolfensberger (1972) in North America. Normalisation was renamed Social Role Valorisation (SRV) in 1983 by Wolfensberger who stated that

“the most explicit and highest goal of normalisation must be the creation, support, and defence of *valued social roles* for people who are at risk of social devaluation” (Wolfensberger, 1983, cited in Dalley, 1992, p. 101). Wolfensberger critiqued the Nirje and Bank-Mikkelsen interpretation as overly concerned with equality and rights at a price that a de-valued person could not defend (Culham & Nind, 2003). Wolfensberger (1983) explained that valued and devalued human characteristics vary within societies and depend on multiple factors within society so there are some similarities with the social model of disability (UPIAS, 1976) with regard to its ‘social constructionist’ perspective. Within SRV there are five key issues which are identified in the work of Wolfensberger (1998) and Race (1999):

- i. The devaluation of vulnerable individuals is the root of SRV
- ii. Devalued roles and the part played by services in perpetuating them are key elements of devaluation
- iii. SRV is one of many ways to address devaluation-actions will ultimately depend on values
- iv. The goals of SRV operate at three levels: The primary goal-‘the good things in life’; The secondary goal - the facilitation, support and defence of valued social roles for people; The tertiary goal-the maximisation of both social image and personal competency
- v. SRV actions take place at various levels of social groupings-not just at the individual level. (Race, Boxall & Carson, 2005).

The theoretical roots of Normalisation are rarely discussed in the core literature; though the influence of Goffman’s symbolic interactionism (1963) is evident through its uncomplicated acceptance of deviance, labelling and stigma theories. Wolfensberger’s model, though not indifferent to human rights, drew more upon deviancy theory than did Nirje and Bank-Mikkelsen (Culham and Nind, 2003). This can perhaps be at least partly explained by Wolfensberger’s academic background in psychology.

In Normalisation theory the absence of challenge to social ‘norms’ and acceptance of ‘stigmatised identities’ is said by some writers to resonate with a Parsonian functionalist perspective (Bleasdale, 1994). Whilst seeking to improve the position of devalued people in society, SRV does not seek to change society itself and critically, the power relationship between professional and individual stays unbroken with the professional applying SRV to the disabled person. Although SRV was seen to give

professionals power and credibility, it was never adopted as a model of change by disabled people or their client organisations (Oliver, 1994; Chappell 1998).

Although superficially appearing to help embed inclusive practice and sit comfortably with human and civil rights for people with learning difficulties, the normative and relativistic tone of the term 'Normalization' implies that one uncritically accepts and 'works towards' complicity with the norms of society regardless of their moral status (social norms can often be flawed, stigmatising and oppressive). This element of normalisation has engendered some misgivings (Moreau, Novak & Sigelman, 1980; Bleasdale, 1994). Illustrated by this critique is the notion that people with learning difficulties cannot or should not expect to be accepted simply for who they are and the ways in which *they* choose to exist in the world (Culham & Nind, 2003).

3.1.2 The legacies of Normalisation theory

The Normalisation paradigm has left a considerable legacy in terms of evaluation tools and methods to determine to what extent services are using its principles e.g. PASS and PASSING (Wolfensberger & Thomas, 2007). It has been used to spur on de-institutionalisation (Young & Ashman, 2004) and influenced the development of Person Centred 'Thinking and Planning' (Sanderson, 2002). Normalisation has influenced the formation of the guiding principles of various learning difficulty organisations (Culham & Nind, 2003); and been used to promote participatory forms of research (Walmsley, 2001). However in relation to the voices of people with learning difficulties being heard (and having impact) in relation to policy and professional practice comparatively little progress has been made. The requirements of schools, colleges and workplaces to adapt to accommodate people with learning difficulties are often minimal. Lifestyles are often arranged for people with learning difficulties rather than actively chosen by them (Culham & Nind, 2003). From a human rights perspective, why should we have to re-construct any citizen as "valued"? Surely all humans have inherent dignity and value and their own unique contribution to make to society? In searching for a deeper and more focussed analysis of the pre-conditions of the social oppression of disabled people let us turn to the work of Marx and post-Marxian theory.

3.1.3 The impact of Marx

Whilst it is not possible or relevant within the remit of this thesis to conduct an exhaustive exposition, analysis and critique of Marxist theory, the powerful and enduring impact of Marxist thought within critical theory, activist/critical social work and its role in the development of the Social Model of disability warrant discussion. Marx's work is also alluded to in the work of Gewirth (1996) in respect of Human Rights theory, which is significant to this thesis.

Marx in context

It was the material transformation brought about by the Industrial Revolution, primarily in Britain, which inspired Marx to rework the Hegelian dialectic and make theoretical interpretations of the dynamics within social, economic and political structures.

Marx intended his theory as a 'grand narrative', the basis of a scientific theory of history, and, in particular, of the capitalist mode of production (Callinicos, 1983, p. 177). According to Marx, society develops as a result of the interaction between man and nature. This 'production and reproduction of life' stems from the biological imperative for humans to survive and sustain their existence. As the production of food and other resources occurs within communities, social relationships are similarly produced and this process of social development is what constitutes history. Marx outlines his theory of social differentiation and class when he stated:

... men enter into definite connection and relations with one another and only within these social connections and relations does their action on nature, does production take place (Marx and Engels, 1958, Vol. 1, p. 89).

Pre-capitalist societies embrace elements of domination and subordination, for example, between a feudal lord and the serfs bonded to him but alongside these are the ties between individuals and the serf's to the land which, Marx argued, gave serfs some means of control over production. Capitalism gradually saw a shift away from a society where workers laboured under their connections to the land leaving them only with labour power to offer as a means of survival. Marx acknowledged some diversity of social grouping with regard to their relationship to the means of

production, but above all, he emphasised that classes are not income groups; they are an aspect of the relations of production. Within a capitalist system characterised by large industrial concerns and universal competition, he predicted a progressive shift of these extraneous classes (landowners, petty bourgeoisie, and peasantry) becoming subsumed into two polarised classes; the bourgeoisie (the dominant) and the proletariat (the dominated). Subsequently, Marx claimed that class relationships are pivotal to the exercise and manoeuvring of political power and the growth and functioning of political institutions (Giddens, 1971, p. 39).

Consistent with Marx's social relational thesis is the notion that human consciousness, language and ideology are socially produced. Language, wrote Marx, is:

As old as consciousness, language *is* practical consciousness that exists also for other men, and for that reason alone it really exists for me personally as well (Marx & Engels, 2004, Vol 1. p. 51).

Marx observed that it is only through our relationship to society that we acquire language which sets the boundaries for understanding our consciousness. The political nature of language and knowledge was initially identified by Marx and this assertion fundamentally challenged the idealism within enlightenment philosophy and traditional historiography. The economic power of the dominant class enables it to "disseminate ideas which are the legitimations of its position of dominance" (Giddens, 1971, p. 41) and simultaneously suppress ideas which might challenge its supremacy. Marx's prediction was that social structures will ultimately be transformed through a succession of class struggles, the final phase of which will be communist society where the workers control the means of production and the class dichotomy is no more.

Marx's theoretical tools and perspectives continue to be used to explain social phenomena and drive social change. There are, five key strands to his approach expressed over the course of his works: the Hegelian concept of the 'self creation of man' (by 'human labour' according to Marx in 1844); the notion of 'alienation' as an historical phenomenon; a distinct theory of the state; historical materialism as a

perspective for the analysis of social development; and the theory of revolutionary *praxis* which describes the unification of both theory and political activity as a means of provoking social change (Giddens, 1971, pp. 19-20).

Critique of Marx's work

Critique of Marx is wide ranging. From a practical perspective, many state that Marx's 'hypothesis' has simply been refuted by history itself, for example Russia, in the wake of the 1917 Revolution is widely hailed as a political and economic failure of Marxist philosophy, despite the fact that Marx insisted that socialism could thrive only when implemented on a world scale (Callinicos, 1983, p. 179). Callinicos made the distinction between communism and 'bureaucratic state capitalism' (p.182) which characterises the current relations of production in some allegedly 'communist countries'. Callinicos explains the status of these nations as a consequence of a failure of the revolution to spread, and the enduring (ideological and material) impact of the capitalist world system.

The second practical criticism is that Marx was indeed a product of his own time and thinking and his perspectives cannot adequately explain capitalist economics today. However, monopoly capital was central to Marx's philosophy (Giddens, 1988; Callinicos, 2004) and he predicted a "constant decrease in the number of capitalist magnate" (Marx, Capital, 1867, p. 929) and the eventual separation of the ownership and control of capital. The dominance of certain companies in globalised markets, the spread of neo-liberalism and attendant de-regulation are more than obvious (Goodman & Pauly, 1993).

3.1.4 Critical Theory and Feminist Theory

Proponents of critical theory seek to raise consciousness about present exploitation, promote social change and to demonstrate a future free from all kinds of alienation. Social work and social research has been highly influenced by Critical and Feminist theories for these reasons (Martin, 2002).

Many writers and activists continue to support Marx's thought and draw directly from his ideas. Some Critical Theorists focused on a reinterpretation of Marx and others attempted acknowledge his legacy but move beyond Marxist thought altogether.

Critical Theory emerged in the 1920s and is associated with the Institute for Social Research established in 1923 (Agger, 1991). Emerging primarily as an attempt to explain why the revolutionary theory of Marx did not occur as expected and facing the challenge of reconfiguring the ideas of Marx relevant to the twentieth century, Critical Theory can be roughly divided into three generations. Firstly, Horkheimer, Marcuse, Pollock, Lowenthal, Fromm and Benjamin; the 'second generation' is characterised by the work of Habermas. The current generation consists of Honneth and others. On an abstract level the major assumptions of the critical theorists can be summarised as follows: knowledge is socially produced and not value free; that society is constantly in flux; the dominant discourses of class, culture, race, gender continue to affect the everyday lives of citizens; and that such, domination is internalised and reproduced in human consciousness (Agger, 1991).

Habermas is probably the most influential critical theorist in the field of disability. He considered the reconstruction of a critical theory of society to be crucial and believed that understanding the relationship between social structure and human agency is of continuing relevance. His ongoing influence is visible in the theoretical grounding of Participatory Action Research of many writers (Freire, 1970; Fals-Borda & Rahman, 1991; Cocks & Cockram 1995; Kemmis, 2008), a research paradigm which is significant to this study. For Habermas a critical social science is one that goes beyond critique to critical practice so that the agents engaged in enlightened critique also bring about transformative action (Carr & Kemmis, 1986, p. 144).

Feminist theory in its many forms has been critical to the emancipatory project of many oppressed social groups, the development of emancipatory forms of research, and the valuing of alternative forms of knowledge. The work of feminists such as Oakley (1981, pp.30-59) helped to re-configure the qualitative research paradigm by challenging the infiltration of traditional 'masculine' methods of inquiry and the myth of the 'objective researcher'. Feminism has also mounted strong arguments against attempts to down-grade participatory inquiry (Humphries, 1997). Learnings from feminist theory are acknowledged to have facilitated many productive research projects in collaboration with disabled people (Walmsley, 2001). Feminist Standpoint Theory (Harding, 2004) is located in the realms of critical theory. Such theories must represent the social world in relation to the interests of the oppressed group; provide

a version of their world which is accessible to the members of the group and also provide an account of their problems which is usable by group members to improve their circumstances.

Critical disability theorists Meekosha and Dowse (2007) emphasised the importance of emancipatory paradigms “which place the views of disabled people as central to the change process” and stated:

Full citizenship for disabled people remains a dream. Social workers need to be equipped to decide whether they are going to work for the dream or remain within the confines of managerialist practices and discourses and within outmoded approaches to conceptualising and responding to disability. Attitudinal change is not enough, structural and organisational change is necessary. Turning attention to the practices and organisational culture of social workers' own agencies constitutes a beginning. In the words of the disability movement 'nothing about us without us' means that *the way forward must be a dialogue between disabled people and the profession* (Meekosha & Dowse, 2007, pp.180-181 *my emphasis*).

This highlights a need to consider what perspectives have clearly been developed by disabled people themselves and therefore brings us to a discussion of the social model of disability.

3.1.5 The social model of disability

The development of a materialist perspective on disability

Scholars and activists concerned with effecting social change for oppressed groups, including those in the field of disability, have gained much from adopting a materialist approach to an understanding of disability and the conception of 'disability' as social oppression:

...disability is a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over their own lives, and (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people. (UPIAS and The Disability Alliance, 1976, p.3).

It is somewhat ironic that one of the most systematically critiqued social theories has influenced one of the most powerful tools for social change for disabled people. The

architect of the social model was Marxist influenced Vic Finkelstein (Oliver, personal communication 9th September, 2010) who had been an anti-apartheid campaigner in South Africa in the 1960s. Finkelstein, also a wheelchair user, was imprisoned for his activism. When released in 1967, he was made subject of a 5 year banning order under the Suppression of Communism Act (Finkelstein, 2001). As he read the banning order, Finkelstein recalled that he realised that most of the activities it listed as prohibited were already inaccessible to him anyway. He moved to the UK in 1968 as a refugee and started working with activists within the emergent Disability Movement, including Paul Hunt, Mike Oliver and Colin Barnes. Oliver, also influenced by Marxist thought, coined the name the 'social model of disability' and endeavoured to apply the fundamental principles for use in social work practice for students he was teaching at the time.

Oliver (1990, 1996) developed the argument that the cultural meanings of disability and its production vary from society to society and depend upon a whole range of material and social factors. For example in some countries, people can *become* disabled because they suffer from infectious disease, poverty and illness which might otherwise be prevented by the deployment of appropriate public health measures, vaccines, treatments and such which are readily available to people in more affluent Western European cultures. This can be related very specifically to the so-called 'developing countries' where impairments such as blindness and deafness are more common than in industrial societies.

With regard to industrial societies, as long ago as 1979, Townsend clearly indicated the links between poverty, ill health and disability. Conditions such as heart disease and spina bifida, for example, are also more common in industrialised societies. The Black Report published in the UK in 1980 provided strong evidence of health inequalities between different socio-economic groups. Human differences which are perceived as 'disability' also vary from society to society. For example the discovery of an isolated tribe in West Africa where many members, for filial reasons, were born with two toes, illustrates this point. This condition was not seen as a disability by the tribal members with two toes themselves or indeed the rest of the tribe. However in the West, the occurrence of this natural genetic variation would, without doubt, be

viewed as grounds for medical intervention in respect of the 'afflicted' individual (Oliver 1996, p. 15).

Gwaltney's study in 1970 of filial blindness in a Mexican village showed that blindness in this context was "culturally accommodated"; the village community subsequently provided for a sophisticated array of informal social mechanisms to ensure the participation and integration of blind people in the community. Groce (1985) studied the culture of Martha's Vineyard, an island off the New England coastline. There was a much higher proportion of deaf people in this community due to intermarriage and the presence of a dominant deafness gene. The deaf people however, were not excluded from society because everyone learned sign language and therefore were functionally bilingual. Groce & Scheer (1988) were led to acknowledge the universal and social-relational nature of disability and the fact that disability has always existed and will always exist.

In addition to citing a number of studies in support of his argument that responses to impairment are culturally constructed, Oliver (1990) used the work of Comte and Marx to explain what happened to disabled people with the development of Capitalist society. Using a materialist perspective Oliver explained that in understanding humanity we need to understand our relationship with the material environment as it both produces and satisfies human needs. As the complexity of a society increases so will its limits upon certain freedoms. The socio-economic structure of society at different points in history influences types of working practices, living conditions and the relationships between individuals, groups and social institutions.

The social model of disability has now been in existence for over three decades. It asserts that it is not impairment which disables a person but the social and economic exclusions which people with impairments face in societies. Following from this, the social model of disability more specifically defines impairment and disability as a twofold classification:

Impairment: lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body;

Disability: the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from the mainstream of activities (UPIAS, 1976, pp.3-4).

The social model is now generally considered to be inclusive of people with a learning difficulty (Tregaskis, 2002).

The social model has been criticised generally for its neglect of the very real impact of impairment (Morris, 1991, French 1993 and Crow, 1992); its simplistic separation of the impairment (medical) from disability (social); and the subsequent denial of the complexity of the lived experience of individuals with a disability; and the impossibility of a “barrier-free utopia” (Shakespeare, 2006, pp. 200-201). However, the above social model definition does not deny the impact and individual complexities of impairment. There is scope within the social model for discussion and exploration of these issues which Thomas (1999) refers to as “impairment effects”. The personal narratives of individuals have inherent value and validity whether impairment is present or not. The lens of the social model, with its emphasis upon the cultural, historical and material context of individual experience, can only enrich the analysis of experience (Barnes, 2001). Criticism of the social model on the basis of a supposed ideal of a ‘barrier free utopia’ seems unfair. Seldom do we criticise a human rights framework on the basis that its utopian ideal would be a world where no-one’s rights were ever violated. An ideal is typically on an ever-receding horizon.

The strength of the social model is that it seeks to overturn medical and individualised models of disability which perpetuate a focus on the deficits of disabled people and the ‘personal tragedy’ brought about by their impairments. Its logic can be easily understood, interpreted and applied by both academics and non-academics alike. If the worth of any political model can be measured by its influence in the broader community, the social model has undoubtedly had the most impact (Barnes, 2001). It has been used in anti-discriminatory legislation (Disability Discrimination Act, UK, 1995) and has influenced the World Health Organisation to

develop an International classification of Functioning, Disability and Health (WHO, 2001) to replace its individualistic and discredited antecedent: the WHO International Classification of Impairment, Disability and Handicap (Wood, 1981). The model emphasises civil rights, socio-political access and inclusion (De Jong 1979; Finkelstein 1980; Oliver 1993, 1996) as strategies with which to tackle disability.

The implications of the social model for people with learning difficulties

Thirty years ago many people with learning difficulties were neglected in isolated long-stay hospitals. Now they are neglected by the social model of disability which ought to promise them so much in terms of its analysis of their experience and strategies for change (Chappell, 1998, p. 211).

Whilst the social model was initially wrought by people with physical impairments, the 'disability' (social oppression) of people with learning difficulties is similarly socially constructed, arising from powerful medical, professional, political and economic interests (Richardson, 2000) as discussed in Chapter 2. One further critique of the social model of disability has been a failure to significantly and adequately incorporate the concerns of people with learning difficulties and the politics of learning difficulty into its important social movement (Chappell, 1998). There is much scope for this still since the social model approach provides a radical alternative to other dominant perspectives and not only illuminates social barriers which impinge on the rights of citizens with learning difficulties but also provides a radical vision of the potential for their lives were such barriers to be removed.

3.1.6 Postmodernist perspectives and learning difficulty

Defining post-modernist thought in the context of late modernity

The contribution of postmodernist perspectives to our understanding on disability theory and strategy is essential. Defining timeframes and terminology in respect of modernity, modernism and post-modernism is generally held to be difficult (Callinicos, 1991; Fawcett & Featherstone, 1998; Giddens, 1998; Lyotard, 1994). However, in order to usefully discuss and critique these concepts one needs to define them.

Modernity in relation to intellectual thought, is most traditionally associated with the culture of the Enlightenment; an 18th century philosophical movement stressing the importance of Reason and the critical reappraisal of existing ideas and social institutions.

“Modernism” is seen as influenced by yet distinct from “modernity” by some writers (Delanty, 2007) beginning in the 19th century. Modernism can be seen as intellectually dominated by meta-narratives such as Marxism, psycho-analysis, economic rationalism, biosocial determinism (in terms of race and gender classifications) and structurally orientated analyses (Bauman, 1992; Sarup, 1993; Fawcett, 2009). In the field of sociology in particular, writers such as Leppert (2004) have noted that modernity can be defined via a pre-occupation with ‘evidence’.

Post-modernity is referred to as the post-modern condition and postmodernism is used as a means of understanding that condition (Williams, 1992; Fawcett, 2009).

The dawn of post modernity is seen by some writers as occurring in the 1970s. Certainly, postmodernism entered the ‘philosophical glossary’ in 1979 with the publication of ‘The Postmodern Condition’ by Lyotard (Aylesworth, 2005). The relationship between post-modernism and post-structuralism is also seen by some writers as problematic. Post-structuralists in France started work on the Marxist critique in the 1950s and 1960s. May 1968 is identified as a watershed for modern thought and its institutions, especially the universities. Foucault, for example, repeatedly denied in interview that he was a postmodernist but his application of genealogy to his description of formative moments in modernity’s history and his experimentation with subjectivity (Foucault, 1971) place him within the scope of the postmodern discourse. Fawcett (2009) observed there is a need to forge links in order to apply concepts and argued that to concentrate on associations and definitional issues is to ‘miss the point’ of the postmodernist project.

Post-modern approaches contrast with ‘modern’ approaches as they eschew reason and essentialism and embrace an assortment of themes: theories of knowledge which are based on the critique of grand theories, other accepted theoretical frameworks and a critical review of enlightenment assumptions, especially those about reality and truth; (Shakespeare & Corker, 2002 ; Fawcett, 2009); an

ontological emphasis on uncertainty, instability, hybridity, contingency, embodiment and reflexivity; a methodological emphasis on genealogy, deconstruction and located knowledge; the 'decentering' of the subject and the social world, often through an emphasis on language, discourse and culture; altered relations between knowledge and power; new ideas about knowledge acquisition and the body and new ideas about ethics and social justice (Shakespeare & Corker, 2002, p. 4).

Critique of post-modernism

Commentators have argued that emphasising open-ended subjectivity can have a fragmenting and individualising effect and therefore threaten the transformative projects of disadvantaged social groups who have used categorizations of class such as race, gender, disability, sexual orientation to *strategically* advance their interests; to free themselves from the constraints of prevailing stereotypes constructed via the forces of sexism, racism and homophobia. Oakley (2000) stated:

If there are really no such things as 'facts' about the way people are treated, then there is no such thing as discrimination or oppression. Post-modernism is inherently political. It drives the enforced injustices of social inequality into the personal cupboard of privately experienced suffering (Oakley, 2000, p. 298).

As discussed in Chapter 2, Ishay (2004) noted that collective action formed a major force in the realisation of many human rights. In the face of oppression by those who hold sway via material wealth or political power, often the only political influence some groups of people have is their collective voice and collective action.

Accordingly, contemporary Marxists such as Callinicos (1991) critiqued postmodernism for its celebration of the 'local' whilst leaving unchallenged the ongoing substantive social structures and relations of inequality and oppression of class, race etc., thereby tacitly facilitating the ongoing reproduction of dominant power/knowledge and its political effects. Barnes & Mercer, (2003) also observed that deconstructionist analyses often "fail to address issues regarding the production and maintenance of discourses as well as their demise" (p.82). Connected with these observations are those of Parton & Meagher (2004) who indicated that postmodernist approaches have failed in many ways to challenge dominant

discourses and the drive to neo-liberalism and market approaches to service delivery.

Whilst the notion of resistance is reasonable, there is little emphasis on the “individual/body as a creative force”. Surely our bodies and minds are “more than an artefact of discourse”? Barnes & Mercer (2003, pp. 85-87) made the assertion that our bodies and minds are “more than an artefact of discourse”. Human beings are influenced but not wholly defined by their culture or epoch, a point made earlier by Perry (1997). The critique of practical reason is held by some to be insufficiently addressed by postmodernists. For example Foucault (1977) deals with a ‘paradigm shift’ from monarchical to disciplinary forms of punishment. Arguably, if Foucault did not have knowledge outside of culturally constructed paradigms of thought and action he would be unable to discern and explain that such a shift had taken place. Similarly, ‘bridgeheads’ of shared linguistic understanding must exist for us to begin to communicate with and understand each other on such matters (Hollis, 1994, pp. 245-246).

Applying post modernism to social work practice and social research

The application of post-modernist perspectives to policy and practice has centred upon linkages of modern and post-modern discourses. Acknowledging a need for a human rights platform and the political gains made by the strategic standpoints located within modern feminist, Marxist, disability and anti-racist movements is a necessary component of critical postmodernism. The strength of critical postmodernism primarily resides in its emphasis on context and process (Fawcett, 2009a) and the questioning of culturally entrenched assumptions.

Critical postmodernist approaches with regard to social work and disability will therefore entail some of these perspectives: the critical examination of accepted professional “knowledge” and recognition that knowledge is constructed at different points in time within different cultural contexts and power discourses; a commitment to negotiatory mechanisms, processes and inclusion within practice; valuing and engaging the perspectives of service users and consumers in decision-making and service development; acknowledging the infinite multi-faceted nature of the individual with whom one is working, the varying conceptualizations of the self and the process

of (and capacity for) constant change and development; and the acknowledgement of “gaps, omissions, contradictions and inadequacies of modernist theory” (Fawcett, 2009a).

Key to the critical post-modernist project is change and action and the promotion of ‘positive citizenship’ as freedom from discrimination, exclusion and oppression. This development brings postmodernist tools into the realm of activist/critical social work and human rights advocacy and it becomes, if not a theory of practical intent (Alway, 1990), then a collection of critical *perspectives* of practical intent. As a more explicitly emancipatory project then, critical postmodernist perspectives may be used not only to query or deconstruct rigid perspectives and standpoints but question the limitations of existing theory and help activists formulate strategies to develop and enhance such theory and practice.

Poststructural approaches to learning difficulty

Foucault’s work is particularly relevant to the field of learning difficulty. In the course of his writing he makes three observations of particular significance: Firstly he explains the proliferation of the ‘caring professions’ whose power is produced via the ‘truth claims’ of social science knowledge:

Take the example of philanthropy in the nineteenth century, people appear to make it their business to involve themselves in other people’s lives, health, nutrition, housing, then out of this confused set of functions there emerge certain personages, institutions, forms of knowledge, public hygiene, inspectors, social workers , psychologists . And we are now seeing a whole proliferation of different categories of social work (Foucault, 1980, p.62)

Foucault asserted that these bodies of knowledge in turn, produce norms and processes of normalisation. As outlined in Chapter 2, the modernist phenomenon of ‘Learning difficulty’ is evidently defined via clinical processes:

“Who are the persons in a community who are really mentally retarded?”, “What is the right prevalence rate?” are nonsense questions, questions that are not capable of being answered. Persons have no names and have no class until we put them in one. Whom we call mentally retarded, and where we draw the line between the mentally retarded and the normal, depends upon our interest and the purpose of our classification (Mercer, 1973, p.1).

Foucault claims that the caring professions are key players in the process of normalisation and they have contributed to the surveillance and disciplining of certain social groups (Foucault, 1977). Foucault describes the sinister 'internalisation' of examination and surveillance techniques via the exemplar of the Panopticon. Jeremy Bentham's design for his Penitentiary Panopticon dates back to 1791. On the periphery of this circular building no prisoner could ever be sure that he was not being watched by guards stationed in the central watch-tower. Panopticism was first used in barracks, schools and hospitals. In these institutions professionals such as doctors, teachers and social workers established themselves through utilizing techniques of surveillance and examination; gradually these practices have filtered through society. Hence power-knowledge is realised in a system of human surveillance which is internalised and exercised continuously as each individual becomes his or her own 'supervisor'. It is the emergence of processes which stimulate this constant 'policing of the self' and the subsequent 'carceral' nature of modern society which is alluded to in the subtitle of *Discipline and Punish: The Birth of the Prison* (Dreyfus & Rabinow, 1982, pp. 197-202).

As he opined on the nature and evolution of professional/social science knowledge, Foucault also opened the door for different forms of knowledge production:

A whole set of knowledges that are either behind more dominant knowledges but can be revealed by technique or have been explicitly disqualified as inadequate to their task or insufficiently elaborated: naïve knowledges, located low down on the hierarchy, beneath the required level of cognition or scientificity (Foucault, 1980, p. 82).

An example of critical postmodernists within the learning difficulty field are Goodley & Rapley (2003) who align themselves with the political project of the social model of disability but take issue with the 'fixity' of impairment as a phenomenon grounded in a bodily fact (Young, 2002). Through drawing upon post-structuralist methods of inquiry, namely deconstruction, they strongly challenge the notion of 'learning difficulties' as innate impairment where "naturalisations of impairment are at the core of oppression" (p.138). Suggesting instead that 'learning difficulty' is socially constructed, Goodley & Rapley (2003) called for the "resocialisation of impairment" as part of, and in addition to, materialist understandings of society.

Although this work importantly contests the fixed category which people with learning difficulties often find themselves cast within, this path could possibly entail some form of ‘denial’ of any impairment and the need for some forms of additional support at least at some points in our lives. Even if we need a great deal of support in order to function and live participatory lives, arguably this should not affect our inherent status and dignity as human beings. Actress and self-advocate Ruth Cromer in her speech at a 2008 NSW charity fundraiser stated clearly: “It’s OK to have an intellectual disability”.

3.1.7 John McKnight

Foucault is not alone in his analysis of the nature of professional power and its disempowering/controlling effects upon individuals and communities. McKnight discussed the ‘disabling effects’ of the professions upon society as a whole (McKnight, 1977, 1995). He advanced the thesis that service cultures actually weaken communities through encouraging dependency on professional knowledge and intervention. McKnight advocates that communities need to harness their own ‘assets’ and look to be more self-supporting. Criticism of McKnight’s thesis abounds however, from both right and left in the sense that the case for ‘de-professionalisation’ is hugely overstated. He also seemed to make the assumption (sometimes implicit in the work of Foucault) that professionals cannot genuinely and reflectively care for people, that they have nothing of use to offer others. One can well imagine the consequences of an appropriation of this way of thinking by neo-liberalists. A possible reduction of services to communities could constitute cost cutting under the guise of ‘community independence’. McKnight does illustrate an important point however, that services alone cannot ensure the emancipation and participation of disabled people.

In the wake of the closures of the large institutions which started to occur in the 1970s and 1980s McKnight guided a project (1988-1990) in British Columbia, Canada aimed at the “inclusion of isolated, labelled people in the organisation, associations, groups, families and enterprises of their cities” (McKnight, 1990, p.1) and suggested six guiding principles to enhance community participation available in Table 1:

Table 1. Guiding principles to enhance community participation (McKnight, 1990, p. 1)

1. Isolation from community life is the worst disability: *people who have labels like “developmentally disabled”, “mentally retarded” etc are usually most disabled because of the effects of their isolation from the life of their community.*
2. Every person has gifts to contribute to the community: *No matter what label people might have, they have gifts abilities, talents and skills to contribute to their community and its people.*
3. Communities grow stronger when all people can contribute: *As labelled people contribute their talents the power of the community grows and the disability of isolation diminishes.*
4. A special citizen effort is necessary to open community life to isolated people: *some citizens will initially need to reach out and open the doors to community, guiding the labelled people to places where they can contribute their gifts.*
5. Isolated people need to be introduced to groups in the community: *Community is about the relationships of groups of people. As isolated people are introduced to these groups and offer their gifts they will find that special relationship known as friendship.*
6. Well-connected people are the most effective community guides: *The most effective ‘connectors’ will be people who are well known and respected and active in community life (Adapted from McKnight, 1990 pp. 1-2)*

There is an obvious similarity of perspective to the social model (UPIAS, 1976; Oliver, 1990) in the first principle which identifies disablement as community isolation, a lack of access to the mainstream community. McKnight’s major contribution is to emphasise that the social connection of labelled, devalued community members needs to be an intentional and facilitated process. His work had a profound influence on the development of PLAN (Planned Lifetime Advocacy Networks) Canada (www.plan.ca) discussed later in this chapter.

3.1.8 Empowerment and Enablement

Some further clarification of language used is required at this point. ‘Resistance’, ‘emancipation’ and empowerment are terms which are used at various times within this thesis. They are all terms which have been employed in various contexts when discussing moves to challenge the social oppression and exclusion of people with learning difficulties. Resistance has commonly been used in the context of resistance to oppression but in a more contemporary sense it forms an integral plank of

Foucauldian theory, as discussed earlier. Foucault postulated that “there are no relations of power without resistance” (1980, p. 142).

Empowerment is similar to inclusion in the sense that it is a term which has become ‘amorphous’ and needs consistent clarification. I have, for this reason refrained from using the word in the thesis unless contextually qualified however, the term warrants some discussion. The meaning of empowerment in relation to people with learning difficulties is credibly defined and explored by Ramcharan et al (1997). Empowerment embraces a constellation of factors including hearing the voices of people with learning difficulty; the use of the social model; autonomy and choice; the need to consider the position, support and voice of the family; community participation; and the need for formal rights models (Baldwin, 1997). Emancipation is associated with freedom from bondage, release from a controlling influences in both practical and attitudinal form e.g. to emancipate from prejudice or error. Emancipation has taken different forms over the years and associated with significant historical movements such as freedom from slavery and the rights of women to vote.

What is ‘enablement’?

The notion of enablement is used in this thesis as the opposite of disablement. The definition was derived via consideration of the language of the social model:

Impairment: lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body;

Disability: the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account or people who have physical impairments and thus excludes them from the mainstream of activities (UPIAS, 1976, pp.3-4).

A possible working definition of ‘enablement’ therefore may be as follows by switching the language of the social model definition of ‘disability’ from the negative to the positive:

Enablement is....the growth and expansion of opportunities which facilitate the participation of people with impairments in the life of the community on an equal level with others and the removal of physical and social barriers which impede this process.

It is this working definition of enablement, derived from the social model which is reiterated and utilised later on in this thesis.

3.2 Listening to the experts

Whilst people with physical disabilities were the architects of the social model of disability, it notable from the previous discussion that none of the theories discussed were actually formulated by people with learning difficulties. People with learning difficulties, along with people from minority ethnic groups, older people and mental health system users are markedly under-represented in disabled people's campaigns (Barnes & Mercer, 2003 p.130). There are various reasons for this not least of all the fact they are often segregated and the academic community has seldom included their writing (or even accessible versions produced by their advocates) in its journals. This section seeks to explore the issues facing young people using their voices and gleaned from collaborative writing and research projects which deal directly with them at the level of their personhood and experience of citizenship.

3.2.1 Defining a 'good life'

How do people with learning difficulties define a good life for themselves? What arrangements and support do they see as important? In his review of relevant research, Richardson (2000) identifies five factors which people with learning difficulties report to be important to the quality of community life as follows:

- The importance of maintaining and developing friendships, relationships and family ties;
- The need for structured approaches to domestic activities;
- The need for information about personal medication, health, finances and grievances;
- The need for support for self-advocacy and autonomy; and
- The need for structured days.

3.2.2 Exploring segregation: Anya Souza

Using a narrative approach, Souza (1997) assisted by Ramcharan takes us through some of the important parts of her life journey. Her experience illustrates some of the 'dimensions of oppression' as discussed above but also describes both her own and her mother's methods of resistance and their creativity. Souza, who has Down syndrome, discusses 'four separations' which occurred in her life (1997 p.4-10);

firstly the negative labelling by some medical staff at her birth and her mother's resistance via a commitment to locate her in the mainstream of society where she belonged. Secondly her early experience at a "Special School" where the nursery nurse did everything for her and the reflection that she "would not have learned anything" had she continued within that environment. Souza reflects "It doesn't matter that we might not learn in the same way as everybody else. What matters is being with everybody else." As her supporter and advocate, Souza's mother resisted this low aspiration and moved her from the school after the first term into a mainstream school. The 'third separation' may have occurred after primary school (it is often the case that children with learning difficulties mainstream until high school then enter Special School facilities) but she continued on into a mainstream Comprehensive school to gain qualifications until the age of 16 and planned to stay on into the sixth form. Souza's actual third separation occurred when a new Head took over and objected to a "mongol person" being at the school. Once again Souza's mother fought and went to the High Court who immediately overturned the Head's decision. Souza decided to leave school as the experience had soured and damaged her feeling of wellbeing in that environment. Returning to the special education system however, Souza notes that she was never taught anything of practical use at the school 'it was as if they were preparing students for a worthless life, because they felt that was all they could expect. This time Souza took her destiny into her own hands and wrote to a theatre company and entered a part-time drama course. The fourth possible separation Souza suggests is from the workplace, when she notes the disinterest of her school careers officer. With characteristic tenacity however, Souza has developed herself as a formidable public speaker and self advocate challenging the devaluation of people with Down syndrome via sterilisation and selective abortion (1997, p.12). Souza concludes, she is a "person first". Souza does more than resist oppression however, she is fighting for her rights and those of others; she is a humanitarian and an artist.

3.2.3 Self-advocacy and communication

Souza's skills raise this next topic; self advocacy is the civil rights movement led by people with learning difficulties and their supporters and is based on people with learning difficulties 'speaking up' for themselves (Longhurst, 1994). The concept of self advocacy also embraces the notion that people may call on support from others

but are ultimately entitled to be in control of their own lives, to define themselves (Souza, 1997; Williams, 2002). Aspis (1997) recalled that she always had an acute sense of justice from a young age. Although self-advocacy has its roots in the civil rights movements of the 1960s and 1970s, in many ways it is still a growing movement.

Aspis (1997) makes an important point, that effective self advocacy is both a personal issue for people with learning difficulties and a political and collective one helping to determine and shape the future social policy, and social structure. Many authors would agree with Aspis; writing about social exclusion and different levels of participation in society, Steinert (2003, p.45) identified that participation of this nature is participation in its highest form.

Self advocates stress the value of peer support from other people with learning difficulties at various times, drawing on each other's experience as a source of strength. In the process of de-institutionalisation for example self –advocate Martin (2006) noted that peer support is vital as only those have made the transition to community living truly understand the challenges and implications. However many funders and officials do not recognise this need. Martin laments that others believe that “they know best when sadly they do not really know at all” (2006, p.5).

There is a mounting body of evidence to support inclusive schooling and impact on communication ability. Buckley, Bird, Sacks & Archer (2006) report the findings of a large scale study of young people with Down syndrome involving two large cohorts of young people. Communication continued to improve through teenage years for the included children but not for those in special education classrooms. There were no significant differences in overall outcomes for daily living skills or socialisation. However, there were large significant gains in expressive language and literacy skills for those educated in mainstream classrooms. Conventional and/or fluent communicative skills are not accessible to all people with learning difficulties however.

Many people with learning difficulties have communication problems in that they do not employ communication techniques which many non-disabled people find easy to

understand. Once again, this aspect of personhood for many people with learning difficulties has been extensively medicalised. Many people with learning difficulties are 'dual-diagnosed' and given multiple labels. These can include such as 'dyspraxia' or 'speech disorder'. Various studies have estimated between 50% -78% of the population of adults with a learning difficulty in the UK would have some form of communication difficulty (Van der Gaag, 1998). The influence of the social model on later thinking has led to the view that the abilities of people with learning difficulties must be viewed within in a broader social and environmental context (Shakespeare & Watson, 1997). This requires that those who interact with and work alongside people with learning difficulties need to take more responsibility for changing and adapting their own communicative behaviour. In this vein, innovative work however has been undertaken however by activists such as Murray & Penman (1996, 2000). Murray in particular has developed a wide range of methods via which effective consultation can be undertaken with people who have no *conventional* communication (www.ibkinitiatives.com). Techniques such as 'photo-voice' and the use of software programs can augment the existing communication capacities of many people with learning difficulties. This movement indicates that professionals need to be encouraged to think of innovative ways of meeting the individual communication needs of people with learning difficulties rather than concluding that an individual cannot communicate.

3.2.4 Friendships and Relationships

Hughes, 1999 reported how relationships provide for practical support, emotional support, information, assistance with decision-making and opportunities to broaden existing support networks as well as safeguarding against loneliness, stress and psychological ill health (McVilly, Parmenter, Stancliffe, & Burton-Smith, 2005). Knox and Hickson (2001) in their research with four people with learning difficulties revealed that it was important to their informants that they enjoyed friendships with compatible people, the importance of enjoying a shared history and making time for regular contact with friends.

Burke (2005) heard from young people with learning difficulties about the importance of group activities, that these constitute spaces where social inclusion can occur and where a shared identity can develop in a safe environment.

3.2.5 Intellectual disability culture and identity

Walmsley and self-advocate Downer (1997 pp. 35-47) collaborated to elucidate the fact that “learning difficulty is not an all-encompassing identity” (p.39) and elaborate on the varied identities of people with learning difficulties and potential conflicts of self advocacy. They discuss the ‘gender-blindness’ of concepts of normalization such as SRV (Wolfensberger, 1983) and the way in which issues of race and culture have been unexplored in relation to people with learning difficulties (1997, p. 41). Downer expresses the reality that people embrace multiple and fluctuating identities of which gender, race and ethnicity exist as dynamic components. For example, Aspis (2008), herself Jewish, intimated that she felt disabled by Jewish society warning us not to assume that people with learning difficulties are automatically aligned with the norms and practices of their wider cultural/racial group.

Seldom reported is the reciprocal interest that people with learning difficulty have in the culture and identity of others around them. Japanese student, Aya Iwamoto (2005), who has Down syndrome, shared that she was studying French at University and is interested in studying French culture. Diverse social and psychological mechanisms and experiences help to form our identities, for example travelling, education and meeting different people. The lives of most people with learning difficulties are limited due to oppression, as previously discussed so they may have limited opportunities to develop, to take risks and find out more about themselves (Aspis, 1997). Linked to this is the point made by Borland & Ramcharan (1997) who examine the formation of self identity of people with learning difficulties and make an important point; “to what extent will carers and advocates be socialised and see the world in terms of limited options and couch their actions, advocacy and decision-making in terms of the limited options on offer?” a shrewd observation (Borland & Ramcharan, 1997, p.67).

Barriers to social inclusion identified by people with learning difficulties

In a study involving 68 people with learning difficulties, Abbot & McConkey (2006) found that barriers to social inclusion according to the group spanned a number of attitudinal and practical issues including accessible facilities and support staff practices. The group prioritised self advocacy, gaining appropriate skills and travel training as important in overcoming barriers. The overarching message here appears

to be that living in the community does not automatically mean one becomes socially included. There is a need to define social inclusion more clearly and look carefully at what social inclusion means to groups of 'excluded' people.

3.2.6 Learning difficulty in the context of the family

Families play a pivotal role in the lives of their sons and daughters who have a learning difficulty. The emotional and practical impacts of having a child with a disability have been the subject of much research. This is an area which has been explored by psychologists and sociologists alike. This following section is not an exhaustive review of material but serves to raise some issues which are pertinent to this thesis.

Specific challenges to families

Difficulties and stresses occur in all families however, it would be naïve and inconsiderate not to acknowledge additional challenges which may face families where a member of the family has a learning difficulty. Barnes (1997, p.74) lists some factors:

1. Coming to terms with having a disabled child.
2. The reduced attention available to siblings and the additional responsibilities which may be placed upon them.
3. The social isolation which may be experienced by the family as a whole and the restrictions which may be placed both on employment and recreational opportunities of parents (mothers in particular).
4. The continued support required and provided by mothers in particular beyond the period when they would expect to provide such support to their child.
5. The problems experienced by parents in gaining access to and negotiating appropriate support and respite services.
6. The financial costs of caring (Barnes, 1997 pp 74-75)

Other sources of concern expressed in literature written by Australian parents (Broughton & Broughton, 2005, p.131) stress that they always had the fear that

“people would take advantage” of their daughter Deb who has Down syndrome. The theme of ‘letting go’ runs throughout their story of her transition into adulthood and living independently. They also discuss worries about her future support and the difficulties of being able to plan with her for the future (p. 156) due to extreme shortages of accommodation for disabled people.

The fact that many people with learning difficulties are deeply embedded in families and amongst carers has prompted philosophical consideration. Kittay (2001), herself a philosopher and mother of a daughter with learning difficulties, considers that we should advocate for the ‘cared for’ by also advocating for the caregiver. Acknowledging the needs of the family or caregiver therefore requires an augmented model of social justice. In working and researching alongside people with learning difficulties therefore, it appears that we need to respect and work in partnership with those people who offer support.

Parental grief

Grief is defined as being ‘deep or intense sorrow or distress, especially at the death of someone’. The plethora of academic, professional and ‘grey’ literature in the area confirms that the grieving process is in itself a much debated and contested field (Perrault, 2007) and responses to loss are extremely diverse. But is the birth and presence of a person who has a disability a ‘loss’?

Social factors have impact on the emotions of parents of children who have learning difficulties with the impact of stigma and devaluing discourses (Green, 2007, p.161; McKeever & Miller, 2004, p.1178) being noted. Kaly (1998, pp. 19-20) shares some of the assumptions made about her ‘psychological responses’ as she became a parent to her son, Anthony, who has Down syndrome. She notes how a psychologist told her that she would have to go through a period of mourning before she could accept her ‘handicapped’ child. Kaly resolved that she would not waste any energy on embracing the notion of grief. It was also suggested that the effort she put into her son’s development emanated from a “sense of guilt” and later it was alleged that her aspirations for her son meant that she was “unable to accept his disability and its inherent limitations” (pp.19-20). Notable here is the certainty with which ‘others’ felt able to predict and pronounce on this mother’s emotions and behaviour and the

unspoken assumptions inherent in such statements where, in effect, the birth of a child with learning difficulty is automatically likened to a bereavement; one should have low expectations of a child with a learning difficulty; and helping them to reach their full potential is a sign of distorted thinking. These attitudes to disabled people and their families run deep in the veins of society. Brown (2007) in her study in relation to recurrent grief and mothers of adults with learning difficulties concludes that grief depends on a mixture of contextual and socio-political factors.

The impact of conceptions of disability upon parents

Many parents bring their children up in 'medicalised environments' where dominant discourses of labelling and deficit result in negative constructions of their children. Such environments are often devoid of the language of oppression, human rights and citizenship. Murray & Penman (1996) illustrated the impact of a different way of conceptualizing disability had on them as parents in the UK. They point to the influence of the social model of disability as a framework for understanding their experiences which gave them the "confidence to reject negative messages" about their disabled children (1996, p. xiii).

These interpretations lead us to see grief that may exist quite differently. Where grief is caused by the loss of a loved one and the validity of the love a parent feels for their child is constantly questioned. This leads us to query as to whether grief, amongst other issues, can sometimes ensue from a lack of exposure to more emancipatory models and understandings of disability.

Stigma

Stigma has been discussed at length in Chapter 2 of this thesis however, it is reiterated here as a phenomenon which can impact upon all the family and the ways in which the families need to emotionally support a loved one who has learning difficulties:

My family became a disability family. Because I had a disability they were shunned by the rest of our family and their friends." (Martin, self-advocate, 2006, p.126).

I know I am special. My family is always telling me that. They really help and encourage me to feel that I'm someone; I am not just a worthless thing. Lots of times in my life I have felt really worthless, no good." (Deb Broughton, in Broughton & Broughton, 2005, p. 149).

3.2.7 Strategies to enhance the inclusion of people with learning difficulties

Some strategies for social inclusion have been fairly widely supported by self-advocates and their relatives.

Person-Centred Thinking and Planning

Person Centred Planning (PCP) is said to have originated in North America in the 1960s and 1970s as a means of furthering the principle of Normalisation (O'Brien & O'Brien, 2002; Robertson & Emerson et al 2007) and it essentially describes a collection of approaches to organise and steer social change for people with disabilities with the assistance of their families and other allies (O'Brien & Lovett, 2004). Sanderson (2002) describes Person Centred Planning as:

A process of continual listening, and learning; focussed on what is important to someone now, and for the future; and acting upon this in alliance with their family and friends. It is not simply a collection of new techniques for planning to replace Individual Programme Planning. It is based on a completely different way of seeing and working with people with disabilities, which is fundamentally about sharing power and community inclusion (Sanderson, 2002, p.2).

Critical to PCP is that the 'focus' person with a disability is kept at the centre of the process. It aspires to construct a vision for a person's life as part of their community. Generally, the process involves: discovering and responding to concerns and wishes of the individual; understanding and exploring the central issues for the focus person; exploring and involving the focus person's informal social network and service/statutory resources in making and implementing a 'plan'; and reviewing and updating the plan with the focus person as necessary. PCP is said by some to be theoretically located in Normalisation theory however and a similar critique ensues for person centred planning.

The impact of Person-Centred Planning (PCP)

PCP has garnered wide support over the years and has formed a central plank of policy in relation to people with learning difficulties in the UK. The 2001 White Paper Valuing People (UK Dept of Health, 2001) proposed the extension of PCP to people with learning difficulties on an unprecedented scale. Mansell & Beadle-Brown (2004) raised concerns about a lack of empirical evidence to support such an initiative and whether such planning is necessarily followed by person centred action which would

actually evoke genuine social change and improvement. However a study by Robertson, Emerson, Hatton, Elliott & McIntosh et al. (2007) involving 93 participants over a two year period showed 'statistically significant' impacts such as increased friendships, family contact and community based activities for participants. This success however is clearly reliant upon a range of contextual factors. Barriers to the success of PCP have been identified in terms of a lack of adequate training and support for facilitators (Robertson et al, 2007) and organisational and system issues (Kilbane & McLean, 2008). The need for robust leadership in implementing PCP in organisations has been noted (Cambridge & Carnaby, 2005).

'Circles of Support' or 'Intentional Networks'

Circles of support are sometimes called 'circles of friends', 'teams of champions' and 'intentional networks'. They are generally intimately linked with Person Centred Planning but not always. The idea developed firstly in Canada and North America about 20 years ago. Circles are now being used in various countries and communities world-wide. They have been set up to support students with disabilities in mainstream schools for example, with some positive results.

McKnight (1990), previously discussed in Chapter 3, inspired the work of PLAN Canada (www.plan.ca), circles of support and other projects. Planned Lifetime Advocacy Networks (PLAN) Canada is perhaps the most longstanding and successful working example of this approach to community capacity building (www.plan.ca), accessed, 3rd June, 2009) in the area of disability. PLAN was conceptualised by a group of relatives of disabled people in Vancouver, Canada around 22 years ago. Over the years the organisation has developed and now offers families personal future planning, personal networks, advice and referral on government social services, service monitoring, advice on finance and assets management in relation to disabled relatives and also engages in systemic advocacy to help remove barriers which deter families from assisting their relatives in leading a secure and included lifestyle.

The PLAN model is unique in that it operates independently of state provision. Its framework has been adopted by the PIN (Planned Individual Networks) Project in Western Australia (<http://www.pin.org.au/> accessed 7th August, 2011).

The following extract from (Stevenson, 2009) gave an accessible explanation of a circle of support and its intent (Table 2):

Table 2. Explanation of a personal circle of support (Stevenson, 2009).

Members of the circle might include family members, friends, community members, and organizations. Paid 'care staff' may participate but it is generally the case that circle members are there purely because they care about the person and are there to support the person overcome barriers to participation, provide friendship and give moral support. It is a great opportunity to 'build capacity' in families and communities as people who want to support the focus person can be given a clear role in doing so by the person themselves.

It is usually a two-way street and circle members often get the opportunity for connections, opportunities and possibilities themselves. The circle makes its plans in consultation with the focus person and meets regularly to re-visit original plans, update and stay on-track with its activities.

Not everyone needs a circle of support, and even those who do take up the idea might just have the circle when they need one. Members can move in and out of the circle as the years go by, new members join and others leave as people often have changing life commitments which take them away from the circle temporarily or permanently (Adapted from Stevenson, 2009, Section 2 p.2).

One clear critique of this model is the same lack of theoretical 'core' that which can be levelled at the term 'social inclusion'. There is no guiding perspective on what actually constitutes 'disability' as identified in PCP. For example there is no clear perspective on how the focus person and circle members perceive and frame learning difficulty. The manner in which disability is perceived will influence how the circle responds to the wishes, hopes and dreams of the focus person.

3.3 Concluding remarks

This review of social theory reveals that Normalisation theory has tended to dominate thinking around policy and service provision for people with learning difficulties and its multiple achievements must be acknowledged. On a theoretical level however, it did not emanate from consultation with people who have learning difficulties. Normalisation/SRV does not identify oppression as an ongoing 'dynamic'

of learning difficulty and hence does not explicitly challenge individualised and medicalised assumptions made about people with learning difficulties. It places little emphasis on the human rights and voices of people with learning difficulties and fails to identify them as equal citizens with their own agenda for how they would wish to live their lives.

There appears to be some endorsement of the notion of social inclusion from people with learning difficulties and this is embedded in human rights frameworks. Various authors have identified problems in clearly defining what social inclusion actually means. There is scope for a clearer theoretical positioning of social inclusion and some 'unpacking' of the different 'dimensions of inclusion' in terms of what it may mean to people with learning difficulties themselves. In this respect it is allied to debates in Chapter 2 about the nature of social citizenship, a similarly nebulous and vague concept.

The social model, in contrast with the theory of Normalisation names 'disability' as social oppression. It is not a theory of disability, it is a political strategy, a tool via which to analyse and address social oppression. It seeks to "overturn" individualised and medicalised interpretations of disability. Questions can be raised in terms of the extent to which people with learning difficulties have had access to this model (Chappell, 1998) for understanding their oppression. Certainly, some parents of people with a learning difficulty have reportedly found its messages liberating (Murray & Penman, 1996, 2000). The political gains of the social model have been considerable to date (Barnes, 2001). Social model theorists have also taken the step of providing principles of EDR to ensure the integrity of research into the lives of disabled people. In contemplating research into the area of learning difficulty both questions and understandings can be applied to open up the possibility of new knowledge.

4. The Research context

The fact is inescapable that physical or intellectual disability (*learning difficulty*) today equates almost ineluctably with lesser opportunities, services, social inclusion and quality of life that the rest of the community takes for granted (Commonwealth of Australia, 2007, p. 99).

Having performed a wide-ranging review of literature in the area of learning difficulty, this section of the thesis locates the research project in its context within New South Wales, Australia. A brief history of relevant legislation, policy and provision is provided here. The Non-Government Disability Organisation within which the research took place (the 'Host Disability NGO') is described. Finally, this chapter documents the structure and journey of the Circles of Support project within which the Voices for Change doctoral research took place.

4.1 The legacy of de-institutionalisation

This study was concerned with young people living with their families in the home as opposed to those living more independently in the community. The effects of social segregation have been discussed in Chapter 2. It is noteworthy that in Australia, de-institutionalisation has been slow to occur compared to similar movements in North America and Europe (Young & Ashman, 2004). The process largely involved residential relocation of people with intellectual disability into geographically dispersed group homes with five or fewer residents, serviced by community support work (Ashman, Young, Roach & van Kraayenoord, 1991). De-institutionalisation globally has been largely based on the principle of normalisation (Nirje, 1995) which, as previously discussed, has dominated the development of services for people with learning difficulties in many western countries and continues to have impact in NSW. Unsurprisingly, the impact of de-institutionalisation has been largely positive for people with learning difficulties (Conroy, 1996; Lister, Brook & Bowler, 1995; Stancliffe & Abery, 1997). It has also triggered debate and activity at legislative, policy and practice levels about disability rights and social inclusion in NSW.

4.2 Relevant previous legislation in NSW, Australia

Cocks (1998) documented some of the major legislation impacting upon the human rights of people with learning disabilities in Australia and NSW in particular. Table 3 below lists some of the major developments.

Table 3. NSW legislative history

1948: UN Declaration of Human Rights
1956: formation of the peak advocacy body NSW Council for Learning Disability
1971: United Nations Declaration on the Rights of Mentally Retarded Persons, ratified by Australia.
1974: Federal government passed Handicapped Person's Assistance Act.
1975: United Nations Declaration on the Rights of Disabled Persons, ratified by Australia.
1977: NSW Anti-Discrimination Act made discrimination illegal in a wide range of circumstances; in 1981 extended to cover people with physical disability; and in 1982 to cover people with learning difficulty.
Source: Cocks, 1998 NSW Council for Intellectual Disability Website: http://www.nswcid.org.au/ accessed 23 rd February, 2010.

Since 1981, stimulated by the International Year of Disabled Persons and the work of disabled self-advocates, activists and their supporters, momentum has steadily gathered in Australia in favour of improving the rights, welfare and inclusion of disabled people in NSW (Roth, 2007). Roth cited the major policy developments as continuing de-institutionalisation; a disability service system based on rights and outcomes; a movement towards 'open employment' in the labour market; the passing of anti-discrimination legislation; policies to facilitate access to mainstream government services; and the standardisation of Federal/State responsibilities for disability services.

4.3 Current legislation and policy

4.3.1 The NSW Disability Services Act

The current legislation governing services for people in NSW is the 1993 Disability Services Act (NSW) which was based on the 1986 Federal Act (Disability Services Act). The objects of the Act are as follows:

- a) To ensure the provision of services necessary to enable persons with disabilities to achieve their maximum potential as members of the community
- b) To ensure the provisions of services that:
 - i. Further enable the integration of persons with disabilities in the community and complement services available generally to such persons in the community; and
 - ii. Enable persons with disabilities to achieve positive outcomes such as increased independence, employment opportunities and integration in the community; and
 - iii. are provided in ways that promote in the community a positive image of persons with disabilities and enhance their self esteem, and
- c) To ensure that the outcomes achieved by persons with disabilities by the provision of services for them are taken into account in the granting of financial assistance for the provision of such services, and
- d) To encourage innovation in the provision of services for persons with disabilities, and
- e) To achieve positive outcomes such as increased independence, employment opportunities and integration in the community, for persons with disabilities, and
- f) To ensure that designated services for persons with disabilities are developed and reviewed on a periodic basis through the use of forward plans.

People with disabilities, their families and advocates had considerable involvement in the development of the 1993 Act through the NSW Safeguards Coalition (Cocks, 1998) and the influence of the language of normalisation (Wolfensberger, 1972) can be detected in the 1993 Act (e.g. section b ii above).

4.3.2 The Disability Services Standards

The National Standards for Disability Services (FaHCSIA, 1993) were devised in the context of the Commonwealth/State Disability Agreement to flow from the provisions of the Commonwealth Disability Services Act 1986 and the NSW Disability Services

Act 1993. They elucidate the underlying philosophies of both Acts and set out both the rights of consumers and the responsibilities of service providers.

4.3.3 Current policy impacting on young adults with learning difficulties in NSW.

In May 2006, the NSW Government initiated a 10 year disability strategy named “Stronger Together”. The strategy promotes the strengthening of families, community inclusion for disabled people, and corresponding increases in system accountability and capacity (Roth, 2007). It has explored concepts and practices such as Person Centred Planning (ADHC, 2009) and endorses various other community capacity building initiatives. It is currently concerned with making adequate provision for people with learning difficulties who are supported by “ageing carers” (NSW Health Website, accessed 20th March 2011). The Australian context however is unique in many ways and presents diverse challenges for the implementation of approaches which originated elsewhere.

Five years on from its inception, “Stronger Together” is having some impact. There is evidence that some of the ‘service silos’ evident prior to its implementation are breaking down for people with learning difficulties (NSW Family Advocacy, 2010) and at the time of writing this thesis, the move towards individualised funding options for disabled people in NSW is in progress; a two day government summit was held in July 2011.

4.4 Post-school provision

For young disabled people with ‘moderate to high support needs’ there are two post school programs on offer: “Community Participation” and “Transition to Work”. Community Participation is aimed at young people who may need an alternative to open employment or further education. The programme seeks to engage young people in activities of their own choice within the community and lays emphasis on “skill building and activities to increase their independence”. Transition to Work comprises a two year programme focusing on the acquisition of skills needed for employment or further education and includes work placements and skill building to increase independence (ADHC, 2011 accessed 3rd March, 2011). Both of these post

school options were current throughout the time the Circle of Support Project took place.

4.5 The location of the doctoral research project

The working title of the doctoral research was 'Voices for Change'. In order to provide clarity for the reader, Figure 2 locates the 'Voices for Change' research within the Circle of Support Project which was hosted by the Host Disability NGO.

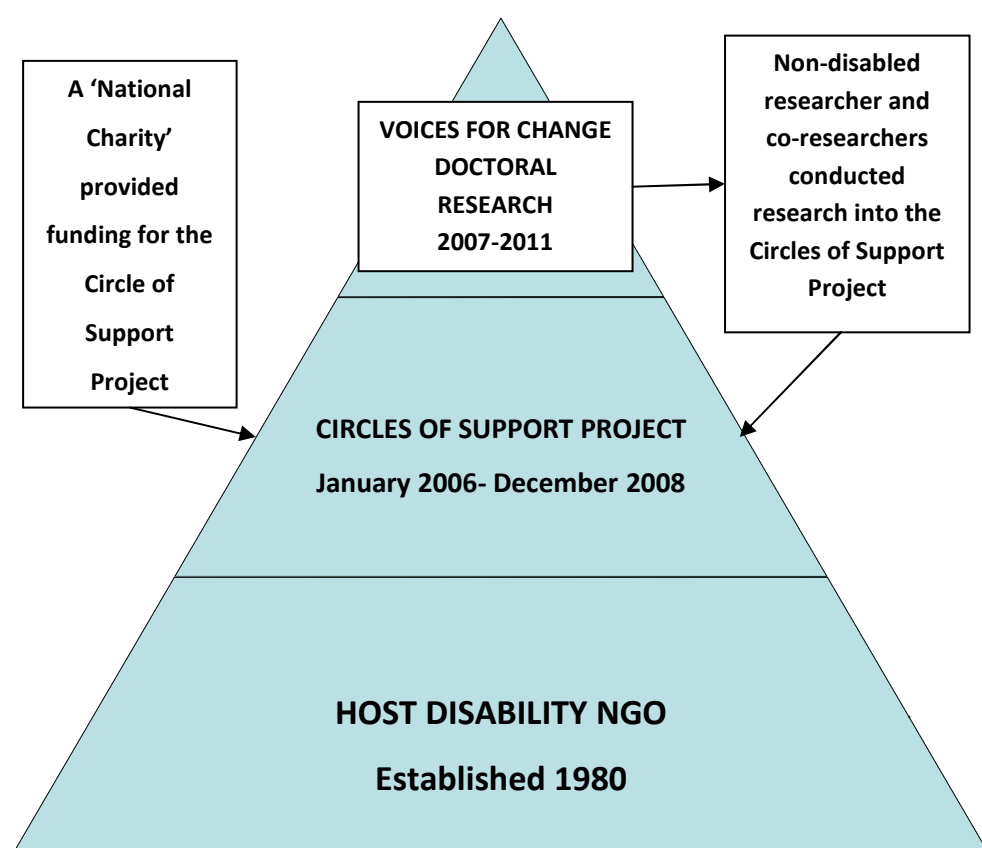


Figure 2. Diagram to illustrate the location and timeframes of the Voices for Change.

4.5 The Host Disability NGO

The Host Disability NGO is the Non-Government Organisation (NGO) with registered charity status, within which the Circle of Support Project took place. This is a very brief description of the organisation in order to preserve confidentiality. The Host Disability NGO was established around 1980 by parents who had sons or daughters who have Down syndrome. The initial motivation for setting up the NGO was to offer

parents support and its brief has broadened as the organisation has grown. Currently around 70-80% of the staff group are parents. The Host Disability NGO aims to support children and adults with Down syndrome and their families. All its projects are, to an extent, dependent on the availability of funding. Within the timeframe of the Circles of Support Project, the Host Disability NGO ran a range of services and projects funded via membership contributions, charitable contributions and grants. It provides information to the public about Down syndrome from pre-natal diagnosis through to late adulthood, telephone and direct support from staff, opportunities for families to meet and receive mutual support and state-wide educational seminar programs for parents and professionals. It holds a large library of resources including books and DVDs. Prior to the advent of the Circle of Support Project, the major resource with regard to participation for adults who have Down syndrome was their Young People's Club for people with Down syndrome aged 18-25. The Young People's Club is described on the Host Disability NGO website as a "social programme to enable young adults with Down syndrome to establish and maintain friendships with peers".

4.6 The Circles of Support Project Story: 2006- 2008

The following section describes the Circle of Support Project within which the Voices for Change doctoral research took place. The Circles of Support Project itself was crafted via close consultation with young people aged 18-25 who were members of the Young People's Club.

Following an application from the Young People's Club coordinator, in 2005 a National Charity funded consultation work with club members with the aim of setting up a project which might benefit this age group in the future.

Consulting with the young people about the Circles of Support Project

The Young People's Club coordinator organised a camp in rural NSW and about 25 young people with Down syndrome aged between 18 and 25 years went off to camp to think and talk. The camp leaders set exercises and questions for the young people which encouraged them to consider and articulate what they wanted their lives to be like in the future. One such exercise was: "Imagine you are 30 years old, write a letter to a friend and tell them what your life is like now."

Some of the young people wrote their own letters, others were facilitated to do so. In their letters, young people on the camp described to their 'friends' a variety of life goals and lifestyles. They would be playwrights and actors, office workers, chefs. They would go for nights out regularly to the cinema and the theatre. They would have their own home or shared a home with their friends. They would invite friends over for meals or go out to the city with them; they would have interesting jobs in the city. Some would have a partner and children. They would lead fit and healthy lifestyles. In other words, the young people on camp had the kinds of dreams and goals for their lives akin to those of any other group of young people. This summarising statement became the leading objective of the future project:

[We want] "To do stuff in our life like everybody else, -like getting a job, moving out, seeing friends, going out, having a relationship and helping others" (Young People's Club, 2005).

The young people also recognised the need for moral and practical support in achieving their life goals. The consultation process identified family members, friends, community members and agencies as being potentially key supports and hence the concept of the Circle of Support (or what was initially called a "Team of Champions") was adopted in the construction of the project model.

The findings of the consultation were collated and the coordinator of the Young People's Club developed a multi-media presentation which enabled the young people to express their views first hand to the National Charity. Funding for a three year project was agreed by the end of 2005.

The initial Circles of Support project model

The initial Circles of Support Project was subject to constant review and modification in line with what activity worked in the project in favour of the young people and what did not. There was an evolutionary vision for the project which was grounded in a practical sense but was not 'framed' academically as such. The objectives underpinning the project, and stated in the initial project plan agreed between the National Charity and the Host Disability NGO were:

- i. To bring together a steering group made of young people with Down syndrome, researchers and workers from the disability sector, family members and an employed coordinator to action the initiative.
- ii. To give young people with Down syndrome a chance to think and talk about their future and come up with personal goals.
- iii. To bring together a team of champions around each person involved, that can support the person to reach their goals.
- iv. To support the teams through training, facilitation, ongoing contact and by providing relevant information.
- v. To ensure the goals identified by the young person with Down syndrome remain the focus of the work of each team
- vi. To provide the opportunity for young people involved in the project to give and receive support from each other through regular contact.
- vii. To provide the opportunity for team members (champions) to network and problem solve together through regular contact.
- viii. For the program to achieve sustainability by the end of three years.
- ix. For information gathered through Teams to be passed on to peak bodies for use in systemic advocacy.

The initial basic model for the Circle of Support Project is outlined in Figure 3.

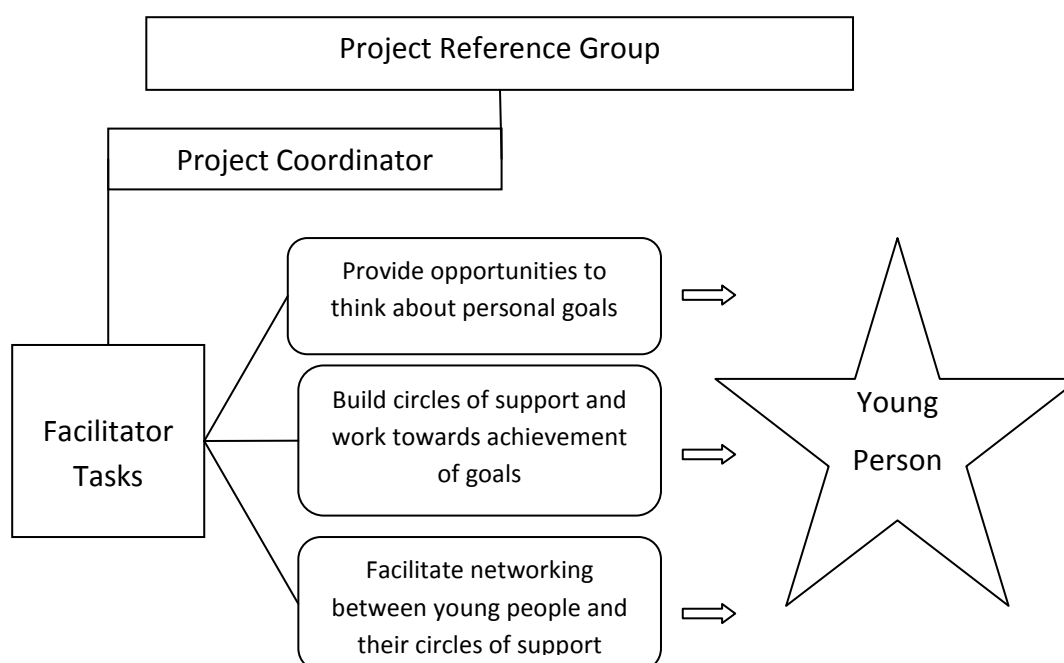


Figure 3. Outline of the initial Circle of Support model structure and objectives

The Circles of Support Project Reference Group

A reference group was set up for the Circles of Support Project in 2005 initially at its planning stage. The reference group consisted of a team of people with an interest in the project ideas, a vision for the project and some 'expert advice' to offer. The reference group consisted of the CEO of the Host Disability NGO, the project coordinator, parents of young adults with Down syndrome, the Team Voice (to be explained later) and housing, education, employment and Disability Rights specialists and a representative of the National Charity who funded the Circles of Support Project.

I arrived in NSW from the UK in July 2005 and applied for the position of coordinator in January 2006. For the coordinator interviews, a panel of parents, Young People's Club coordinators and young adults with Down syndrome was convened. I was appointed in February 2006. My job was to recruit participants, train and support project staff and coordinate the project in line with the strategic plan, reviewing the plan as we progressed.

Selecting Circle of Support Project Participants

In March 2006 a flyer was placed in Host Disability NGO newsletter advertising for participants for the project. I sent out accessible information and a simple application form to those people who contacted me. We had 13 applicants in 2006, a mixture of young men and women. A young woman with Down syndrome helped me to select the first group of 8 participants. We selected a balance of young men and women in the older age group. Younger applicants would still fall in the age range for the project in the next year and we did not want anyone to miss out on the opportunity to be part of the project. We also considered applicants support needs and who might benefit from the project.

I visited each of the participants and their families to introduce myself. At this stage there was more dialogue about the aims and objectives of the Circles of Support project and I was able to check that they were happy to make the commitment to being in the project.

Employing and training Team Coaches

By the end of April 2006 we had also appointed our first 4 'Team Coaches'. This was the term we used as an alternative to 'facilitators' as it was easier to pronounce for some people. At every interview for the Team Coaches a young person with Down syndrome sat on the panel. We prepared carefully for each interview and asked questions using a 'case scenario' which was given to each candidate thirty minutes before the interview. Team Coaches employed had a variety of backgrounds; some had tertiary qualifications and/or experience in the disability field, others not so. It was initially decided that each Team Coach would work with two participants and a team of four coaches, one team voice and the coordinator would make for a good sized project staff group.

In June 2006, I arranged training for the Team Coaches in "Working with families where a son or daughter has Down syndrome" provided by parents from the Host Disability NGO. Also arranged was a short course about "Disability and sexuality" from the Sydney Family Planning Association and one in "Disability Rights and Choices" delivered by Chief Executive Officer of People with Disabilities Australia.

I ran a workshop on professional ethics and 'duty of care' for the Team Coaches to confirm that they could practice in an informed and safe way with the young people and stay safe themselves.

We also bought some books on person-centred planning methods for the Team Coaches to read for inspiration. To assist their continuing development, all project staff had access to the Host Disability NGO library which is well-stocked with books and DVDs and an excellent source of information about Down syndrome and learning difficulty.

The Team Voice

In July 2006 we recruited our Team Voice, Andrew, a young man who has Down syndrome. His level of involvement was initially set at two hours paid employment each week. His role was initially to work with myself (coordinator) and ensure that the views of the project participants were represented on the project reference group. Andrew embraced the role with great enthusiasm and he and I formed a

positive working relationship. Andrew (who also had a job in a sheltered workshop and his own music business) generously gave a day a week of his time to working with the project and attended and hosted nearly all the monthly workshops held once a month on Saturday mornings. He used his IT skills to write reports and newsletters for the project and attended progress reviews with participants and families. Andrew chose to adopt a high profile becoming part of the leadership of the Circles of Support project and was a finalist in the 2007 Disability Awards of Australia as a result of his significant work in the disability field.

Matching participants with Team Coaches

Also by July 2006, the Team Coaches had been matched with participants and went out to meet them. All our participants came from the same Metropolitan area as we wanted to make sure that they were in a close enough radius of each other to be able to meet as a group on a regular basis (as required in the initial plan) and hopefully form a kind of 'project community'.

Initiating a project manual

I developed a basic manual as a resource for Team Coaches using the original strategic plan for the project. It was also influenced by person centred planning which I had gained interest in during my time working with young disabled people in the UK. The manual became a 'work in progress' and developed as 'learnings' from the Circle of Support Project and 'Voices for Change' research emerged.

Project workshops and meetings

From September 2006, regular monthly half day workshops were established for participants to get together and share their experiences. We met at a local community social club which was near to public transport so convenient for all to attend. Some of the young people decided to travel train with their Team Coaches so that they could travel by themselves to the meetings. At the first meetings the young people told each other about their lives, their dreams and their personal goals. At subsequent meetings we ran 'developmental' sessions in line with what they wanted to work on. The subject matter included relationship skills, nutrition, money management and disability rights. Some of the workshops were led by specialists in the area, according to budget.

Team Coaches, met with myself and the Team Voice, Andrew, once per month at our offices for team meetings to update and share with each other about how things were progressing in the project. Similarly, I also met with the project reference group on a monthly basis (for the first 18 months or so), reporting to them on progress and receiving their expertise and guidance when needed.

The ‘ripple effect’

There is a ripple effect, it just keeps growing...

(Emerald, Parent)

Over the next 18 months the Circle of Support Project blossomed. Most importantly, the young people took ‘ownership’ of the project. They felt from the outset that the project and the opportunities it presented were *theirs*. Parents were also key people in the process and gave enormous support to their sons and daughters to participate. Participants showed energy and commitment in achieving their goals and most stayed the course of the entire 18 months working with Team Coaches. There were some slight changes in the Team Coach group as people came and went according to other commitments but we retained a core staff of 4 Team Coaches at all times over the project’s 3 year duration. Andrew remained as the Team Voice for the duration of the project and we formed a close working relationship.

It is important to note that although the project is here called the “Circles of Support” Project in accordance with the initial plan, as an entity the project produced many processes. Some families enthusiastically embraced the actual “circle of support” idea and went into recruiting members for their circle very quickly, others just stayed with a ‘family circle’. Some young people decided they did not want a circle at all but wanted to work with their Team Coach to gain skills and be involved in the workshops and other activities which developed within the project.

Refining the Circle of Support Project Model

The ‘Circles of Support’ project was responsive to the wishes and needs of the young people and their families. There was a good deal of flexibility built into the planning. Reports were produced for the project every 6 months along with acquittals for the funds spent. As the project plan slowly unfolded, we were able to continuously modify the initial ‘model’ of the project as we went along according to

what actually worked for each family. In doing this we were given the opportunity to draw closer and closer to the kind of support project which would most help our young people develop, make connections in the community and achieve some of their goals. The final model of the project, informed by the Voices for Change doctoral research, I have named the Citizen Engagement Project. The new model is explicated in Chapter 9.

Making the DVD

This was the first 'high engagement' disability project funded by the National Charity. In late 2006, they had expressed a keen interest in funding some published work from the project. The idea being that we were learning a good deal from this experience and this could be shared to help other groups and individuals. A submission was made to the National Funding Body for funds to produce a DVD and manual about the project. We were successful in our submission for core funding and went on to gain more grants from various other sources.

An experienced film producer was employed along with two other young film-makers. We worked with the producer in writing submissions to raise further funds for the project DVD from charities and state grant bodies. Filming began on the project DVD in Spring 2007. This experience enriched and energised the project and the young people enjoyed the film-making workshops and working with a Sydney based 'hip hop' DJ to make the DVD sound-track. One participant wrote a song which was recorded by a group of participants free of charge at the University of Sydney Conservatorium recording studio. A number of the participants each demonstrated their diverse abilities and shared some of their life experiences, views and opinions on film.

In 2007 another group of 8 young people were recruited. Team Coaches began a similar process with our new participants. The first group of participants continued to attend the monthly workshops and acted as mentors to the new participants.

Through the making of the DVD, one of the Circle of Support Project participants was invited to make a short film, with a part especially written for him by one of the

young film-makers. The short film they made together won Best Film and Best Actor at an international short film festival.

The 'Voices for Change' research

The 'Voices for Change' doctoral research added theoretical and practical dimensions to the project. These will be fully described in the chapters which follow.

Endings and new beginnings

In 2008, work on the project was consolidated and by the end of the year I needed to increase my earnings to meet our family living costs so I moved on to other projects. I retained my involvement with the 'Voices for Change' research group and with the many friends I made whilst working at the Host Disability NGO.

Although funding for the Circles of Support Project from the National Charity concluded at the end of 2008, a large fund-raising event held by the Host Disability NGO raised enough funds to run the project for a further year under a new coordinator. Funding lapsed for a short time in 2010. Further funding was obtained in 2011 to employ Team Coaches in a different region of NSW to work with participants there.

In 2009 the manual and DVD were launched at the Sydney Opera House (who, after minimal persuasion gave us a room free of charge!). As well as families, an array of individuals and organisations from the NSW disability sector were invited to see the film including staff of a NSW state disability services provider. Inspired by the Circles of Support Project, the state disability services provider, in partnership with the Host Disability NGO and NGO service providers, launched a state-wide action research style initiative in 2010. The aim is to adapt the model to meet the needs of people with learning difficulties in families where caregivers are ageing. It is an ambitious but none-the-less exciting venture in which I am currently involved.

At the time of writing this thesis over 25 young people with Down syndrome have been involved with the Circles of Support Project and all participants have achieved at least some of their goals.

4.4 Concluding remarks

This chapter serves to describe the setting for the Voices for Change research.

Speaking as a practitioner and the first coordinator of the Circle of Support Project, establishing the project was exhilarating but not unproblematic. I had to familiarise myself rapidly with the services and cultures around learning difficulty in NSW. Although there had been comprehensive consultation with young people with Down syndrome in the planning of the Circles of Support Project, there had been little focussed consultation with parents. This lack of early involvement in planning led to some anxieties about the motives of the project and what it was setting out to achieve. Some parents expressed concern that the project was going to prematurely propel their son or daughter into a romantic relationship or into leaving the family home for example. Reassurance needed to be given to the contrary. This issue highlights the importance of holistic consulting with families at the outset of new initiatives and throughout their course.

Notably, no formal assessment tools or formats were ever used in the Circle of Support Project. Information about participants and families emerged in terms of what was relevant to the process of identifying and achieving goals set by the participants. Consultation, creative action and review were processes of paramount importance in bringing about participation and change.

On a wider level, the social inclusion policy framework, a federal initiative implemented by the Rudd federal government in 2007 (Buckmaster & Thomas, 2009) and the NSW Department of Ageing, Disability and Home Care (ADHC) “Stronger Together” policy agenda for disabled people in NSW initiated in 2006 (Roth, 2007) have followed roughly the timeframe of the Circles of Support Project from its inception. Research into service models which seek to promote social inclusion was, and continues to be therefore valuable in informing the practical implementation of such policies.

5. Methodology

Having described the context of this research and its relationship with the Circles of Support Project, I now explicate the philosophy underpinning the conduct of inquiry into the 'Voices for Change' doctoral research.

The methodology of disability research and, in particular, research involving people with a learning difficulty, raises vital philosophical, political, and practical issues. The literature review has established thus far that people with learning difficulties have a strong and pervasive history of oppression which has persistently ignored their voices and violated their human rights. Their status as citizens with equal rights has historically been regularly compromised or overlooked altogether (Kittay, 2001). These understandings strongly suggest that the methodologies which underpin research should identify social oppression, must be actively anti-oppressive and promote human rights. As a non-disabled researcher seeking to involve people with learning difficulties in research with and about them I needed to firmly ground the research methodology in a cogent and explicit theoretical framework.

This chapter draws on the review of literature in Chapters 2 and 3 to construct the theoretical framework of the research method that I use. My research framework utilises a modified social model of disability. The modification process begins by contextualising the social model within a human rights framework. I closely adhere to the principles set out in the principles of Emancipatory Disability Research (EDR) model; principles defined by various groups and authors within the disability movement which are intended to ensure the integrity of disability research design and practice. It is argued that these principles are commensurate with the tenets underpinning the United Nations Convention on the Rights of Persons with Disabilities (2008). EDR principles are discussed in relation to other types of 'anti-oppressive' research, which have been undertaken alongside people with learning difficulties. The positioning of myself as the 'activist researcher' is explored within this chapter. I then discuss some relevant studies as exemplars of good research practice and the variety of messages they have provided to inform the approach to this research project.

The participatory research method is described including the aims of the research as articulated via the research questions. Ethics are carefully considered, the sampling strategy from the Circles of Support participants, data collection and data analysis methods. Finally, I discuss the criteria for quality in qualitative research.

It is important to note that research participants in the Voices for Change doctoral research included young people who have Down syndrome, their parents and project staff. Although not all of the research participants therefore carried “learning difficulty” labels, exploring methodology and ethics in some depth enabled the development of an approach which accommodated all the research participants.

5.1 The theoretical framework of the research

5.1.1 Introduction

The Circles of Support Model initiated by the Host Disability NGO was in good faith conceived of as an action research model. The action was provided by the Host Disability NGO in consultation with the young people. In the spirit of this initial conception of the Circles of Support project evaluation, my doctoral research set out to be participatory. As my thinking progressed I realised that the social model demanded the use of emancipatory research which would lead to action or ‘praxis’. It is clear that participatory action research as described by Freire (1970) in “Pedagogy of the Oppressed” is intended to be emancipatory and socially transformative. Human rights however are of elemental importance to the framework of this research.

5.1.2 The rights of People with a learning difficulty to be researchers

As the foundation of the social work task (AASW Code of Conduct, 2010), human rights are fundamental to the theory, practice and findings of this research. Rather than ask the question: “Can I research people with a learning difficulty?” it is better to start with a justification as to “Why?” As discussed in Chapter 2, all people have human rights. The United Nations Universal Declaration of Human Rights (1948) is designed to benchmark standards, entitlements and codes of behaviour by which we should be treated as human beings. Human rights do not deny individual and cultural differences; rather, they assert inherent entitlements due to all of us, regardless of

such differences, by mere fact that we are human. Our basic Rights, therefore, should be unassailable in the face of cultural and individual differences. What logically follows is less frequently discussed but equally as important:

A Human Rights framework bestows a means of perceiving and relating to other people which dignifies us as humane and requires us to value others as equal to ourselves, regardless of any mutual differences (Stevenson, 2010, p.37).

The universalism of human rights means that rights advocacy for one person's human rights is, in effect, advocacy for everyone's human rights and vice versa.

5.1.3 Human rights: a vital discourse

Human rights have emerged by means of a variety of pathways, however the grounding of human rights is of obvious ongoing academic relevance and is of great significance to this thesis. As discussed in Chapter 2, Post-Kantian philosophers such as Gewirth (1981, 1996) use deductive logic to cogently argue that 'absolute rights' do exist. Gewirth argues that certain basic moral rights, namely, 'the rights to freedom and well-being' are necessary for human agency. Such absolute rights cannot be culturally 'relative' and are non-negotiable. Other authors such as Ife (2001) do not wholly support this position and hold that there are not fixed and will alter over time. For the purposes of this methodology however, I applied the United Nations Universal Declaration of Human Rights (1948) and the United Nations Convention of the Rights of Persons with Disabilities (CRPD 2008). I hold that such rights are global, universal, enduring and, ideally, should underpin the agency of all people (with or without a disability) in all social spheres and activities, including research.

The assertion of the 'non-negotiability' and reciprocity of basic human rights is critical, particularly for disadvantaged and marginalised social groups (Doyal & Gough, 1991). The United Nations Convention on the Rights of Persons with Disabilities confers no new Rights but was passed due to the delayed recognition of the human rights of people with disabilities relative to other disadvantaged groups. The 'guiding principles' of the Convention emphasise respect for dignity, autonomy, independence of persons, non-discrimination, full participation and inclusion in

society, respect for difference and acceptance of human diversity, equality of opportunity, accessibility, gender equality, respect for the right of children with disabilities to preserve their identities and for their 'evolving capacities' to be respected (UN Enable website, Guiding Principles of the Convention, accessed 20th June, 2011).

The role of research in the promotion of human rights

It is evident that the existence of human and civil rights alone cannot ensure inclusion and equality for people with learning difficulties. Whilst we might try to address their social disadvantage through legislation, regulation and positive rights (positive discrimination), this tends to progress no further than providing an agenda aimed at meeting the basic needs of people with a learning difficulty and protecting them from harm (Young & Quibell, 2000). A variety of 'enabling' strategies are required to progress inclusion. Arguably, one avenue of determining the best strategies to use is to involve people with a learning difficulty about matters which concern them through research.

5.1.4 The positioning of the 'activist' social researcher

If you come here to help me, you're wasting your time. If you come here because your liberation is bound up with mine, then let's work together.

Lilla Watson

Australian Aboriginal Organiser, Academic and Visual Artist

Having recognised that Rights advocacy is not about charity or benevolence but legitimate activity designed to preserve the dignity of humanity, we need to ask; "What makes a human rights activist researcher?" What kind of researcher is oriented towards action and 'praxis'? I have established that a human rights perspective orients disability researchers towards an activist approach; but, how do we further define this position and how do we determine a grounded and credible model of engagement?

Healy (1996, pp. 2-3) offers a useful starting point when she explicates the concept of 'activist social work' and identifies four defining strategies for 'change orientated' social work. My additions (in italics) render this typology congruent with features of the "activist researcher":

- a) A commitment to standing alongside oppressed and impoverished population (Leonard, 1994, p.17).
- b) The establishment of practice relations in which workers/researchers and clients/ *co-researchers* work as co-participants engaged with and still distinct from one another (Fine, 1992, p. 220).
- c) The worker/*researcher* adopts a self-reflexive and critical stance (Fine, 1992, p. 220) in that the worker/*researcher* is alert to those barriers within the practice/*research* context and beyond that which serve to disadvantage clients/*co-researchers* and deny possibilities for dialogue between workers/*researchers* and participants/*co-researchers* (Leonard, 1994, pp.10-15).
- d) A commitment to the 'study of change, the move towards change and the provocation of change' (Fine, 1992, p. 220). In particular this involves an orientation to the transformation of those processes and structures that perpetuate domination and exploitation (Leonard, 1994, p.17; Yeatman, 1994, p. 9).

Healy's third point concerning 'disadvantaging barriers' leads the non-disabled researcher strongly in the direction of the social model of disability, (UPIAS, 1976; Oliver, 1990) and the emancipatory disability research paradigm (Oliver, 1992; Barnes, 2002), mentioned in Chapter 3, both of which have been largely developed by people with a disability and have enormous credibility and impact globally.

5.1.5 Linking human rights and the social model of disability

At this point it is instructive to consider the possible theoretical convergences and dissonances of the CRPD (2008) and the Social Model of disability (UPIAS, 1976; Finkelstein, 1980; Oliver, 1983; 1990; 1996) which has been described and critiqued in Chapter 2. A major strength of the social model is its proven political efficacy (Barnes, 2001). It provides a strategic viewpoint on disability which can drive social change.

Whilst writers such as Finkelstein (2002) have asserted that the social model is not a rights-based model, arguably one underlying epistemological assumption of the social model of disability, or certainly its strategic use, is that all people, including people with impairments, are complete people, of equal value as human beings and have human rights. This universalistic presupposition is essential to the emancipatory project of the social model otherwise there would be no basis for resistance against 'disabling' cultures and practices, or reason to assert that discrimination on the grounds of impairment is unacceptable. The fact that the social model has been so widely recognised and applied also resonates with global 'civil rights' agendas. Its influence is again evidenced in the United Nations CRPD (2008) which supports a global 'paradigm shift' in attitudes and approaches to people with disabilities and advocates:

[a movement away from] viewing persons with disabilities as "objects" of charity, medical treatment and social protection towards viewing persons with disabilities as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on free and informed consent as well as being active members of society (UN Enable website, Convention on the Rights of Persons with Disabilities section, para. 2).

Oliver (2004) described the social model as a practical tool and as such it has proved an important vector for the realisation of human rights on many levels. The UN Convention (2008) similarly declares itself as a "Human Rights instrument with an explicit, social development dimension" (UN Enable website, The Convention in Brief section, para. 3 accessed, 7th June 2010). Though academic debate will no doubt continue, for an activist researcher, there is little tangible to gain from a 'disarticulation' of the social model from human rights advocacy. Authors in the field of learning difficulty however have noted that it has remained a largely untapped resource in the field of learning difficulty (Chappell, 1998). This is particularly the case in Australia which, whilst it has embraced 'social models' of disability, has been slow to embrace the UPIAS definition of the social model in respect of disability. Use of this model with regards to research in the Australian context is therefore warranted.

5.1.6 Principles of Emancipatory Disability Research

The social model forms an important cornerstone of Emancipatory Disability Research (EDR), which began to develop in the 1980s as researchers with a disability and non-disabled researchers began to draw on people's own experiences of disability to illustrate the complexity of the process of disablement with reference to environmental and social forces (Barnes, 2001). This research paradigm emerged alongside the research and writing of critical theorists, black writers and feminists who aligned themselves with oppressed groups (Truman, Mertens, & Humphries, 2000). Different forms of research based around social power-sharing such as Participatory Action Research (Freire, 1970; Fals-Borda & Rahman, 1991) gathered momentum and credibility. It is of note once more that Healy's (1996) typology is reflected in the social/historical preconditions of this paradigm, linking oppression and activist workers, researchers and writers to the development of liberationist research models.

The Emancipatory Disability Research paradigm (EDR) was identified in 1991 in a set of seminars funded by the Rowntree Foundation. Presentations from the seminars were published in the *Disability, Handicap and Society* (now 'Disability and Society'), Special Issue; 'Research Disability' 1992 (C. Barnes, personal communication, 21st October 2009). Barnes (2002) reiterated seven emergent core principles which are summarised in Table 4.

Table 4. Principles of Emancipatory Disability Research (Barnes, 2001)

1. **Control:** Unlike conventional approaches, (EDR) must fully involve disabled people throughout the research process. Non-disabled researchers may be involved but they must be accountable throughout the entire research process to a research advisory group or committee controlled and run by disabled people.
2. **Accountability:** Research processes and practices must be open and explained to research participants and participating organisations. The findings and implications of research must be disseminated in appropriate guides to all relevant audiences, including disabled people.
3. **Practical outcomes:** EDR must attempt to leave disabled people in a better position to confront the disabling barriers in their lives and must not exploit their experiences for career benefits to researchers. EDR should produce knowledge, understanding and information that will have some meaningful practical outcomes for disabled people in their struggles to overcome the barriers they face in disabling societies.
4. **The social model of disability:** EDR should adhere to the social model of disability. This reflects the growing demand by disabled people for a more holistic approach to the problems commonly associated with disability. EDR focuses on the economic, environmental and cultural barriers encountered by disabled people and their families.
5. **The 'problem of objectivity' and need for methodological rigour:** Researchers must ensure that they openly state their ontological and epistemological position and their choice of research methodology and data collection strategies must be logical, rigorous and open to public and academic scrutiny.
6. **The choice of methods:** Whilst EDR has generally been associated with qualitative rather than quantitative data collection strategies; the choice of methods must adequately reflect the needs of the project concerned and the wishes of disabled people.
7. **The Role of experience:** Discussions of disabled people's experiences, narratives and stories should be couched firmly within an environmental and cultural context in order to highlight the disabling consequences of societies increasingly organised around the needs of a mythical, affluent non-disabled majority (Adapted from Barnes, 2001; British Council Of Disabled People website, 2007).

Barnes (2001) explains EDR as a dynamic process so there is no suggestion that the EDR model is written on a tablet of stone and cannot be further developed. Fundamentally, however, researchers must explicitly represent the politics and practice of their research activity. Critically, disability research methods need to be reconstructed to bring about a shift in the 'social relations' of disability research

production and not replicate and perpetuate the oppression of people with a disability (Oliver, 1998).

5.1.7 EDR and other forms of anti-oppressive research

There are a number of 'denominations' of disability research which place emphasis on the active involvement of disabled people. As a consequence, a substantial amount of blurring and crossover occurs between each. Added to this, each research paradigm is open to some interpretation and development as the contexts within which research projects are conducted are, of course, diverse. Nind (2010) explained that three terms are currently employed to describe this field of research in relation to learning difficulty: 'Participatory Research' which "actively involves people with learning difficulties in decision-making and conduct of research"; 'Emancipatory Research' "which is under the full control of people with learning difficulties" and "Inclusive Research" which is based on "continuity and reciprocity" between these two paradigms. Walmsley & Johnson (2003 p.16) identified three features of Inclusive Research: "it must address issues which really matter to people with learning disabilities; it must access and represent their views and experiences; and reflect that people with learning disabilities need to be treated with respect by the research community." Further to this, the term "collaborative research" has been used by Knox, Mok & Parmenter (2000) to describe research which is based on a partnership consisting of different skills and perspectives but equal relationships within the research enterprise.

The principles of EDR are quite specific however and in line with the ideological agenda of the social model of disability (Chappell, 2000). For example, EDR requires any research undertaken to be of tangible benefit to disabled people, researchers need to use the social model of disability and researchers must be accountable and openly state their epistemological position. Fundamentally it was developed by people who identify as 'disabled' and arguably, are more conversant with the mechanisms of social oppression in relation to impairment than non-disabled people. In terms of the conduct of inquiry, EDR stipulates that methods need to be appropriate to the task and in line with the wishes of disabled people. These principles do not necessarily therefore mean that qualitative methods are always appropriate or are required, neither are participatory approaches. For example, a

group of disabled researchers who use wheelchairs may wish to investigate issues of access amongst other wheelchair users on a large scale in order to obtain information which strengthens their campaign for improved access to public buildings in NSW. They could decide that an online questionnaire survey which allows them to harvest data from a large number of people and interpret lots of statistical information very rapidly could be the best way forward. This is not a participatory/qualitative method but could still adhere to the principles of EDR.

Inclusive, collaborative and participatory forms of disability research may be governed by different principles and theoretical perspectives to those of EDR; they may or may not use the social model of disability for example. These forms of research may sometimes constitute 'experiential' research which, although not without great merit, may not actively seek to yield political outcomes (Finkelstein, 2002). Taken at 'face value', however, EDR presents 'compliance' issues for independent research production and control by many people who have a learning difficulty and also for non-disabled researchers seeking to involve people with a learning difficulty.

5.1.8 Adapting the EDR model

Arguably, the answer to these problems is not to exclude people with learning difficulties from EDR nor attempt to abandon the principles of EDR. The main progenitor of EDR, the social model of disability, was first developed by people with physical disabilities. Disabling cultures have conspired to give articulate people with a physical disability a stronger voice in its creation. Very different 'impairment effects' (Thomas, 1999) and forms of disablement are likely to exist between people with a physical disability and people with a learning difficulty and indeed between these groups and people who may have both a physical impairment and a learning difficulty. The EDR model principles need to be further modified, enriched and augmented iteratively via analysis, reasoned debate and the dissemination of messages from learning difficulty research. There are two major issues in realising this; 'control and agency' and the 'myth of homogeneity'.

Control and agency

Primarily for EDR is the issue of the 'control' of research by people with learning difficulties. Some people with learning difficulties may be fully capable of initiating, controlling and conducting all aspects of research, however, some would not. Due to their intellectual impairment their 'rights bearing agency' (meaning their ability to independently assert and seek fulfilment of their human rights), may be compromised. They may not be able to easily argue important matters for research and subsequent social reform. To prohibit people with learning difficulty from research production on this basis would be a human rights violation and an act of 'disablement'. Evidence-based (or certainly evidence informed), policy and practice is rapidly developing as a 'new paradigm' in the social care field (Howard, McMillen & Pollio, 2003) and it would be negligent to exclude evidence from people with a learning difficulty. For example, in creating services to provide assistance to people with learning difficulties, should we not try to find out from them how, what, when, where and so on such services should be provided? Within our contemporary social structure the groups and individuals who have the power to initiate and facilitate participation in research for people with a learning difficulty are mostly non-disabled people. Their action in supporting others to access their rights is permitted by the universalistic principle of 'other advocacy equals self advocacy' therefore it is entirely logical to have a vested interest in the preservation of all human rights and therefore the emancipation of others (Gewirth, 1996; Stevenson, 2010). Interconnected with this rationale, it can be argued that some legitimacy of agency is given to the activist researcher as discussed earlier (Healy, 1996).

The myth of homogeneity

Critical postmodernists Fawcett and Hearn (2004) in their discussion of researching 'others' asserted that it cannot be assumed that all disabled people identify with other disabled people or that having an impairment is the most important aspect of a person's identity or social position. Should EDR engage in 'false universalising' by assuming there is homogeneity of opinion, perception, type of impairment/s and so forth? Even in groups of people with the same disability label, for example Down syndrome, caution should be exercised as 'all categories mask differences'. Ironically, perhaps one of the disabling effects of the medical model has been to facilitate the stereotyping of people according to their disability labels. The continued

widespread practice of IQ testing for example, although discredited by many authors (Gould, 1981; Ysseldyke & Algozzine, 1983, Smith 1991), has done much to generate an almost universal ‘assumption of incompetence’ in respect of people with a learning difficulty (Richardson, 2000). Also, whilst some parents of people with learning difficulties have access to emancipatory conceptualisations of ‘disability’ and hold a vision of an ‘included’ life for their sons and daughters (Murray & Penman, 1996; Kaly, 1998) which serves to drive them as advocates, other parents may internalise oppressive discourses and become socialised into a tacit acceptance of low expectations for their disabled children (Ramcharan & Grant, 2001).

Having impairment, being a relative of a person with impairment, or being part of a specialist organisation dealing with disability issues does not *necessarily* produce activism or advocacy. There are many documented and anecdotal accounts of ‘internal politics’, power-play and self-interest within specialist disability organisations (e.g. Humphrey, 2000), which can detract from wider enabling agendas for people with a disability, including their meaningful participation in research (Moore, Beazley, & Maelzer, 1998).

In the field of Learning Difficulty many researchers who conduct research alongside people who have learning difficulty labels have stepped away from embracing or ‘claiming’ the EDR model due to the difficulties in compliance with ‘full control’. In the light of the above deliberations however there was every reason to debate but also embrace its principles as a guide in the ‘Voices for Change’ research process.

5.1.9 Linking EDR and Participatory Action Research (PAR)

As discussed, for the purposes of this research, the EDR model presents a distinct set of governing principles of disability research, which can not only be used as a guide to ensure (or at least improve) the integrity of disability research production but also assist in determining its validity and trustworthiness.

The Emancipatory Disability Research model requires that research techniques are suited to the field of inquiry (EDR principle 6). Although it is often seen as a distinct research paradigm in itself, Participatory Action Research (PAR) was chosen as

congruent with EDR and used as a means via which to define the field of inquiry and generate data. As mentioned in the exposition of the Emancipatory Disability Research paradigm, various forms of research based around social power-sharing (Freire, 1970; Fals-Borda & Rahman, 1991) blossomed from the 1970s onwards. PAR was especially appropriate for our project as it is congruent with activist approaches to research and a commitment to social justice in working alongside oppressed groups (Healy, 1996, 2001), all of which set out to challenge barriers to participation. Exponents claim that PAR is educational and empowering (Freire, 1970; Fals-Borda & Rahman, 1991), data collection methods are flexible and attuned with local, cultural, economic and political conditions and are therefore context specific. Arguably, if this is not the case, findings may not be comprehensive and accurate (Mok & Hughes, 2004).

Emancipatory Action Research

Oliver (2002) alluded to the need for a consistent and emancipatory form of PAR. Carr and Kemmis (1986, p.136) described their own brand of action research as 'emancipatory action research.' and this provides an important theoretical consistency within this research framework. Their epistemological position (Kemmis, 1985) is heavily drawn from the philosopher Habermas (1972, 1974) who aims to synthesise the classical concern for praxis (wise and prudent action) with the logical and theoretical rigour of Rationalist philosophy. His thinking was inspired by much reflection on the human rights violations of the Nazi regime in Germany and questions as to how this could be prevented from recurring. He observed in interview about how quickly people became focussed upon the details of the trial of the war criminals whilst ignoring the 'meta-narratives' of a "politically criminal state" (Horster, van Reigin, Habermas & Smith, 1979). Habermas postulated that the content and form of our thinking are socially constructed and suggested that the search for knowledge was guided by self-interest of different kinds, broadly associated with each of the Aristotelian forms of reason:

- Technical: Instrumental knowledge directed towards the control of nature. The knowledge is accumulated through empirical-analytical sciences. The medium of social organisation in which the knowledge can be used is work;
- Practical: The interest is directed towards mutual understanding and wise action within a coherent framework of values. The knowledge is generated in the form of

interpretations of social life and is pursued through hermeneutic or interpretative sciences. The medium of social organisation in which practical knowledge can be used is language (communication); and

- Emancipatory: This interest is aimed at emancipating people from the dictates of taken for granted assumptions, habits, tradition, customs, etc. It is positively shaped by classical aspirations towards rationality, justice and fulfilment, but it must proceed by the critiquing of existing modes of thought and action. In particular though the medium which science has most relevance, power, as in political organisation (Habermas, 1972).

In 2005, Kemmis & McTaggart reiterated the intentionally emancipatory nature of PAR:

Participatory action research is emancipatory. Participatory action research aims to help people recover and release themselves from the constraints of irrational, unproductive, unjust and unsatisfying social structures that limit their self determination and social development (Kemmis & McTaggart, 2005, p. 570).

PAR is also a process whereby people “learn about research through doing research” (Freire, 1982, pp. 29-37). It is therefore necessarily iterative and non-linear. It unfolds in accordance with the development of each project as new understandings and opportunities arise. This also allows for diverse engagement, new activities and new questions to emerge and be addressed in the course of the project. All these features are necessary if the research is to challenge barriers and work creatively to solve problems. Arguably, if we want to move ‘outside of the prison’ (Foucault, 1977) we cannot operate by its incarcerating rules. PAR is a form of research which is now particularly widespread throughout Latin America, Australia and New Zealand (McNiff & Whitehead, 2000).

Before I move on, a few caveats. On one level PAR can present many exciting opportunities for all kinds of participation. Because of its evolutionary nature however, no-one can truly predict what will happen in the research process. It is therefore logical to assume that there may be many unforeseen pitfalls, road-blocks and disappointments. There may be aspects of the journey and outcomes which can

be termed 'emancipatory' and others which are not, participants in such research are unique individuals and will experience the process in different ways. In terms of impact, few researchers (whether they are disabled or not) can control what happens when their research has ended and findings have been disseminated. With the best of intentions and the most ethical of practices, it is quite possible that nothing tangible will eventuate from the research other than new knowledge.

5.1.10 PAR, the Circles of Support Project context and the Voices for Change research

Although the Voices for Change PhD project was initiated after the inception of the Circle of Support Project itself, PAR was particularly congruent with the Circles of Support project which was crafted as action research in close collaboration with young people who have Down syndrome. As explained in Chapter 4, the overall aim was practical; to respond and adapt to the wishes and requirements of the young people and their families and identify support processes that were useful to them in working to achieve their life goals. Traditionally, Participatory Action Research progresses through a number of cycles (Dick, 2002). This thesis deals with one cycle of the research and so it is highly exploratory in nature. A diverse body of data was produced which allowed a number of research questions to be answered. Its findings also lead to recommendations for a modified Circle of Support Project 'model' (re-named a 'Citizen Engagement Project'). These are presented in Chapter 9 of this thesis. Obviously, beyond this 'groundwork', further action research cycles are possible.

Modelling the theoretical framework for the research

In search of an ethical basis for the Voices for Change Research, the above discussion has made meaningful links between the 2008 Convention on the Rights of Persons with Disabilities, the social model of disability and the EDR paradigm and PAR as a basis for activist research (Healy, 1996) alongside people with a learning difficulty. This framework is demonstrated Figure 4:

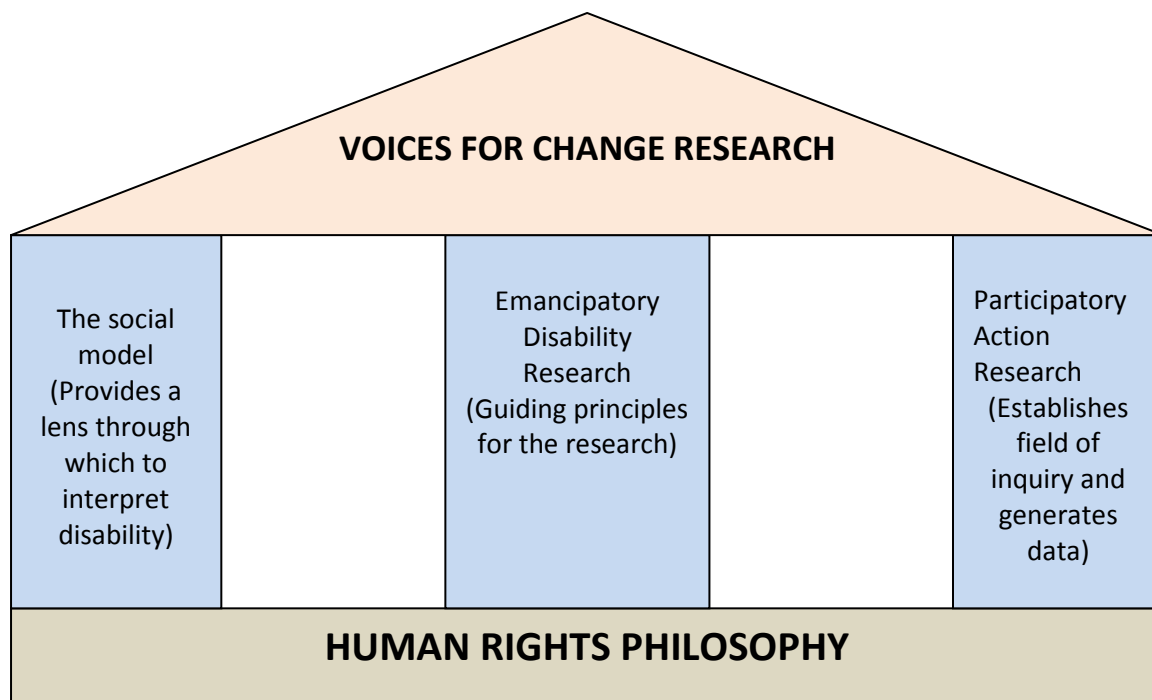


Figure 4. The theoretical foundations of the Voices for Change research

Figure 4 displays human rights core values (freedom and well-being) with the social model, EDR and PAR as conceptual pillars. With these theoretical and practical considerations in mind I proceed to the research method.

5.2 Messages from (disabled and non-disabled) researchers

In undertaking the Voices for Change research there were lessons to be learned from other research projects. Successful self-advocates such as Aspis (2000) and Harrison, Johnson, Hillier, & Strong (2001), have clearly argued that researchers should share their skills with people with a learning difficulty. As noted previously, there is now a small but significant body of research where people with a learning difficulty are identified as co-researchers/researchers. They are becoming appreciably involved in research processes which are traditionally the domain of university academics; tasks such as ethics applications, the development of research questions and hypotheses, collecting and analysing data and the distribution of findings (Nind, 2008). Likewise, non-disabled researchers are responding to the theoretical and methodological challenges inherent in these activities.

Walmsley (2001) observes that the notion of 'inclusive' research has been promoted through various ideologies such as Normalisation theory (Wolfensberger, 1972), the

social model of disability, feminist theorists and self advocates. Some funding bodies such as the UK- based Rowntree Foundation now require that applicants identify how they are going to actively include people with learning difficulties in their research projects (Walmsley, 2001).

One major 'inclusion breakthrough' is recorded in the work of Ham, Jones, Mansell, Northway, Price, & Walker (2004) where a group of self advocates and university based researchers collaborated from the inception of the research on an application to an ethics committee. Self-advocate volunteers and academic researchers together decided on the approach to the study (focus groups). Information and consent forms were developed using accessible language, symbols and photographs and produced a 'user-friendly' version of the ethics application (usually a long and complex document) for access by all the team. The team practised their presentation with a 'mock' committee. When the ethics committee gave their approval for the research the self-advocates were clearly acknowledged as 'researchers' both within the research team and externally. Practices such as this may help to combat some barriers to inclusive research created by well intentioned but sometimes overzealous 'ethical protectionism' (Iacono, 2006; Ramcharan, 2006) on the part of some ethics committees.

In terms of gathering data from people with a learning difficulty, Richardson (2000; 2002) in his participatory study with six people researching aspects of their own lives noted the use of focus groups which were largely unstructured and hence allowed participants to select topics for themselves. This allowed the research to be self-directed and themes to be emergent and non-intrusive. Regular weekly meetings over two years also allowed for data analysis and member checking by participants. It is quite possible that this reasonable time span allowed the growth of trust and confidence between Richardson and his co-researchers who were also included in the distribution of research findings via co-presenting at conferences.

Inclusive researchers have also developed different methods of gathering data from people with learning difficulties to maximise opportunities to express their views and feelings about various issues. Devices have been used which augment existing communication ability or provide a communication medium for those people who do

not use verbal communication such as Cue Cards (Lewis, Newton & Vials, 2008) , Talking Mats (Murphy, 1998) and participatory photographic research (Aldridge, 2007). Writers such as Murray & Penman (1996, 2000) also demonstrated that poetry, life history and artwork can be used to consult with young people with learning difficulties to augment and propel their 'voices' into the public domain.

These examples illustrate that research which involves people with learning difficulties can be challenging on both a theoretical and practical level. Factors that foster the pursuit of research participation include transparency, consultation, flexibility, accessible resources, alternative 'voice' techniques and prior training/practicing for roles (where possible). These observations also underline the fact that people with learning difficulty labels are a diverse group with a vast range of abilities. A 'one size fits all', prescriptive and rigid methodology would not work. Also highlighted is that fact that participation in research is 'made manifest' in a myriad of different ways.

5.3 Aims of the research

The aims of research are usually articulated via research questions. The process via which the questions were developed is now explained.

5.3.1 The guiding research question

As documented in Chapter 4, I commenced as coordinator of the Circles of Support project in February 2006. I conducted a review of literature in the first year of my enrolment in my PhD, producing an initial research proposal en route. I received ethical approval for the research in February 2007 (Appendix 1).

An important aspect of Emancipatory Disability Research is that disabled people decide on what the research problem is. It was important that the research pertained to the Voices for Change research participants and was relevant to their situation as they saw it. As shown by the above discussion, discerning the wishes and feelings of people with learning difficulties on matters is not always a straight forward process. In the case of this research however, the Circle of Support Project had been crafted in close consultation with the young people. Their collective 'summarising statement' in 2005 was very clear:

[We want] To do stuff in our life like everybody else, -like getting a job, moving out, seeing friends, going out, having a relationship and helping others.

This statement could also be interpreted as a plea for the enjoyment of citizenship rights, the citizen being a 'rights bearing agent' (Marshall, 1950; Gewirth, 1996), or a plea for full 'social inclusion'.

From this statement by the young people, it was fairly easy to deduce a straightforward primary research question which was compatible with the more practical aims of the Circle of Support Project and the Voices for Change research therein:

What aspects of the Circles of Support project can assist young people in working towards fulfilment of their personal goals as citizens?

This broad research question could serve several purposes including gathering data from participants which would also function 'evaluatively' and influence the shape of the modified 'project model' which is discussed in Chapter 9. There was also exciting potential to add to theory which would be informed by and work in favour of disabled people and their families. Secondary research questions evolved and were posed as the doctoral research progressed.

5.3.2 Devising the secondary research questions: an evolutionary process

The secondary research questions developed iteratively throughout the course of our project. The following outlines my critical reflections in this regard.

As coordinator of the Circle of Support Project, objectively measuring the 'effectiveness' of the project purely in terms of its specific outcomes e.g. achievement of goals for different participants, was going to prove almost impossible for a number of reasons. Firstly, the common ground was that all the participants carried a medical diagnosis/label of Down syndrome and were in the 18-25 year age

range. Apart from this similarity, the participants and their families were an extremely varied group of people living in a variety of circumstances – just as one would expect in the non-disabled population. The young people expressed what their goals were when they entered the Circles of Support project (on their application forms) but these, for various reasons, sometimes changed. As mentioned in Chapter 4, no formal assessment tools were used to determine eligibility for entry into the project or produce a ‘before and after’ results/ability score of any kind. This was not a process to which I was drawn as the coordinator. People with learning difficulties are frequently assessed. This process creates ‘the assessor’ and ‘the assessed’, (Gilman, Swain & Heyman, 1997) and this distancing and ‘fixing’ effect was counter to the egalitarian and participatory spirit of our project. As work commenced within families via the Team Coaches, it was obvious that each participant had a range of pre-existing skills and capacities. The project work therefore had to be adaptive and responsive to the wishes and circumstances of participants and families. Any research comparing one participant with another, or one family with another therefore would have proven unproductive. Furthermore, the project was an entirely ‘new’ enterprise for all the families involved. They had had no previous experience of any similar project to compare it with. In an environment where services and activities were in short supply, participants and families were, in the main, appreciative that an innovative project had emerged which presented some fresh opportunities for them to engage in a range of activities. Because the project constituted a resource which they would not have otherwise had access to, they were very loathe to ‘critique’ the project in any way. This issue alone would influence any findings.

Areas for inquiry arising from the review of literature

As a consequence of both my deepening foray into disability studies literature and my coordination of the project, some areas emerged as intersecting with, and relevant to, the Voices for Change research:

- (i) The prolonged, multifaceted (and ongoing) history of the oppression of people with learning difficulties and the need to work within robust human rights frameworks (explained in Chapter 2);
- (ii) My interest in Gewirthian human rights philosophy, the social model of disability and the need to ground and ‘unpack’ the vague concept of

‘inclusion’ (Buckmaster & Thomas, 2009). Similarly the concept of the citizen as a ‘rights bearing agent’, and the need for more grounded and practical definition of social citizenship (Beckett, 2003).

- (iii) The importance of ‘voice’ and self advocacy (Aspis, 1997; Souza, 1997, 2003; Martin, 2006). Research within the project gave an excellent opportunity for the voices of the young people to be heard. Indeed, the initial Circle of Support Project plan had been crafted in close collaboration with the young people group as described in Chapter 4. There needed to be continuity of this progressive ‘voice’ throughout the Circles of Support project and the Voices for Change Project was a vehicle for this.
- (iv) The extent of positive engagement with the Circle of Support Project at an early stage was quite striking. The ideas and practices within the project generated an energy and enthusiasm from participants, parents and staff alike. I became most interested in what features of the project the various parties perceived as positive, facilitatory or enabling.

As the research progressed, thus the primary research question ‘evolved’ into three secondary research questions:

- 2a Bearing in mind issues of human rights, the young people’s status as ‘rights bearing agents’ and social citizenship; what personal and social activities were of high importance to the young people? How might the young people define some aspects of active social citizenship for themselves?
- 2b Which processes, concepts and practices within the Circles of Support project as a whole did the families and staff find positive, enabling or facilitatory within the course of their involvement with the project? What features of the circles of support project were viewed positively by the parents and staff (Team Coaches)?
- 2c What could the families and staff in the project tell us about disablement (social oppression) as defined through the lens of the social model?

5.4 Issues of power in the research process

‘Empowerment’ and the manifestation of power in the lives of people with learning difficulties is a multifaceted and complex concept as discussed in Chapter 3 by Ramcharan et al (1997).

Power is exercised however by the university based researcher at all stages when the researcher decides what questions to ask, harvests the data from the informant, analyses the data and the researcher then finally theorises from the data. This process is not dissimilar to forms of biomedical research where, for example, the researcher takes blood from the patient goes into the laboratory, analyses the blood, collates the findings and disseminates them at conferences and in journal articles. The research ‘subject’ in reality becomes objectified and the researcher retains complete power and control over the process. In true bio-medical research this is (sometimes) understandable and in some forms of qualitative research this is required. Given the re-statement of human rights in the 2008 CRPD, the ethics of social research indicate a need to maximise participation. Progressive research funding bodies such as the Rowntree Foundation in the UK stipulate consideration of inclusion as a requirement rather than an added ‘extra’ (Walmsley, 2001).

The aim of my research was to try to ‘share researcher power’ by listening to, observing and including the young people within the project as much as possible in tasks traditionally performed by a university-based researcher. My ability to achieve this ‘approach’ was enhanced by my position as a project coordinator working within the Host Disability NGO. I was contextually immersed in the current issues facing people who have Down syndrome particularly as many of my colleagues in the Host Disability NGO were parents. I also had a vested interest in steering the Circles of Support Project accountably and successfully. This gave me a different (though certainly not superior) position and perspective to that of university-based researcher who perhaps comes into an organisation specifically to conduct interviews amongst disabled people, families and staff.

In aspiring to the EDR ideal, all the young adults with Down syndrome involved in the Voices for Change research were regarded as potential 'co-researchers'. Exploring their potential for decision making and participation in research activity as we proceeded through the project was a key feature of my theoretical and methodological approach. Another factor is the power and authority of the academe itself. Most people with learning difficulty are excluded from academic life (Stevenson, 2010). There is a clear tension between meeting recognised academic criteria whilst at the same time appropriately representing the experiences and participation needs of people with learning difficulties. This has been clearly acknowledged (Stone & Priestley, 1996; Aldridge, 2007). From another perspective, some authors have set about challenging the traditional assumption of a 'binary' position which can create an over-simplified 'divide' between disabled and non-disabled people (Tregaskis, 2004; Tregaskis & Goodley, 2005). Fawcett & Hearn (2004) asserted that:

Research carried out into disability by a disabled researcher cannot on the basis of *experience alone be seen to be more legitimate than research carried out by a non-disabled researcher*. It is how the research is conducted, how the participants are involved, how attention is paid to ethical issues and the extent of critical reflexivity that have to be regarded as key factors (Fawcett & Hearn, 2004, p. 218 *my emphasis*).

It is perhaps therefore in the area of ethics and through constant reflection in the course of each research project that power issues can be exposed and addressed. These issues are considered contextually in Chapter 6 which describes and reflects upon the participatory research process.

5.5 Ethical considerations

This section outlines a consideration of ethical issues as advocated by Fawcett & Hearn (2004). Ethical considerations are a fundamental aspect of any research, whether quantitative or qualitative and need to be examined early in the research process (Robson, 1993). The theoretical framework for this research asserted that people with learning difficulty labels have a right to be involved in research and non-disabled people have a right to conduct research with them. This in itself is an overarching ethical consideration. After acceptance of this, it became important to

consider the detailed ethical framework of such research. What are ethics in practice? This study required great sensitivity on the part of myself as a non-disabled researcher and careful 'positioning' (and continuous re-positioning) of this role within the overall 'picture' of the research.

People with learning difficulties can be broadly seen as a 'vulnerable' population. Vulnerable populations can be defined as:

...groups of people who can be harmed, manipulated, coerced or deceived by researchers because of their diminished competence, powerlessness, or disadvantaged status (Rogers, 1997, cited in Sutton, Earlen, Glad & Siminoff, 2003, p. 106).

Historically, in the research arena, people with learning difficulties have been widely subject to different kinds of oppressive practices: foremost they have often been excluded from decision – making and involvement in research, as have their families. They have seldom been facilitated to initiate or request their *own* research projects in terms of what is important to them. Historically, their diminished rights status as human beings (supported by eugenicist thinking) has meant that they have been made unwitting subjects of experiments which could harm their health and well-being. There has been (and still is in many cases) a considerable emphasis on biomedical forms of research practice documented in Chapter One (e.g. Krugman, 1985; Lott, Patterson & Seltzer, 2007). People with learning difficulties (especially those who have Down syndrome) are 'highly researched' both medically and psycho-socially as a 'category' of people but are rarely given a direct 'voice', highlighted by Annison (1999).

The vulnerable and the 'invulnerable'?

For all these reasons people who have learning difficulties can be seen as a 'vulnerable research population'. This is not always a straightforward or necessarily helpful category. Paternalistic arguments which position people with learning difficulties as highly vulnerable can have a disabling and exclusory effect. Iacono (2006) and Ramcharan (2006) illustrated how adults with learning difficulties can sometimes be restricted by ethics committees from participating in social research on the grounds that they are not assessed as being able to give informed consent.

This approach could lead to a participatory 'dead end' (and further labelling) for those people who are assessed as unable to give informed consent. Ramcharan (2006) suggested that advocates who have an established caring and trusting relationship with the potential participant (e.g. members of a circle of support) could be called upon to support people with a learning difficulty in making decisions about research participation.

Reviewing the literature concerning research ethics and so-called 'vulnerable populations', arguably such provisions could apply to *any* social group. After all, when recruiting participants in any social research project, the researcher will not know at the outset all the particular 'vulnerabilities' of a participant. Are we not all vulnerable (Beckett, 2006 p.195)? For example many people who may become research participants could have very sensitive emotional and psychological 'vulnerabilities' which are hidden or 'undiagnosed'. Some research participants (including disabled people) may have been victims of undisclosed abuse or domestic violence for example. Participation in some research projects may thence 'trigger' difficult feelings, memories and raise issues for these participants. This should not necessarily mean however that others should decide that they cannot be participants or that participation cannot prove positive for them. What is important is that the researcher respects and pays attention to the freedom and well-being of the participant (Gewirth, 1981, 1996). She ensures appropriate and ongoing consent is given, is sensitive, flexible, well-prepared and has the capacity to respond appropriately to participants in a caring and trustworthy manner. The researcher herself also needs support to maintain consistent good practice in all these areas.

The usefulness of the building a framework of ethics of research based on literature which considered 'vulnerable populations' was that the exercise demanded that I reflected, in detail, on many issues that may have arisen. I looked into myself time and again regarding my motivations and behaviours as a researcher. With these deliberations in mind, the following considerations were made from the outset. These are not exhaustive; there was a need to remain 'ethics sensitive' as there were possible situations which could not be predicted from the outset, particularly as the Voices for Change research was a participatory journey into 'uncharted territory'.

5.5.1 Ethical research practice: Some key considerations

With regard to vulnerable groups, it is incumbent upon researchers to design protections necessary to ensure that the rights and welfare of the subjects are not violated. Alderson (1995) and Alderson & Morrow (2004) devised key questions which need to be addressed in any research which involves 'vulnerable' participants including six that are relevant to this research:

- a) What is the purpose of the research?
- b) What are the costs and benefits for participants?
- c) What will be the impact of the research on participants?
- d) What are the privacy and confidentiality issues?
- e) What was the involvement of participants in planning the research?
- f) Did the participants consent to being involved in the research?

Although initially designed for research with children, social researchers have applied these questions to ethical considerations in respect of adults in situations which may render them vulnerable (for example, Waugh & Bonner, 2004). Each issue was considered in preparation for submission of the University Human Research Ethics Committee application. For clarity, I set out each of the above areas and report on my 'ethical preparation' for the research project, writing in the first person as the non-disabled researcher.

Consideration of the purpose of the research

Because the primary research question was around the effectiveness of the Circles of Support Project which could add to knowledge in the area, its overarching purpose was quite clear. The participants and parents and staff were enthusiastic about the project, it was a live and dynamic process, a process they were part of and could easily 'relate' to. By the time interviews were commenced in 2008, most of the research participants (including parents and project staff) were embedded within the project activity. I ensured that the purpose of the research was communicated in a meaningful way to each research participant in the company of at least one parent, taking into account any special communication needs. Any questions from participants (or their identified advocates) were answered openly and honestly.

Trust and rapport were important to the research process and outcomes. I was not 'going in cold' and my continuing dual roles as both the Circle of Support Project co-ordinator and Voices for Change non-disabled researcher rendered me visible, accessible and accountable to the Host Disability NGO and open to questions and dialogue about both roles.

Consideration of the cost and/or risks to the participant

I meditated upon a number of issues and responses in relation to the costs and risks. The research required time from the participants and time from parent/s or other advocates. These were issues of cost. Scheduling in time for an interview would take some organising so there I was prepared to work very collaboratively and flexibly with families. I needed to make sure that the interviews took place where the participants had privacy and felt at ease. Comfortable surroundings with refreshments on hand were important. People with Down syndrome sometimes use augmentative communication methods (signing etc) so preparation was made for this possibility although the need did not arise in this research.

Connected with the above discussion, it was important that the research did not constitute an 'intrusion' into the lives of the participants, families and staff.. Alderson & Morrow (2004) stressed this point in relation to research with vulnerable populations. A sensitive approach is evidenced in the work of Richardson (2001) who also highlighted the need for respect in explaining disablement in the lives of people with learning difficulty. These points were taken into consideration both in terms of my interaction with research participants, method of data collection and in the development of interview questions.

Relating one's personal experiences can evoke painful memories and/or therapeutic needs may be indicated. As a trained and experienced social worker of some 20 years post-qualifying experience, with a background in child protection work and working with young adults with learning difficulties, I felt confident in my awareness and handling of sensitive issues and could identify when there may have been a therapeutic need to be addressed. For example, a participant may disclose/indicate abuse; there could be ongoing adult protection issues; and/or the adult may still have unresolved issues around abuse in which case the opportunity to access therapeutic

help is essential. Other mental health issues may have been indicated. I identified referral pathways (in the NSW Department of Community Services) which would enable me to identify/liaise with appropriate personnel in order to prepare for this possibility. I had also trained and worked within “Adult Protection” procedures whilst in the UK so this experience could have been drawn upon if necessary. As the Circles of Support Project coordinator I was similarly prepared to tackle these issues if they arose.

A participant may have felt they were betraying a carer/professional/family member or institution if they reported any negative experiences relating to them in the interview and feel anxious about any consequences of this. I therefore had to be clear of the ‘parameters’ I would report within.

The participants could have been misunderstood and / misrepresented in findings. Every research participant has a right to be understood. Prior to each interview, I made an ‘informal assessment’ of each participant’s method of communication (again, this was facilitated purely via my relationship with the participants). In some instances it was necessary to work closely in the interview with an advocate (usually a parent), in order to ensure a clear and meaningful account.

Consideration of possible benefits to the participant

Sharing information about oneself can be beneficial or even therapeutic. Sharing even difficult experiences with someone who is interested, sensitive and who responds appropriately (shows empathy, maintains confidentiality) can be validating and can raise self-awareness and self esteem.

Not all research will directly benefit the individual participant but may offer future benefits for others. Participation in research which may help agencies to understand the support needs and contribute to effective models of support of other people with learning difficulties is a laudable activity. I believed that most participants and their families and the project staff would justifiably feel positive about this.

Consideration of the possible impact of the research upon the participant

My dual role of coordinator and researcher may well have impacted upon the image that research participants and their families would have of myself and the relationship I had with them. It may also have impacted upon the relationship I had with the Team Coaches and Team Voice. Some of those potential impacts are considered above. The needs of the project as a whole had to take precedence over any university research process; professionalism demands that, in the context of social work agencies, the interests of the 'client/service user' are always paramount. The Voices for Change research project therefore needed to be an enhancement to the Circles of Support Project and not constitute a burden or unnecessary intrusion into the lives of the participants, staff or parents (Richardson, 2001). Whilst the road ahead could not be predicted, I made a firm decision that the doctoral research would produce as many positive experiences as possible for participants.

Privacy and confidentiality issues

With all information given by research participants, non-traceability is an important matter (Cohen et al, 2000). Hence ensuring that a participant was not identifiable was important. All participants in the study were given a pseudonym. Data was (and is) stored on password-protected software. All interview transcripts shared amongst the co-researchers for data analysis were de-identified. They were de-identified *again* for publication in this thesis. All hard documentation will be maintained securely for 7 years.

Involvement of the participants in planning the research

The fact that research was happening within the Circle of Support Project was acknowledged and valued by the Host Disability NGO. This is fundamental to the Participatory Action Research method employed. The Circle of Support Project reference group served as a regular forum via which to monitor research. Andrew, the Team Voice (who became a research participant/co-researcher) was also part of this forum. Research steering groups were held in the course of the project.

Informed consent and vulnerable populations

Guidelines for reasonably informed consent in respect of *all* participants in the study were observed and information was given to the participants based on the following:

- i. A fair explanation of the research process to be followed and its purpose.
 - ii. A description of any problems/difficulties in participation reasonably to be expected.
 - iii. A description of the benefits of participation reasonably to be expected.
 - iv. An offer to answer any questions about the research honestly and openly.
 - v. A guarantee that the participant is free to withdraw from the research at any time without prejudice to that participant.
- (Appendices 2-5).

Access and acceptance

Bell (2005) advised that researchers speak to people who will be asked to co-operate and make the project outline available and accessible to all participants; be clear about the parameters of anonymity and confidentiality; give assurances that feedback will be given; inform participants what will be done with information provided; ensure that participants are aware that they can withdraw from the study at any time. All these guidelines were incorporated into my discussions with the National Charity, the Host Disability NGO and the Circles of Support Project reference group prior to the ethics application.

The National Charity who funded the Circles of Support project considered that participatory action research within the project would be a good idea but the stipulated that the necessary conditions and consents lay with the Host Disability NGO. The Board of the Host Disability NGO was approached regarding my request to conduct empirical research within the Circles of Support project in 2006. The Board (comprised mostly of elected relatives of people with Down syndrome) discussed the request and concluded that they would take into account the recommendations of the project reference group of the Circles of Support Project. The project reference group were concerned that issues of privacy, confidentiality and informed consent to the study were dealt with in the research proposal and I was

provided with a letter signed by the President of the Host Disability NGO and its Chief Executive Officer for the application to the Human Research Ethics Committee (HREC). These issues were dealt with in the application to the Human Research Ethics Committee (HREC) which was submitted initially in December 2006, then amended and resubmitted in February 2007. In February 2007 HREC finally approved the application (Appendices 1-5) and I received the letter of approval in March 2007.

5.6 Data collection

The Circle of Support Project took place over three years and provided a number of opportunities for gathering various forms of data. However, I needed to be specific at the stage of the ethics committee as to what forms of data collection I would use. At the time I was considering the various options and hence my ethics application and consents literature covered interviews, focus groups and videos. The primary research question demanded inquiry into what the different groups thought about the project. My participatory approach required the young people to be as involved as much as possible in the project. It was also important that data collection could be integrated as smoothly as possible into the 'flow' of the Circles of Support Project.

I decided against the use of video as, from 2007, there was a great deal of filming undertaken in the project due to the production of the DVD which Circle of Support Project participants had agreed to. Two interviews were filmed but I decided it was inappropriate to add to that pressure by pursuing this path; there was certainly enough data from other sources. In terms of focus groups, I would have had to ask Voices for Change participants, staff and parents to attend specific group sessions, thereby again prevailing upon their time. Many people are 'time poor', and the families and staff were spread over quite a large area of a busy global city. Many parents in particular had already made extra commitments in terms of supporting their sons and daughters with travelling to attend the Circles of Support Project activities such as the project workshops. Organising a time for all the parents to be together at once would have proved very difficult. I needed a method of gathering data which was flexible and could fit around the needs and schedules of the research participants and one which potentially the young people who have Down syndrome could undertake as co-researchers. It was for this reason that I chose to interview Voices for Change participants, staff and parents using a semi-structured

interview guide. This meant I could interview the participants of the study in a location under conditions and at times that were comfortable and convenient for them.

5.6.1 Interview guides

The use of interviewing to solicit information from individuals is now so widespread that commentators have now said that we now live in an “interview society” (Silverman, 1993 cited in Fontana & Frey, 2003, p. 62). The individual generally cited as being the first person to conduct a social study using interview was Booth who surveyed the lives and living conditions of the London public in the early 20th Century (Converse, 1987). Booth was also credited with triangulating his work by supporting his interview findings with his own ethnographic observations.

Fontana & Frey, (2003, pp. 61-106) explicate the many different types of interviews available to researchers. Classical structured interviews are designed to elicit a response to a series of pre-established questions. The recording of responses is usually required to comply with a pre-determined set of codes. There is generally little opportunity to elaborate on such responses or raise different issues. This type of interview is often used for consumer surveys via telephone and ‘on the spot type’ interviews where members of the public are intercepted and the interview needs to be short and succinct. I rejected this type of interview for several reasons. Particularly with regard to the young people who were the focus of this study, I did not want to replicate the oppressive interview style which has so often been used whilst interviewing people with learning difficulty (Annison, 1999) and force ‘yes’ or ‘no’ answers from them, neither did they need to constitute “interrogations” (Attride-Stirling, 1996, p.113). The interview context provided a unique opportunity to provide richer data about the Circle of Support Project. Human beings are complex and creative creatures with unique patterns of life experience. I wanted them to reflect upon that experience. The participants of the Circles of Support project were in the throes of participation in a living moving project and they needed to contribute their knowledge and ideas to the interview process itself. Fontana and Frey, (2003) also discuss structured interviews and make the distinction between these and the unstructured interview:

The former aims at capturing precise data of a codable nature in order to explain behaviour in pre-established categories, whereas the latter attempts to understand the complex behaviour of members of society without imposing any a priori categorisation that may limit the field of inquiry (pp. 74-75).

Later they add that unstructured interviewing is to seek “the establishment of a human-to-human relation with the respondent and the desire to *understand* rather than to *explain*”. The essence of the unstructured interview was pertinent to the Voices for Change research, as I already had a relationship with the participants as coordinator of the Circle of Support Project which could not be ignored. There was however a need to provide some structure to keep the discussion on course and, correspondingly to be respectful, unintrusive and not over-presumptive about the nature of this relationship.

The semi-structured interview allows the interviewer to set the agenda for discussion but allows for the “penetration of topics under consideration” (Attride-Stirling, 1996, p.113). It allows for a relaxed interchange where the informant can sometimes guide the interviewer. Rather than attempting to be the ‘objective’ and dispassionate interviewer, in a PAR setting, ideas of relationship are acknowledged and embraced. There is space for more informal discussion within a semi-structured interview. I therefore decided that a semi-structured interview ‘guide’ was the best way to proceed with data collection.

The semi-structured interview guide for the participant respondents/co-researchers

From my prior knowledge of the young people as project coordinator, I knew that all the young people in the study had access to verbal communication. One of the young people was said to have ‘dyspraxia’ although I had worked with him as Team Voice for approximately eighteen months prior to starting interviews so I had learned to understand his speech quite well. Another participant carried a ‘dual diagnosis’ of Down syndrome and autism; he spoke very little but wanted to participate. Some of the other young people were articulate but difficult to understand whilst others had great clarity of speech. In the course of the project I discerned (without surprise), that the young people just wanted to be treated like anyone else, only one young person who had consented to the research used any form of sign language (she had

learned some Makaton with her Team Coach in the course of the project). Language augmentation techniques such as Talking Mats and Cue Cards were not required in this research. The interviews were open processes and not shrouded in secrecy (taking somebody off to a room alone can be quite intimidating). The interviews were planned so the young people could be interviewed in the presence of a parent if they wished and/or needed support with communicating their views. In this research, the interview questions were not designed to elicit information of a highly sensitive nature which needed to be concealed from parents in any way. This approach may not be suitable for all forms of research but it was ideal in our research context which placed a high premium upon transparency of process.

The semi-structured interview guides were rather more detailed for the participant informants as they tended to give shorter answers to questions. The interview guides were formed around accessible topics flowing from and embracing issues that they had already probably already talked about, reflected on and experienced in the course of the Circles of Support project. I was interested in: self perception; what the young people's ambitions were for their lives; what they had done in connection with the Circles of Support project; their working relationships with Team Coaches; the monthly workshops; the Citizen Educators Project; and ,for those who became co-researchers, the research process itself. As not all the families formed their own "circles of support" I also framed support networks as "the important people in their lives". I was interested in whether the project had impacted upon their family relationships and what this might mean. I also added some basic questions about decision making to try and ascertain their views on levels of self-determination.

Before implementation of the questions, Andrew, the Team Voice, checked the interview accessibility as did another two participants. All parties made comments and I amended the questionnaire accordingly. The Semi-Structured Interview Guides for the Circle of Support Participant Respondents/Co-researchers can be seen in Appendix 6.

The semi-structured interview guides for the parent informants

The parent's interview guides followed a similar pattern to that described above. I was interested in how they perceived their sons and daughters; what their

aspirations were for them; what the barriers might be in achieving these goals; their concerns (if any) for their future and then a range of questions about their involvement in the project and its impact including how they felt the project could be improved or added to.

In summary, all the Semi-Structured Interview Guides were designed to be in themselves unintrusive and flexible. The respondents could provide either some very basic information in answer to each question, or they could elaborate and make further points, using the questions as prompts for their wider views, experiences and opinions (Appendix 7).

The semi-structured interview guide for Team Coach Informants

The Team Coaches within the project were responsible for the deployment and implementation of the ideas and strategies within the project. I was essentially interested in their backgrounds; what factors drew them to the work; the impact of the training and information given to them; the type of work they had undertaken with families; what they felt the issues facing participants and families were; their support needs; their own 'learnings' from the Circle of Support Project and their own ideas and visions about how the project could be further developed. These were incorporated into a semi-structured interview guide which is available in Appendix 8.

5.7 Data analysis

The data set is displayed in Chapter 6. The method of data analysis used was Thematic Networks (Attride-Stirling, 2001). I had intended to use computer assisted data analysis (NVivo 7) to assist with the process and started along this track by undertaking some reading and training in the use of NVivo software (Bazeley, 2007). An event at a Research Steering Group Meeting however gave an indication that co-researchers could meaningfully be involved in part of this process. An explanation of thematic networks analysis and justification for this method is therefore contained in Chapter 6 which, as the first of the findings chapters, documents the collaborative research process and the ways in which my 'co-researchers' participated in processes which traditionally involve university-based academics.

5.8 Reliability and trustworthiness

McTaggart (1998) advocates that action research criteria of validity are ‘paradigm specific’ and should meet criteria of “defensibility, educative value, political efficacy and moral appropriateness”. These criteria are all implicit within the Emancipatory Disability Research paradigm set out in Table 4 (Barnes, 2001). Trustworthiness is established through truthful and transparent explanation of the research process and findings.

5.9 Concluding remarks

As a non-disabled researcher grounding my practice in human rights activism I was drawn to the social model due to its political efficacy, the fact that it was developed largely by disabled people and provides a clear lens to through which to perceive disablement as social oppression. This chapter has explicated the theoretical framework of the research which was drawn from Human Rights and the social model of disability. The positioning of the ‘activist researcher’ has been grounded within this framework. Emancipatory Disability Research has been explained and explored as an ‘activist research paradigm’ and its principles are seen as appropriate in guiding the Participatory Action Research (PAR) which occurred within the Circles of Support Project.

The ethical framework of the Voices for Change research flowed from the theoretical framework. It was of great significance in providing for a flexible, evolutionary and ‘safe’ approach to the research. I was committed to the notion that the young people in the research had competence and ability and would wish to be involved in researching what was *their* Circle of Support Project. In this research project, *participation by the young people was as important as the findings from the analysis of data*. What followed in terms of the extent of their participation and the outcomes of their participation exceeded all my expectations.

Chapter 6 is therefore the first of three ‘findings’ chapters. It explicates for the reader the research process and the ways in which the co-researchers worked with myself as a non-disabled researcher to undertake aspects of research production that are normally the domain of university-based academics.

6. The Participatory Research Process.

All hearts contained in the research
(Andrew, co-researcher)

Having laid out the methodology in Chapter 5, this chapter is the first of three 'findings' chapters which form the heart of this thesis. This chapter is a 'hybrid' chapter containing methods of participatory research practice and also reflects on findings from the entire process. A flexible and responsive approach was used in the facilitation of young people as co-researchers in the Voices for Change research project.

Our research unfolded as a participatory journey spanning four years. Participation was spontaneous and serendipitous in many respects. The discussion broadly follows the events in chronological order as they occurred over the course of the research. Some activities, such as co-presentation activity, were ongoing throughout the research timeframe and are continuing to occur as opportunities arise. One particularly innovative step in this research was our work together on data analysis. The steps by which thematic networks analysis (Attride-Stirling, 2001) was identified and utilised as an appropriate tool to guide participatory data analysis are shared here. Documenting this process also serves the purpose of clearly elucidating thematic networks for the reader which became the tool used for analysis of all the data gathered in the research interviews.

Critical reflection is seen as central to the transformative process of PAR (Chiu, 2006). As each process is explained I include my critical reflections on each key participatory process. The focus of my reflection is upon notions of 'power' but other observations on 'learnings' are made where relevant. Specific feedback on the research process was provided by co-researchers and this is also considered in this chapter.

These 'process findings' then lead into Chapters 7 and 8 which fully explicate the findings from the data analysis.

6.1 Language and terms used in the Voices for Change research

6.1.1 Explanation of roles and titles used in the research process

The Host Disability NGO: The specialist Disability organisation in NSW Australia who hosted the Circles of Support Project.

The Circles of Support Project: The three year action research project, hosted by the Host Disability NGO.

Voices for Change Research: The participatory research project, guided by the principles of EDR which took place within the Circles of Support Project.

Circles of Support Project Participants: The young adults who have Down syndrome between the ages of 18 and 25 (at the time of their initial engagement), who participated in the Circles of Support Project at any stage from the beginning of 2006 until the end of 2008.

Team Coaches: The staff (recruited in collaboration with young adults who have Down syndrome) who engaged directly with the families in the Circles of Support Project.

The steering group members: The Voices for Change doctoral research steering group was made up of parents and young people who had consented to be research participants. Over the course of the four meetings which were held a total of four parents and three young people attended the groups and in this context, these individuals were known as 'steering group members'.

The research informants/participants: In this study there were 22 interviews involving Team Coaches, Circles of Support project participants (young adults with Down syndrome) and their parents. In the first instance all the interviewees were therefore 'research informants'. **In writing about the research in this chapter, I simply refer to the various research informants (those people who supplied interview data) as 'Team Coach/es', 'parent/ s' , 'young person/young people.**

The co-researchers: As the research project unfurled, it became possible for me to facilitate the involvement of young people (who were also research informants) to varying degrees in academic research processes including presentations at university seminars and conferences, in undertaking interview; data analysis; dissemination of findings and co-authorship of an academic paper. When writing about their involvement in these processes I refer to them as co-researchers.

The non-disabled researcher: As I do not bear a recognised 'disability' label of any kind, I refer to myself as the non-disabled researcher.

6.1.2 The Voices for Change research group

The table below contains a description of the Voices for Change research participants: the young people (all aged between 18-24 years at the start of the research); the parents who consented to be interviewed and their Team Coaches who gave interviews. Not all parents were involved. Some participants shared the same Team Coach. The description is necessarily brief in order to preserve participant anonymity as much as possible in a small 'community' in NSW. Appropriate pseudonyms have been given with respect to the cultural self-identity of the research participants.

Table 5. Voices for Change research participants

Young person	Parent/s	Team Coach
Jasmine	Heera (Mother) Rupal (Father)	Shanti
Katie	Susan (Mother)	Helen
Carl	Vivienne (Mother)	Emma
Ciara	Mary (Mother)	Helen
Luke	Emerald (Mother)	Anna
Rhonda	Margaret (Mother) Joseph (Father)	Sundari
Isabel	Louise (Mother)	Helen
Andrew	Pamela (Mother)	Team Voice working with Miriam.

6.1.3 The activities of the co-researchers

Seven of the 8 young people had significant involvement in the Voices for Change research activities. It is important that the contribution of co-researchers is clearly understood and acknowledged so I summarise here:

- i. Andrew, Katie, Rhonda, Luke, Ciara and Isabel presented alongside me at post-graduate seminars at the university (on various occasions) in 2007, 2008 and 2009.
- ii. Andrew and Katie presented with me at a conference in Perth November 2007.
- iii. Isabel presented at a Social Work conference with me in November 2008.
- iv. Jasmine and I spoke jointly as invited speakers at an Early Childhood Intervention conference in Sydney, October 2008.
- v. Andrew conducted three of the six interviews with me with young people informants.
- vi. Jasmine interviewed me.
- vii. Katie interviewed Andrew.
- viii. Jasmine and Katie conducted coding and stage 1 and 2 thematic networks analysis using a small portion of de-identified data alongside myself and Linda, a support worker in six, two-hour sessions in 2009.
- ix. Andrew joined us in the data analysis sessions but did not wish to undertake coding. He chose to produce a 2,900 word 'research report' document as his contribution. Andrew completed this on his lap top. This document was analysed as Andrew's personal perspective on the meaning and significance of this research.
- x. Katie produced an accessible paper to accompany a co-authored paper (by myself, Andrew, Katie and Jasmine) about the participatory data analysis.

6.2 Researching together

The following section illustrates key aspects of the participatory research process. Description of each phase is followed by my own critical reflections and any salient points made by research informants/co-researchers.

6.2.1 Recruitment of research participants

Informants for the Voices for Change project were recruited between 2007 and 2008. Similarly Team Coach and parent informants were recruited along this timeframe.

Recruitment was via a flyer put out with the newsletter and subsequent discussions with young people and their parents. As part of the ethical requirements, the signed consent of a parent was required for young people to participate in the project (Appendix 4).

Given my part-time researcher status the number of research participants needed to be manageable. Overall I aimed for no more than seven 'cases' each consisting of a young person, their parent (or parents if there were two and both wished to be interviewed) and their Team Coach. This comprised a reasonable number of interviews (as I intended to self-transcribe) and a manageable yet rich data set which could be usefully analysed.

Reflections on recruitment of research participants

Requiring the consent of a parent was an ethical requirement which I decided to perceive in a positive light. As the primary advocates for their sons and daughters, it was important that parents understood the implications of the research and that they supported their research participation. However, one parent, Susan, challenged the need for a signed consent form (Appendix 4). She refused to sign it and instead wrote on the back of the form in protest:

I feel this is a conflicting form- Katie is 23 years old and is capable of giving her own consent after discussion with myself. If you require any further information or I can assist you in any way please contact me [contact details provided] (Susan, Katie's mother).

Susan supported Katie's participation in the research but felt that the consent form undermined Katie's ability to make her own decisions as an adult. For a parent who had worked hard to support and establish her daughter as a "capable" adult, Susan interpreted this requirement as an 'assumption of incompetence' by the ethics committee and would not accept any arguments to the contrary. Susan's protest raised issues about how the label of 'Down syndrome' places those people so labelled into a 'fixed' category of vulnerability and dependency. In this instance Susan did not wish to have the power to veto Katie's participation in the research, she was actively resisting this ascribed power in order to 'empower' her daughter as an adult.

6.2.2 Co-presentation at university seminars and conferences

Co-presentation was the start of our participatory journey together. As opportunities arose we would discuss who would be interested in participation and co-researchers could elect to either produce a presentation themselves, with support from a parent or team coach, or come into the office and prepare a presentation with me. As a post-graduate student I sometimes attended the monthly post-graduate seminars held at the University of Sydney which were opportunities for doctoral students to meet, discuss and present their research topics. I invited Katie and Andrew to come to a post-graduate seminar with me. We prepared for the seminar by meeting at the offices of the Host Disability NGO and created presentations using computer software. Both Katie and Andrew had good IT skills and enjoyed using the software. We worked out different roles within the presentation and planned the messages we wanted to get across. Andrew was interested in discussing his role of Team Voice. Katie shared some aspects of her life story, her achievements and newly formed 'circle of support'. I talked about the planned research. We all spoke for equal lengths of time during the presentation which generated a sense of equality in the exercise. The presentation went well. In discussion afterwards, my doctoral supervisor suggested that we approach a lecturer at the Australian Catholic University (ACU) Sydney, who might be interested in the research group presenting a seminar for undergraduate students within a social work course module on disability. As Team Voice and my close work colleague in the Circle of Support Project, Andrew again became involved in this process. This time Luke and Rhonda joined Andrew and I as co-presenters at the ACU hence extending the number of co-researchers. Luke prepared a speech focusing on the kind of support he needed from professionals and Rhonda and her Team Coach prepared a presentation using IT software. With support, Luke also led an exercise called 'Same and Different' to actively engage the students. Luke had learned this exercise from the Circle of Support Project workshops. 'Same and Different' demonstrated to the students that we all have similarities and we all have unique differences as people.

In November 2007 I had prepared a peer-reviewed paper for an ASSID Conference in Western Australia and managed to acquire funds for Andrew and Katie to attend. Together we planned all aspects of the trip, and discussed how we would present

the paper. Andrew was again keen to talk about his Team Voice role and how it had developed. This time Katie talked about the planned research.

Again in 2008, Isabel presented alongside me at an international social work conference held in Sydney.

Reflections on co-presentation

As a researcher, the preparation for the presentation co-researchers was invaluable. The time spent together helped build relationships between us as co-researchers. Listening to what the co-researchers wanted to write and talk about in their presentations deepened my understanding of their interests and concerns. Subsequently this made me a more knowledgeable and confident advocate. It also gave me ideas about where to head next in terms of the research and Circle of Support Project activity.

The 'live' co-presentation was one of the research activities that the co-researchers clearly enjoyed. In her written feedback at the end of the research, Katie shared the benefits she had gained:

When you are presenting at universities and conferences this makes you feel proud and you gain confidence when you are happy with the work you've done. Some people get nervous at first but they know they can overcome it and do a good job speaking to an audience (Katie).

Katie's assertive style here needs little interpretation. The self confidence gained through speaking to an audience cannot be underestimated and it is an opportunity to overturn the notion that people with learning difficulty need to be in constant receipt of 'mentorship' or 'tutelage' from the non-disabled population. Information Technology (IT) was harnessed to great effect. Its usage proved highly enabling for the co-researchers and gave a planned, polished and professional 'edge' to the presentations which could be said to be 'empowering'. For example Ciara, whose speech was impeded due to her auditory impairment, used presentation software as well as a video of her engagement in complex dance to convey her story, interests and considerable abilities to the audience. The presentations in varying ways discussed the medical and social models of disability, research participation and

emergent findings. They also constituted an opportunity for co-researchers to self-advocate and talk about the kind of personal support which they found to be of benefit (e.g. Luke's ACU presentation in Appendix 11). There was space for them to express their opinions about the medicalisation of impairment in a self-directed manner. For example on one occasion Isabel came to the ACU having created a software presentation with her mother. She talked about Down syndrome. On one slide she placed a photograph of a chromosomal strand and pointed out where the extra copy of Trisomy 21 lay. This was an extremely confronting moment for the students. Here was a young woman with a learning difficulty speaking clearly and authoritatively about her chromosomal difference, a difference which, had it been detected prior to her birth, would have possibly precluded her future existence. She concluded her presentation (Appendix 12) by challenging the group of students about this genetic 'difference' which holds such authority as a label (Figure 5):

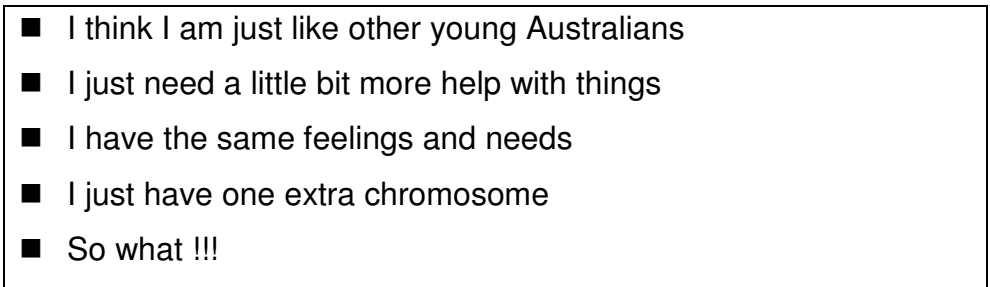
- 
- I think I am just like other young Australians
 - I just need a little bit more help with things
 - I have the same feelings and needs
 - I just have one extra chromosome
 - So what !!!

Figure 5. Slide from Isabel's ACU presentation

The presentations formed a high profile self-advocacy 'space' for the young people where, I believe they were able to define themselves to the audience (Souza, 1997; Aspis, 1996) explode myths, clarify misunderstandings and talk about the forms of support they wanted. The students in turn were able to ask questions and to learn from a research oriented view of social inclusion. They were inspired and motivated by the young people themselves; their own best advocates. This gave a different perspective to the indirect (often medicalised) knowledge of the non-disabled tutor and took our work well beyond tokenistic forms of inclusion.

On a personal note, the grounded approach of my co-researchers was very calming and empowering for me. As a relatively 'new' researcher myself, I initially dreaded public speaking to an academic audience. I drew much of my own confidence as a presenter from observing my co-researchers and their 'can do' attitude. I did not

have to face an academic audience alone feeling stronger when in a team. This highlighted the issue that the co-researcher relationship, is not a 'one way street', there are opportunities to learn and gain support from each in PAR whether one has an identified impairment or not.

6.2.3 Becoming 'Citizen Educators'

The 'presentational' aspects of the project were seen as innovative within the Host Disability NGO. A member of the Host Disability NGO decided to donate \$10,000 for a special project and asked for submissions from the various Host Disability NGO teams. I developed a short proposal for a small 'subproject' aimed at consulting with and supporting young people with Down syndrome to become educators in learning difficulties. Our submission was accepted; the Citizen Educators Project was initiated.

We commenced this work by undertaking a broad 'scoping/research' exercise amongst some NSW universities looking at what information and education would be useful to health and social care students in the area of Down syndrome (and learning difficulty issues in general). This involved consultation with several universities about their course content on disability. After some planning we recruited consultants experienced in the field of learning difficulty to progress the project.

Seven young people, 'Citizen Educators', were recruited to work with two education consultants to produce one day and two day workshops on Down syndrome and learning difficulty issues. The Citizen Educators were paid to work with the consultants for eight, three hour sessions from May-July 2008. The outcomes of this exercise were that the young people received focussed training to become educators. Together they discussed aspects of having Down syndrome and what it meant to have a learning difficulty label. They collaborated on the production of a 'train the trainers' package so that in turn other young people could be facilitated to deliver seminars and workshops. The implications of this venture for future development self-evident and are further discussed in Chapter 9 of this thesis in the suggested 'Citizen Engagement Project' model.

Following this training we returned to ACU to pilot a 'Citizen Educators' workshop in later in 2008 which once again went well. We distributed evaluation forms at the close of the session (collated afterwards by Katie using her word processing skills). The feedback from students was very positive.

We learned about different presentation styles. Jasmine and I were invited to speak at an Early Childhood Intervention Conference in Sydney. Because we did not have use of IT in the venue, Jasmine's mother, Heera, suggested we conduct our presentation in a "Question and Answer" format, this allowed Jasmine to speak spontaneously to the audience in answering the questions and hence proved to be a facilitatory technique. This also demonstrates the wisdom of parents and the importance of learning from their expertise.

6.2.4 Data collection: challenging the binary nature of researcher and researched

Research interviews were commenced in 2008. The construction of the semi-structured interview guides is documented in Chapter 5. Interviews were conducted across 7 'cases'. Each case consisted of: a participant of the Circles of Support Project who has Down syndrome; a parent or main support person (or two parents if both were willing to be interviewed); and the facilitator or 'team coach' matched to each young person. Andrew, the 'Team Voice', expressed an interest in conducting some of the interviews with his peers (with Down syndrome) alongside me. This took some practice as Andrew initially hurried through the questions leaving little space for me to explore points made via supplementary questions. Eventually, we worked out a 'team strategy' whereby he would read out each interview question which his peers would answer. If I wanted to pursue a line of inquiry and ask a supplementary question, I would indicate by raising my hand and he would give me space to ask the question. Flexibility and responsiveness to the wishes of the co-researchers is a key feature of PAR methodology. Having been interviewed by myself, Jasmine and Katie (on separate occasions) decided *they* wanted to conduct their own interviews, one with myself, the other with the Team Voice. Each formulated their own questions. Their interviews yielded further data, provided by myself and the Team Voice, and from the pertinent issues raised *within the questions* that these young women decided to ask both of us as co-researchers.

Reflections on data collection

In reflecting on my initial practice, the questionnaires for the semi-structured interviews of the young people were checked and approved by Andrew and Katie but were essentially designed by myself in order to look at what features of the project were enabling for the young people. This approach, though legitimate, I now view as inadequate from a participatory angle. I tried to offset this by sending out the interview questions to all research participants prior to the interview date so that they might have some time to reflect on how they might like to approach some topics, what points they would like to make and consider whether they might actually *not* want to answer some questions. Only two or three research participants overall read through the questions beforehand however.

The interviews were received well by most people. Katie commented about being interviewed about her current life:

When you are being interviewed...this shows you that they [the interviewer/s] are listening to you and they are interested in you and what *you* want and what *you* do (Katie, *my emphasis*).

Katie was appreciative of the care and attention being given, in interview, to matters that concerned her. She went on to provide further advice for interviewers in her feedback at the end of research processes in 2011.

There are a few good things to consider when you interview people. They are: listening to people you are interviewing. Being calm and friendly so that the person you are interviewing is not nervous (Katie).

Katie teaches us that human warmth and a comradely attitude are key components of building rapport with interviewees.

As Team Voice in the Circles of Support Project, Andrew worked closely with me in organising the project activity for one day a week for three years. As co-researcher he continued in this frame, positioned himself by my side to undertake some interviews with peers. In this scenario then, an 'individualised' strategy was used to embrace and work with Andrew's particular impairment. Working together as an

interview team engendered mutual respect and power sharing in the research process.

Andrew, Katie and Jasmine all effectively challenged the traditional binary positions of the 'researcher' and the 'researched' and the corresponding potential for replication of oppressive social relations therein (Oliver, 1992). Jasmine asked five questions:

- Do you have a disability?
- How do you know I have a disability?
- Do you know someone with a disability?
- How do you feel about this person?
- Would anyone in this group accept a person with a disability?

These questions in particular raised confronting issues about the nature and impact of a disability label and reiterate the need for people with learning difficulties to discuss and deal with 'the label'. Indeed, as the label is medically constructed (Mercer, 1973) and perpetrated via (often oppressive) social processes perhaps some people may wish to challenge or even eschew such a label? Rarely do people with learning difficulties get the opportunity to raise this topic and hence form and articulate opinions on such matters. Jasmine's questions are carefully analysed in the next chapter. Had Jasmine not taken the initiative, an important research finding would have been missed.

Thus by doing the research we learned together as we went along. Working and learning together in this Freirian mode created a positive mutual interdependence in the research. This demonstrates that, via access to participation, human connection occurs. The potential for creativity is enhanced producing, an Aristotelian whole which "is greater than the sum of its parts."

6.2.5 Data transcription

The audio-tape recorded interviews were transcribed verbatim by myself. This process enabled me to familiarise myself numerous times with the utterances and statements of all research informants (Silverman, 2005). The interviews ranged from twenty minutes to almost an hour in length. These transcriptions were reviewed

several times against the voice data to ensure their accuracy. As a collective data set, my transcripts from the young people informants, their parent/s (or main support person), Team Coaches, and my journal notes represented the "undigested complexity of reality" (Patton, 2002, p. 463 cited in Bazeley, 2007), of our project needing organisation to understand and make sense of them.

Reflections on the transcribed data

Transcribing the data gave me an opportunity to hear myself interacting with the co-researchers and reflect on my own approach. I had learned from working with various other groups of people with learning difficulties that I needed to be adaptive in order to maximise their participation in conversation. For example, I sometimes needed to re-phrase and re-articulate my questions and statements to make my communication more accessible (some of this experience could also have been due to my strong Yorkshire accent operating in an Australian context!). Likewise, in interview, I sometimes needed to repeat what I thought been expressed to me by the interviewee and ask for confirmation. This arose from a genuine concern for accuracy of understanding. However, problematic here is that this process can then be construed by those reading transcripts of such interactions as the interviewer asking 'leading questions'. The process can lead to a 'yes' answer if you have understood the person correctly. This can easily then be interpreted an example of automatic acquiescence and agreement on the part of the participant which is not always the case. As Circle of Support project coordinator I had noticed that parents sometimes 'checked out' meaning on occasion when interacting with their sons and daughters and interpreting their speech. Rapley (2004, pp. 78-106) discussed the issue of 'acquiescence bias' in research interviews with people who have a learning difficulty from a discursive psychological perspective and concludes that acquiescence is sometimes employed as a strategy of resistance. Given the above example, the appearance of 'acquiescence bias' could arise from an array of factors connected with the individual, their environment, the relationship between the interviewer and interviewee and the subject under discussion.

6.3 Participatory data analysis

The silenced are not just incidental to the curiosity of the researcher but are the masters of inquiry into the underlying causes of the events in their world. In this context research becomes a means of moving them beyond silence into a quest to proclaim the world (Freire, 1982, pp. 30-31).

Data analysis is generally recognised as the domain of university –based academics. Subsequently, with a few notable exceptions (Williams, 1999; Goodley, 1998; Goodly & Lawthorn, 2005; Richardson, 2002), there is still little published literature to inspire the non-disabled researcher and co-researchers in this critical stage of disability research. The inclusive/emancipatory research which has been undertaken and documented indicates a lack of opportunity for people with learning difficulties to get involved with data analysis. A number of studies (Minkes, Townsley, Weston & Williams, 1995; Lloyd, 1996; Stalker, 1998) also convey problems with the inclusion of people with learning difficulties in the data analysis stage of research.

Added to this, as explained in Chapter 5, is the fact that people with learning difficulty 'labels' constitute an extremely diverse group with a plethora of different abilities, approaches, personalities, modes of communication and so on; an approach which may fit with one group or individual with a disability may not suit another. My co-researchers were no exception.

This situation lays down the gauntlet for the PAR researcher to address. In relation to my work with this group of co-researchers then, my main concern was: How do we meaningfully collaborate at this stage? Could I facilitate a process whereby my co-researchers might themselves 'proclaim their world' rather than have me proclaim only *my* interpretation of their world? Such self-proclamation is compatible with the emancipatory projects of both PAR (Freire, 1982; Kemmis & McTaggart, 2005) and EDR (Barnes, 2001).

In this section I describe the participatory data analysis process which occurred in three phases: First, using a small portion of the data set, an exploratory 'participatory

data analysis phase' was undertaken alongside three of my co-researchers together with a non-disabled support worker. This process is described and the issues identified by co-researchers are elaborated upon. I then performed a more detailed analysis of all the data. Third, the co-researchers then discussed how to write this up into a research paper which we presented at a faculty research forum.

Rich and diverse data was available from the interviews. Table 6 shows the composition of the data set.

Table 6. Composition of the data set

<ul style="list-style-type: none"> • Notes from the project coordinator journal • Comments on the data analysis by co-researchers • A word document produced by a co-researcher (Andrew) • Conference presentations by participants • Written feedback from co-researchers about the participatory process
Interviews:
In total, 22 interviews were conducted about the Circles of Support Project:
1 interview with the coordinator (by a participant co-researcher)
1 interview with the team voice (by a participant co-researcher)
6 interviews with COS participants (3 involving the Team Voice as a co-researcher)
9 interviews with parents (by Miriam)
5 interviews with Team Coaches (by Miriam)

6.3.1 Emancipation Disability Research: Choosing a method of data analysis

Having worked alongside many of the co-researchers for between 2-3 years, by the time we came to analyse the data, I had a reasonable (but not exhaustive) knowledge of their skills and abilities. Given their diversity as a group it was not useful to 'pigeon hole' the co-researchers into predictable skill categories. As such it was impossible to be prescriptive, at the outset of our research enterprise, about how they might engage in the data analysis so a flexible method was needed.

In terms of the EDR framework (Table 4), I derived and applied the following guiding principles: Include disabled people in the data analysis in a way which is meaningful to them (Principle 1); Conduct the data analysis in a transparent, logical and rigorous

manner (Principle 2); Aim to produce findings which can be used for the tangible benefit of disabled people (Principle 3).

I needed therefore to find a method of data analysis which was credible, flexible and within these EDR requirements. Was it possible for the young people to recognise codes and themes in the data?

6.3.2 Responding to the steering group

An event in a research steering group meeting gave me some direction. I brought to the group meeting two de-identified transcriptions and asked my co-researchers to underline and make comments on the parts of the text which they thought were 'interesting or important', or both. Katie underlined words and phrases and made notes in the margin. From this experience, the potential for at least some young adults with Down syndrome to be closely involved with data analysis became apparent.

I began to look for other examples of participatory data analysis used in research which I might learn from. Williams (1999) described a process in her research whereby group members with learning difficulties were assisted to search for relevant text in accordance with themes which had been pre-determined by the research questions. Group members undertook a 'cut and paste' exercise for each theme. Williams tentatively described this method of analysis as "thematic content analysis". I noted that this process was similar to the one which Katie had initiated in our steering group.

The use of thematic analysis (in some form) therefore became a distinct possibility as an approach to data analysis that we might utilise and so continue to meaningfully engage the young people in the project.

6.3.3 Thematic networks as a rigorous analytic tool

Authors such as Bazeley (2009) caution that 'identification of themes' alone is 'endemic in research' and can lead to an over simplistic approach to data handling and a lack of deeper analysis of data. To 'do justice' to the data, Bazeley advocated strategies such as:

Improving interpretation and naming of categories; using comparison and pattern analysis to refine and relate categories or themes; using divergent views and negative cases to challenge generalizations; returning to substantive theoretical or methodological literature; creating displays using matrices, flow charts and models as strategies to enrich the use of qualitative data (Bazeley, 2009 p.6).

Bazeley's pertinent comments followed in the wake of those of other qualitative researchers who also argued for greater transparency of data analysis processes in research accounts (Thorne, 2000; Attride-Stirling, 2001). Such transparency (which is also a requirement of EDR) allows for accurate critique and greater accountability in terms of research findings.

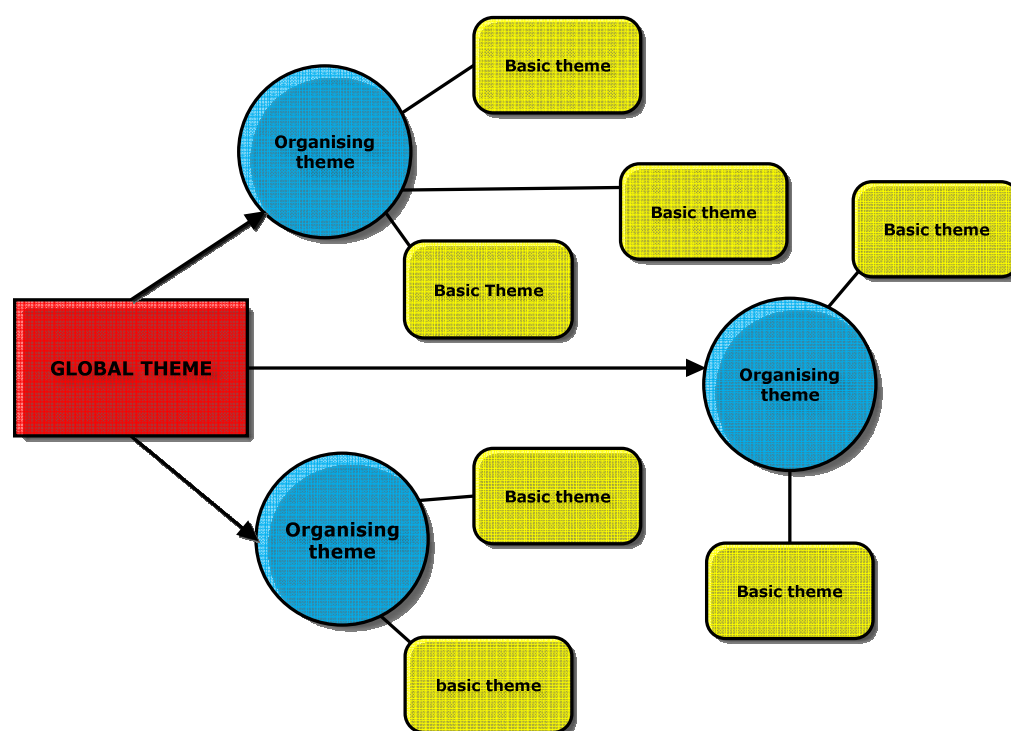


Figure 6. Web-like structure of thematic network. Reproduced with the author's kind consent.

Figure 6 is adapted from (Attride-Stirling, 2001, p.388) and is placed here with the author's kind consent. Thematic networks (TN) appealed to me as an analytic tool. Derived from Toulmin's Argumentation Theory (1958), Attride-Stirling (2001) re-names Toulmin's terms; "*data*", "*warrants*" and "*claims*", as: "*basic themes*", which are the 'lowest order' ideas evident in the text; "*organizing themes*", categories of themes grouped together to form more abstract principles; and "*global themes*" which express or encapsulate the major images in the text as a whole. TN is also a

transparent, explicit and highly developed form of data analysis which could be used flexibly to order and explain our data. Lastly, the networks also allowed for the gradual refining and linkage of themes, as the analyst moves in stages from substantive text to abstract concepts. The resultant ‘organic’ networks constitute very useful visual stimuli for contemplation, modelling and theorising at the latter stages of data analysis. I believed that my co-researchers could participate in the process through coding and identification of basic themes. Thematic networks are also a transparent, explicit and highly developed form of data analysis which can be used flexibly to order and explain our data. I wanted the ‘voices’ of all the research participants to be heard as loudly as possible in the context of this research project. In thematic networks, a number of ‘global themes’ can be produced. These networks simply provide a technique whereby text can be ordered and “explicit reasoning and implicit meaning” revealed. Attride-Stirling (2001) charts the course of thematic networks as a tool for data analysis (Table 7).

Table 7. The stages of thematic network analysis. (Attride-Stirling, 2001, p. 391).

Reproduced with author’s kind consent.

ANALYSIS STAGE A: REDUCTION OR BREAKDOWN OF THE TEXT

Step 1. Code Material

- (a) Devise a coding framework
- (b) Dissect text into text segments using the coding framework

Step 2. Identify Themes

- (a) Abstract themes from coded text segments
- (b) Refine themes

Step 3. Construct Thematic Networks

- (a) Arrange themes
- (b) Select Basic Themes
- (c) Rearrange into Organizing themes
- (d) Deduce Global Themes
- (e) Illustrate as Thematic Networks
- (f) Verify and refine the networks

ANALYSIS STAGE B: EXPLORATION OF THE TEXT

Step 4. Describe and explore thematic networks

- (a) Describes the network
- (b) Explores the network

Step 5. Thematic networks are summarized

ANALYSIS STAGE C: INTEGRATION OF EXPLORATION

Step 6. Interpret patterns

This process availed itself to adaptation for our participatory research process whereby co-researchers participated in the coding and basic theme stage which is Step 1 and 2 of analysis stage A. The strength of thematic networks is that they allow for this type of process modification without any overall loss of transparency or rigour.

6.3.4 The thematic networks process undertaken with co-researchers

Katie, Andrew and Jasmine indicated that they were doing the analysis with me together with Linda, a support person. My PhD supervisor identified a room on Sydney University campus to work in. This gave us a good workspace and an inclusive 'campus experience' for the co-researchers, which they enjoyed. We lunched (and de-briefed) at the campus cafes after every session. We worked together for six, 2 hour sessions on the data analysis from 5th August 2009 concluding on 21st October 2009.

Prior to our sessions I formatted three de-identified transcript documents by placing the text into a table and adding another column in which comments could be written as can be seen by the examples in the Appendices 10-12. The transcripts were 'de-identified' for the data analysis sessions but have been returned to the pseudonyms used throughout the thesis to retain connectedness and coherency for the reader.

Keen to see what perspectives originated from the young people themselves, like Williams (1999), I asked that the young people to highlight/underline and offer comments (if they wished) about what they felt was 'important' or 'interesting' in the transcriptions.

6.3.5 Katie and Jasmine's contribution to data analysis

Katie and Jasmine quickly 'assumed the identity' of researchers. They selected a number of transcripts each and quickly grasped the idea of coding using highlighter pens for words and writing notes in the margins, they soon began to use the terms 'code' and 'transcription' in discussing the data set. Some differences were apparent in both the way they coded; Katie would underline words in the text and make notes in the margins, Jasmine began by highlighting words but later started to make notes in the margins as well. There were also differences in terms of the perspectives by

which they approached the text. At 26 years of age, Katie was somewhat older and more mature than Jasmine (20 years) at the time of the analysis sessions. Both young women became more adept and fluent with the process of coding as the weeks went by. By the end of our sessions, Katie had coded four interview transcripts; three from ‘young person’ research informants (Isabel, Luke and Jasmine) and one from a parent (Margaret). Jasmine coded three interview transcripts; two from young people; Katie and Luke and one from the same parent; Margaret. Jasmine later asked for another transcript (Isabel) which she coded at home and mailed back to me. Examples of both Jasmine and Katie’s coding are included in appendices 9 and 10.

6.3.6 Group discussion of Katie and Jasmine’s data analysis

After Katie and Jasmine had concluded their ‘coding’ the “interesting and important” aspects of the text, we discussed the emergent ‘basic themes’ as a group. We all made general notes in the discussion which were written up purely in list form and then loosely grouped into themes as in Table 8.

Table 8. Summary of group discussion points following data analysis,

<u>Young person informant’s interview transcripts themes:</u>	<u>Parent interview transcript themes:</u>
<ul style="list-style-type: none"> • Getting to be more independent from parents • Getting a good job • Friendships and Relationships • Communication • Opportunities to keep growing and learning • Importance of Faith and culture 	<ul style="list-style-type: none"> • Restoring aspirations and hope for their children with Down syndrome • Learning about sons and daughters true abilities • Learning to step back and gradually let go • Ability for their children to act independently

Reflecting on the group discussion of findings however, I perceived there were two barriers to an accurate discussion of the codes and themes which Katie and Jasmine themselves had identified. Firstly, lack of time availability precluded detailed discussion of the data analysis in the actual sessions (and there was almost no time available to look in detail at Andrew’s report). Secondly, Linda and I shared many of our own observations on the transcripts in that discussion, giving a rather ‘mixed’ result in terms of the themes. So, although all three co-researchers were part of the discussion and there was a general *consensus* on the above themes as a group, I was very keen to re-read Katie, Jasmine *and* Andrew’s work after the sessions had concluded and try to give a ‘purer’, more nuanced and authentic account of the

‘voices’ and perspectives of all three co-researchers in data analysis. A separate form of analysis, based on thematic networks, was used for Andrew’s report as, in effect, he had produced more ‘data’ in relation to the research process.

6.3.7 Exploring co-researcher perspectives on the transcripts

It is important to make explicit the role which Katie and Jasmine played in the analysis, partly because from an emancipatory and participatory viewpoint, the ‘participatory’ activity of co-researchers is as important to this study as the findings from the data. Additionally, an exploration of this initial data analysis process gave valuable insight into what topics Katie and Jasmine perceived and valued within the transcribed interviews.

There is unfortunately little space to do justice to all the analytic work undertaken by co-researchers however, below is a discussion of the key theme of ‘friendships and relationships’. As I discuss each ‘theme’ they found, I offer supporting quotations from the text, I underline what has been highlighted/underlined by each young person from the text and add in any comments which they made in the margin after the quote *in italics*.

The importance of friendships and relationships

Katie repeatedly selected issues connected to friendship for comment; for example, in this excerpt from Isabel’s interview, Katie’s frequent commentary demonstrated not only her own thoughts about the importance of friendship, but also her insight into the multi-faceted nature of friendship:

(Isabel) Well what I actually wrote down was ‘spend time with your friend’ which I don’t see for a long time.

Katie commented: *“That’s an interesting fact and is very important too.”*

(Interviewer) Yes, you have not seen a friend for a long time?

(Isabel) Yes, I’ve not seen her for a long time because she’s been busy and stuff

(Interviewer) Who is that?

(Isabel) My friend called Vanessa

Katie commented: *"Keeping in touch is a good way to catch up"*

(Interviewer) OK

(Isabel) My friend called Vanessa; I haven't seen her for a long time.

Katie commented: *"Sharing her feelings about her friends and how much it means to her."*

(Interviewer) Where does Vanessa live?

(Isabel) She moved town, she moved to somewhere else in another area

(Interviewer) Oh right...do you miss Vanessa?

(Isabel) Yes

(Interviewer) Oh, well maybe you can arrange to meet her?

(Isabel) Yes

(Interviewer)Have you spoken on the phone?

(Isabel) No

(Interviewer) Oh, do you know her number?

(Isabel) Yeah, I've got her number down

Katie: *"Contacting friends to stay friends"*

(Interviewer)... You could catch a movie or have a coffee.

(Isabel) Yeah, we could have lunch

Katie: *"Catching up with a friend is a good thing"*

Via her commentary, Katie clearly makes the point that friendship is important; she is sensitive to the fact because Isabel mentions that she has not seen Vanessa for a “long time” This is significant for Isabel, who has, for now at least, lost contact with her friend and misses her presence in her life. Katie often interprets the text assertively; “catching up with a friend is a good thing” and “contact” is necessary to maintain the friendship, to “stay friends”. She later focuses again on the commentary around friendship in Luke’s interview:

(Interviewer) what do you feel are the most important things you are doing with your life at the moment?

(Luke) well, I like doing horse riding, and I enjoyed myself at every Up, Up and Away workshop that I participate in.

Katie commented: *“make new friends, socializing and participating in workshops and helping others”*

In this instance, Katie is probably adding in her own subjective experience of the Circle of Support Project workshops where the young people would meet, engage in conversation about their lives, and assist each other in performing tasks. These are elements of the workshops which Katie obviously enjoys and values. She picks up again later on the significance of friendship highlighting the word in the text:

(Interviewer) what about your friendships do you know any new people?

(Luke) well I have met Jane and Katie and they have been good friends and we have a good friendship going and we just get along we go on outings with the Club. Some of the guys who I am friends with are real friends who I want to be with in life.

Katie commented: *“socializing and catching up makes a good friend”* And later:

(Interviewer) Have you achieved any of your goals since you joined the project?

(Luke) well one of the goals that I did achieve was to meet CW (NRL [Rugby] Player) and made a great impact on me because I haven't met him before and getting to know him and that and one of my goals that I am still doing is how to e-mail like my family and my friends and all that and my team coach and the project coordinator.....

Katie commented: “socializing on line or by phone to friends”

In this quote, Luke is talking about learning how to email. Katie however emphasises that this is a vehicle by which to socialise and connect with others. Her ‘friendship oriented lens’ is also evident when Luke states that he likes to “spend some time on the phone to my girlfriend just to catch up and I like to listen to my music all the time, watching TV and I like being in the project”. Katie makes a statement at this point “Doing exciting things with friends and other people is more important than being bored at home.” In this observation she is also asserting that friendships are connected with excitement and (possibly) ‘adventure’ outside of the confines of a parental home and that participation in the community outside of the home is “important”.

Similarly, Jasmine identified aspects of Katie’s interview transcript which placed emphasis on friendship:

(Interviewer) When you say you’d like to live independently some day, what would that mean; would you live on your own?

(Katie) I would want to live with friends and friends could come and visit.

Jasmine underlined “friends” and commented “visiting would have to happen”, stressing that engagement with people outside the home is important, she also picks up from Katie’s interview transcript that workshops helped Katie in “meeting new friends, new people...” in so doing she cites and acknowledges the stimulus of fresh relationships. Katie also identified sections of text dealing with relationships (with a boyfriend or girlfriend) as important:

(Interviewer) So what things about your life are most important to you?

(Isabel) Just being myself,

(Interviewer) What do you look forwards to doing?

(Isabel) I look forwards to being with my boyfriend Ian, I like spending time with him.

It will be our anniversary this Thursday.

Katie commented that Isabel *“likes to talk about boyfriends and positive things about them which make her happy”* and adds, next to Isabel’s news of her ‘anniversary’, that it is *“a special moment of her life, being happy.”*

Co-researchers also note some of the challenges of intimate relationships however:

(Interviewer) So do you think workshops wise are there any other things that we could cover, are there any other subjects that we could have talks about as a group?

(Jasmine) I can’t think of anything, we could talk about relationships more and how to stop a relationship when you know that something is going to happen to you.

(Interviewer) How to protect yourself?

(Jasmine) Yes, especially relationships when you are in love with somebody and you have to say no to that person. How you stand up to that?

Katie responded to the question Jasmine poses in her interview transcript by commenting *“Bravery- but be careful when you are standing up for yourself.”* Perhaps Katie has had a difficult response from someone when she has tried to assert herself in the past?

Jasmine and Katie also selected text which dealt with family relationships. For example:

(Interviewer) OK, and who are your team of champions Isabel? Who are the important people in your life?

(Isabel) That would have to be my family and my friends.

Katie observed that the “Team of Champions [Circle of support] helps with a lot of things like building relationships and achieving their daughter’s goals.”

When Luke tells the interviewer “I like to spend some time with dad going to watch the rugby and then spend some time with mum as well when she is not working and when she is not doing anything else I like to spend some time with them going out for walks with them”, Katie advised that “spending time with your family is a good thing to do”. Equally, Jasmine highlighted areas in Luke’s interview transcript concerning family relationships:

(Interviewer) has anything about your relationship with anyone in your family changed?

(Luke) well I am still with my family they still support me and we have all got involved with the project.

Later, in the same transcript, as Luke talks about his family, Jasmine highlighted the text thus:

(Luke)with Lily she said I am getting very independent with what I do in the project and my brother Robert he does his own thing and he like he is very supportive and gets himself involved as well. And Jim says it is so great to have me involved in the project and to meet new people.

Jasmine could relate to Luke’s appreciation of his family’s support and involvement. Interestingly, she underlined ‘independence’ in the second passage indicating a view that ‘needing support’ and ‘having independence’ are not crude, mutually exclusive concepts.

6.3.8 Adapting thematic networks for Katie and Jasmine’s analysis

Through identifying what is ‘interesting and important’ in the data, I inferred that Katie and Jasmine had identified their own basic themes and organizing themes. For example; a basic theme, supported by textual data, would be “going out with friends” and this would be part of an organizing theme called “friendships and relationships’. From the detailed discussion above, it is evident that no theme is categorical or exclusive; many themes are inextricably intertwined in the complex ‘web’ of the data set. From these themes, I then started to construct webs of basic themes around organising themes to register Jasmine and Katie’s work and meditate upon possible global themes. As you can see from the diagram (Figure 7), a distinct global theme

was emerging as an image in the data: 'The need for positive connection with other human beings.', which became further refined to 'HUMAN CONNECTION'.

This global theme was a major outcome of all the analysed data from the young people.

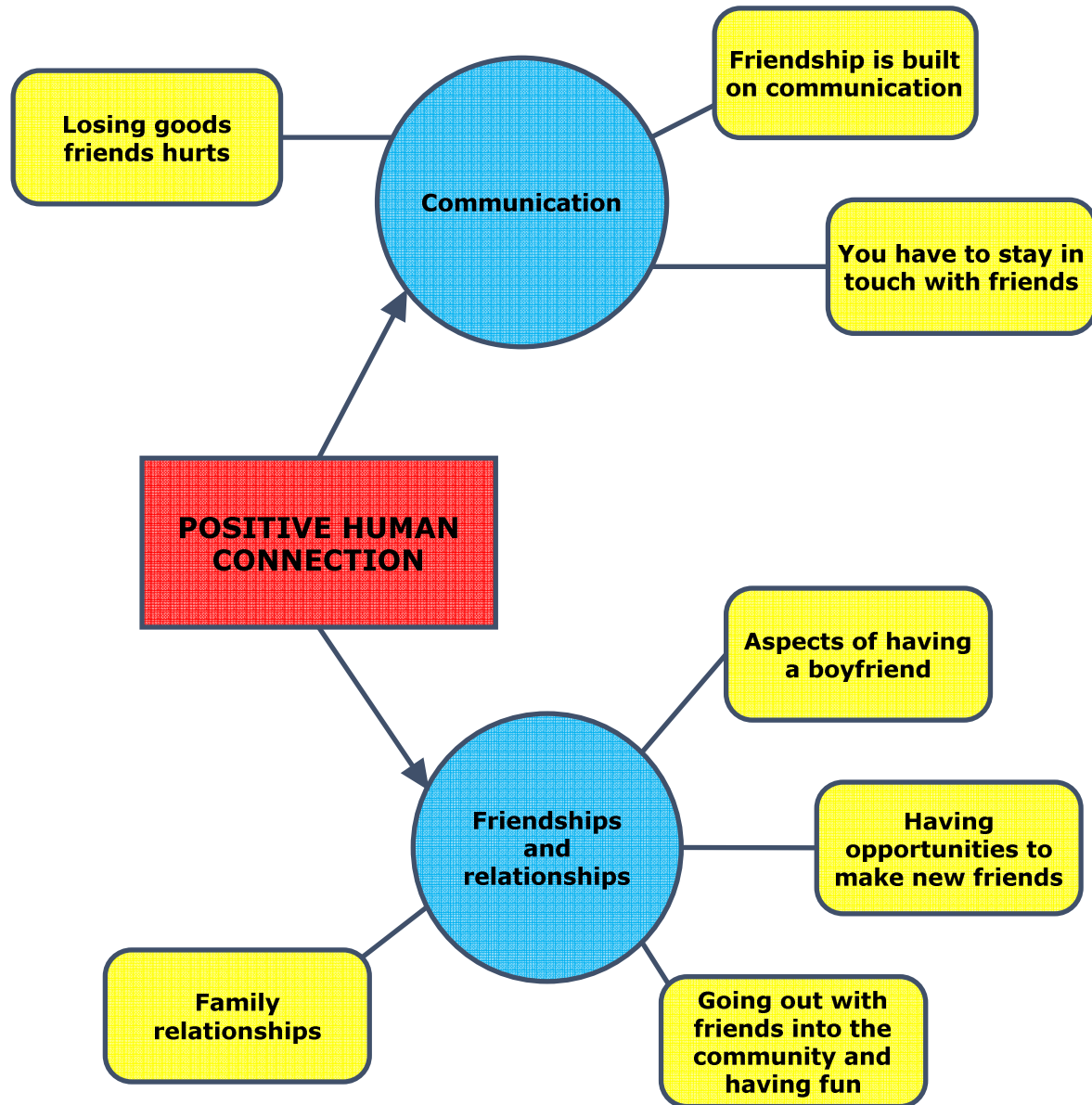


Figure 7. Katie and Jasmine's early thematic web

6.3.9 Completing the analysis: the work of the non-disabled researcher

It is important to explain the links between Stages A of thematic networks analysis with co-researchers and Stages B and C. I organized the 'interesting and important' statements identified by Jasmine and Katie into basic themes and then deduced

organizing themes and identified global themes. The extract in Table 9 is an example of the conduct of this phase.

Table 9. Integrating the data analysis of co-researchers and non-disabled researcher

Interesting and important issues in text; determined by Katie and Jasmine (highlighted words and comments in margin). Non-disabled researcher identifies codes in all young people's transcripts.	Basic themes identified by non-disabled researcher	Possible organising themes identified by non-disabled researcher	GLOBAL THEME
<ul style="list-style-type: none"> • Spend time with friend (R) • Keep in touch (R) • You miss the friends you lose (R) • Catch up with friend(R) • Sharing feelings about friends (R) • Feelings about friends are deep and mean a lot(R) • Keep in contact to stay friends(R) • Get to know each other(R) • Building relationships is a most important goals(R) • Socializing and catching up makes a good friend(R) and (L) 	<p>Friendships where you can share your feelings are very important</p> <p>It's good to have a few friends/meet new friends</p> <p>Friends can help you do and achieve things</p>	<p>The benefits of connections with others</p> <p>Issues associated with building and maintaining connections</p>	HUMAN CONNECTION

I performed a detailed analysis of *all* the data from the young people, refining basic and organizing themes but retained the essence of early organizing themes identified by Katie and Jasmine's work. When all the data had been analysed four global themes emerged which depicted their areas of interest and concern as citizens. These are discussed in the next chapter.

Reflections on participatory data analysis

This is not a 'generalisable' method of data analysis. Appropriate data analysis methods will vary from person to person, group to group and from context to context. Not all people with learning difficulties have access to text but the fact is that some do and coding data can be made accessible to this group. This approach advocates that flexibility and a curiosity about how participation can be achieved, even in data analysis and can lead to some positive experience. Reflecting on the analytic process for herself, Katie had this to say:

I liked coding transcripts and interviewing Andrew about the research. The research was interesting and important to me....The good thing about doing the data analysis.../ was allowed to read and highlight what / think is important from the transcripts (*Katie, my emphasis*).

Co-researcher Katie's feedback here is significant on two levels, firstly through being involved in the process she has evidently gained access to and learned appropriate use of 'research terminology' such as "transcripts" and "coding", which demonstrated both her interest in the research and her continued ability to learn new skills and concepts. Secondly, she almost intimated that it was a privilege to be "allowed" to read (de-identified) transcripts. *Katie* had determined what was important in the text rather than someone else. This comment revealed Katie's perspective on how power is exercised within the research process. Many forms of qualitative research (including elements of this thesis), are based on private interviews where data is collected, analysed, theory is built and then, if practice is good, feedback is given to the group 'en route' in the form of data checking.

Both Jasmine and Katie evidently enjoyed being involved in the analysis. Both young women brought with them literacy skills. This may not always be the case, as Katie advised in her feedback "some people have some difficulties in reading and may need some assistance". Katie here is spontaneously articulating that some people have a learning 'difficulty', not that they cannot learn and participate with "some assistance", which again shifts thinking towards the social model and moves away from medicalised doctrines and language which encourage us to view learning difficulty as a 'fixed' global incompetence (Rapley, 2004). The term 'intellectual disability' possibly also reinforces this. Katie took power as a co-researcher clearly thinking about future participatory research projects like this. She recognised her own potential as a co-researcher and advised me as a non-disabled researcher about the support some people with a learning difficulty may require in the future in participating as co-researchers.

Tuffrey-Wijne, Bernal, & Hollins (2008) made the important point that when we harvest data from people with learning difficulties we seldom ask for their permission as to whether we can build theory from it. This also raises the issue of whether we should harvest data from people with learning difficulties, and then *make the assumption* that they are unable to engage in any kind of theory building around it. If we accept this without question, we perhaps tacitly reinforce ‘exclusionism’ and the elitist notion that only a privileged few academics can understand, build and hence ‘own’ theory. Whilst this research attempted to straddle the (often incompatible) ‘camps’ of the academe and the ‘inclusion needs’ of people with a disability perhaps we need to reflect upon which of these takes priority.

The use of thematic networks as a tool for analysing the data (Attride-Stirling, 2001) was a structured and transparent qualitative analytic process. The clear steps made it accessible for some co-researchers. Both Katie and Jasmine participated meaningfully in the data analysis and identified major issues which informed the creation of two of the global themes discussed in Chapter 7.

6.4. Andrew’s Report: The political voice of the project

6.4.1 Andrew: “writing about research”

Although Andrew had been keen on the idea of data analysis in principle, when we arrived at our sessions and discussed the process, he decided he did not wish to participate in thematic analysis of the data. Andrew made it clear that he preferred the use of IT technology to ‘pen and paper’. We discussed what he would like to do in the time and Andrew indicated that he wanted to use the word-processor to “write about the research” as he put it. The result of his work over the 6 sessions was a 2900 word document which he entitled:

All Hearts Contains In The Research
Transcripted & Researched Disability Advocacy Disabled Of [Host Disability NGO]
New South Wales

At first glance, much of Andrew’s report appeared ‘incoherent’ and I initially found it difficult to understand. This is one of the paragraphs he wrote (preserved in its emboldened font):

The people with disabilities must be in the research become from that rights be involved in the researches decided on the fat of extra efforts into the work of the social work networks about to join in with this research and what takes to come a long at this research from being to desires them being involved with this research and be there best from the mix of the disabilities and social work networks being involved with the research all hearts contains with the research (Andrew, 2009)

On closer examination, however Andrew' work was a puzzle with inherent meaning. He had used sophisticated language which was clearly linked to research and the issues we were engaged with. It is quite possible that Andrew had not received the education in literacy to express his thoughts more coherently. Close reading of his work revealed the repetition of a number of key words throughout his report such as "research", "networks/s", "choice/s", "advocacy", "outcomes", "desires", "policies", "education" and much use of the word "better". Andrew was proud of this piece of work and clearly the terms he had used were significant. Looking again through the social model lens, my challenge as an 'activist researcher' was to tackle the barriers around understanding how to use this work within the context of the analysis phase. I decided to count the number of times he had used certain words and select all the short sentences which 'made sense' and incorporate these in the thematic networks and subsequent discussions (Table 10)

Table 10. Arrangement of frequently used terms in Andrew's report into groupings

Words and frequency	Organising theme	GLOBAL THEME
Research (45- references) Transcript/s (54 references) Matter/s- 42 Issue/s-25 Ethics- 2 references	Research processes and terminology	PARTICIPATORY RESEARCH (ANDREW'S INTERPRETATION)
Option/s-27 references Advocacy- 13 references Desires-11 references Rights-3 references Choices are better- 2 references	Rights and Choices	

Network/s (34 references) Effort/s (13 references) Social work network (7 references) Heart/s (6 references)	Caring and working together	
Better- 141 refs Policies -5 Education- 4 references	Policy and Education	

From Andrew's report it became therefore easier to interpret his writing and distil his thinking about the participatory research process. I was well aware of Andrew's writing style as he had written reports with me before as Team Voice for the COS Project reference group. It is quite possible that Andrew did not receive the literacy education that he needed to enable him to express himself more clearly. Evidenced in his report was that: (i) Andrew had become aware of the terminology associated with research and research processes which had been gain via having access to the 'research arena'; (ii) Andrew had perceived that what we were engaged in was associated with the expression of choice and respect of rights as human beings; (iii) Andrew saw the research could possibly influence policy and the education of others; and (iv) that this was a collective enterprise which required effort, " all hearts" needed to be engaged, in working together and hence "contained in the research":

The mix of the disabilities and social work networks being involved with the research all hearts contains with the research (Andrew, 2009)

"The disabilities", Andrew refers to are disabled people, "social work networks" refers to myself and Linda. Andrew's four organising themes can be represented diagrammatically as a thematic network below (Figure 8):

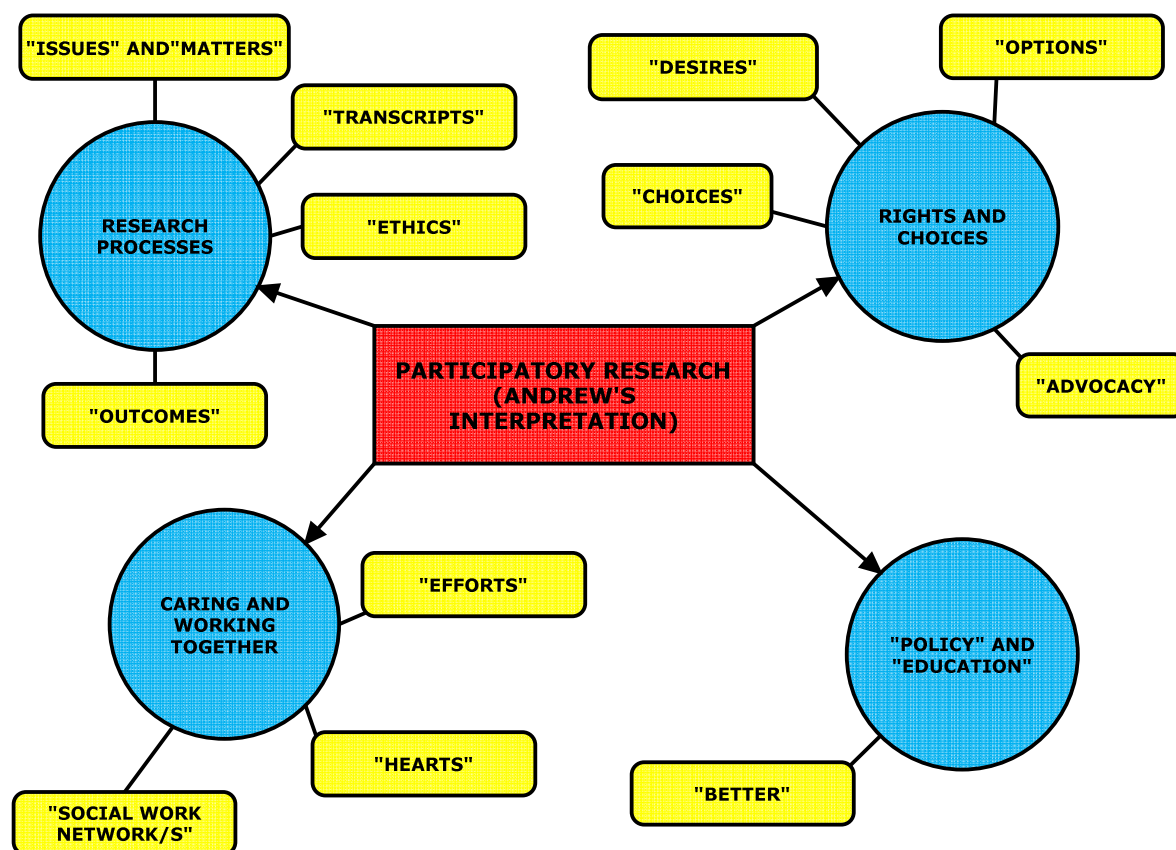


Figure 8. Andrews's interpretation of the participatory research process.

Importantly, although I had never discussed with the co-researchers that our research could influence policy (as it was quite an assumption to make), Andrew expressed an understanding of the political implications of research, the need to participate and the strength inherent of working together. This understanding could possibly have arisen from his involvement in the NSW Council for Intellectual Disabilities.

The people with disabilities must be in the research (Andrew, 2009).

Andrew's self-advocate report was, once more an example of a spontaneous contribution and a product of a flexible approach to how the co-researchers made their unique contribution to the research.

6.5 Further critical commentary on aspects of the participatory process

6.5.1 Barriers to participation within the prevailing academic culture

There are far too many seminars, workshops and conferences by academics for academics, and far too few educational innovations with the 'grass-roots' ... (Finkelstein, 2001, p. 14).

My doctoral supervisors gave support to our research project and other social work academics and students warmly welcomed my co-researchers into the university on numerous occasions showing interest and giving feedback in our presentations. The impact of the university opening its doors to us and including the co-researchers in its processes was significant as identified in the previous discussion. A need for proactive and thoughtful accommodation of community members on the part of the academic community is required. Having conducted data analysis Katie, Jasmine, James and I were inspired to write a research paper about our experience with the hope of publication. We initially wanted to present the paper at a research students' forum at the university, where I am currently enrolled, in June 2010. I wrote the paper and the young people produced an accessible account which was appended to the paper. There was also a faculty prize for the best paper which we decided to enter. Although I had presented at the university numerous times, in the previous three years, with co-researchers, I was informed that I could not enter for a faculty prize with a co-authored paper (even though I had not written it with another student or other academic). Neither could I enter for the prize as a single author and co-present with others. At this stage I decided to withdraw from the competition but sent an explanatory email (quoting Freire, 1982) to the faculty explaining that we were conducting PAR and that my co-researchers had Down syndrome. I received a return email stating that I could co-present but could not submit a co-authored paper for the prize. As we had diligently prepared presentations, we decided to go ahead (see extract in Appendix 13). Although I received a 'Certificate of Appreciation' on the night, I had to request certificates for my co-researchers who had made a considerable effort to be there and contribute. This episode suggested (in some quarters at least) a lack of knowledge about the ethics and practice of PAR and did

not support research activity which set out to include members of an oppressed social group. There was a pre-occupation with research 'ownership' which missed the point of the participatory nature of the project and what we had achieved together as a group. Within a university which has an express community engagement philosophy, I am hopeful that the faculty have learned about PAR from this episode.

Similarly, Katie and Andrew came to present a peer reviewed paper (Stevenson, 2007) with me at a three day specialist learning difficulty conference in Perth in Western Australia in 2007. I managed to pay my registration and accommodation fees via our university post-graduate research support scheme. My co-researchers however, had the same accommodation costs and also had registration costs, even though they were presenting alongside me. Being in receipt of only their disability pensions (benefits) at that time, neither of my co-researchers could fund their attendance. Luckily, a chance meeting with a community charity member (who was enthused by the project), culminated in funding for their participation, which they thoroughly enjoyed. Just as (funded) university based research academics are able to network, share pleasant food and amenities, so were my co-researchers. Barriers to participation were such that my co-researchers had to become 'recipients of charity' in order to attend a conference about learning difficulty. This paradox needs to be addressed.

6.5.2 Sparking interest in more research

Access to the 'conduct of inquiry' generated real interest in not all but some of the participants. In their feedback back both Jasmine and Katie stated that they would like to get involved in more research projects as a result of their close involvement with this research. Notably, the topics they were interested in exploring were not located within what might be regarded as 'Disability Studies.' Katie was enthusiastic about learning about "different countries in the world and how other people live." Jasmine wanted to research caves and geology. Again this reminds us that people with learning difficulty labels may wish to research areas other than those concerned directly with 'disability issues' (Iwamoto, 2005).

6.5.3 Providing opportunities for paid work

The opportunity to offer paid work to co-researchers for some aspects of their research activity gave them some acknowledgement of their contribution which was appreciated. There are very few university based researchers who work for free.

6.5.4 The benefits of a longer term project

The long term nature of the research project, which has been running from March 2007, has enabled myself and co-researchers, parents and project staff to get to know and trust each other and build a rapport which has undoubtedly enriched the research partnership. The broad parameters of our relationship allowed us to discuss more controversial aspects of learning difficulty very openly, for example two of the participants shared with me the fact that they worried that their mothers had become distressed when given the news their babies had Down syndrome. Insights and understandings eventuate which do not evolve from conducting interviews alone. The depth and longevity of researcher relationship with the young people and families maintained my focus upon the central concerns of the research and I was able to gain a much deeper and holistic knowledge of the community. There is great ethical responsibility attached to this privileged position however. Care and respect must be accorded when explaining disablement in people's lives (Richardson, 2001).

6.5.5 The benefits of an action research field of inquiry

This had some similarity to ethnographic research but the participants were not a group I was simply reporting on to an academic audience, rather this was a 'Freirian dialogue', a consensus building, action oriented and collaborative venture.

Although there are challenges in engaging in a living, developing 'entity', from a methodological viewpoint, an action research project appeared to be particularly enabling for co-researchers, providing a 'live' and dynamic field of inquiry. Data was drawn from contemporaneous views and opinions on the lived experience of being a Circles of Support project participant, staff member or parent. A field of 'energy' was generated because every participant was engaged in a 'happening'. The Circle of Support Project processes are having a tangible effect in terms of events, relationships which are impacting on the fabric of the lives of participants in various

ways. It is this *process* knowledge which then becomes a most valuable asset in terms of the research findings.

6.6 What becomes of the co-researchers?

An important issue arising from the participatory research was the co-researchers having due credit for their contribution and some continuity of research engagement. In 2009 I nominated Katie for an honorary degree in social work at the University of Sydney (which unfortunately was turned down). It is important to note that participation in the Circle of Support Project and the Voices for Change research was not pivotal to the daily lives of the co-researchers, nor did it become so. All participants had other jobs or training commitments (as did I). Katie and Jasmine both obtained posts in open employment with companies in the city in 2009/2010. Andrew runs his own evening music business and moves day jobs frequently as he is generally offered unskilled labour which does not engage his interest. In terms of the research group I have maintained my involvement with Andrew, Katie and Jasmine and their parents. I remain a member of Jasmine's personal circle of support. They would all like to participate in more research. We last presented together for an AASW industry night in June 2011 and, although writing up the thesis has led to a rather cloistered lifestyle for myself over the last year, we will no doubt continue to present the research findings at every opportunity and pursue further co-authored papers.

After submission of this thesis I hope to have negotiations with the university with regards to recognition of co-researchers. I have ambitions to set up a PAR research/consultancy group within the Host Disability NGO now that I have reconnected with the organisation to work on their state-wide project.

Concluding remarks

The participation of co-researchers in academic research processes brought about an increased confidence and self esteem, access to learning about research and subsequent evidence of their growing ability to conduct research and reflect on the process hence producing knowledge about the some of the possible support needs of people participating in research. More opportunities for self advocacy both individually and as a 'collective' were generated via presentations at conferences

and university seminars. The data analysis process demonstrated that it is quite feasible for some people with learning difficulty labels to have a role alongside non-disabled researchers in theory building. The participatory process also exposed enabling practices and attitudes and disabling barriers to participation in both specialist disability and academic environments. Had the research been more pre-planned and pre-meditated there may not have been the level spontaneous participation which eventuated. Whilst I initiated, organised and facilitated their participation, the co-researchers brought ideas, views and reflections into play at most key stages in the research. Another important point emerges from the findings on the research process. Jasmine, Katie and Andrew have enhanced support needs in some areas but *also* have access to text and literacy skills. Assumptions of global incompetence are often made in respect of people with learning difficulties and their genuinely diverse skills are rarely acknowledged along with their diverse support needs both of which are often context specific. This level of participation also tells us that once the doors and minds of the academe are opened and social research demystified, there are many people who could meaningfully participate who are currently excluded. The co-researchers were reminiscent of the “border crossers” a term coined by Peters (1996) as he referred to young disabled people whose personal battle to be included in the mainstream can continue to shift established perceptions at a societal level.

Encapsulated in the work of Andrew was the notion of participation and inclusion as paramount. Their commitment to participation over the years of the research process is testimony to this also. This is echoed by other self advocates who have a learning difficulty (e.g. Harrison, Johnson, Hillier & Strong, 2001; Martin, 2006; Cromer, 2002). Their collective emphasis is on being respected as people with abilities, equal citizenship rights and being included in the aspects of community life that they choose. People with a learning difficulty throughout history have been systematically devalued as citizens excluded from society therefore community members need to explicitly and intentionally work with people with a learning difficulty to maximise participation at every opportunity, this includes researchers.

7. The voices of the young people

Chapter 6 documented the participatory research process and early analysis of part of the data set for young people. This chapter discusses the findings of **all** the data analysis from young people with Down syndrome undertaken by myself. Their data is kept separate from that of parent and project staff. An exploration of the thoughts, feelings and insights of the young people foregrounds discussion in Chapter 8 which contextualises the global themes identified in this chapter in the findings from parents and project staff.

7.1 Links with the participatory data analysis

It is important to stress the linkage of this chapter with the process of inclusive data analysis described in Chapter 6. Some of the data which Katie and Jasmine identified as important and interesting was concerned with the organising themes of 'communication' and 'friendships and relationships' which were initially attached to a global theme of 'POSITIVE HUMAN CONNECTION' (Figure 7). The need for human 'connectivity' in terms of peer, family and wider community relationships are supported in earlier literature (Emerson & McVilly, 2004; McVilly, Parmenter, Stancliffe & Burton-Smith, 2005). Friendships in particular, are seen by people with learning difficulty as central to a sense of identity and social inclusion. In turn, this demonstrates the importance of data reduction in qualitative analysis in identifying and crystallising the significant issues within the data set.

7.2 Summary of Global Themes in Chapter 7

Moving on, this chapter contains an analysis of *all* the 7 pre-planned interviews with young people undertaken by myself and Andrew. In addition, the *questions* which Jasmine asked myself, when she decided to interview me as a co-researcher and the *questions* which Katie asked Andrew, in his capacity as Team Voice for the project are included as part of the data set as valuable insights into the concerns of both young women.

From a detailed analysis of all this data, four global themes emerged:

HUMAN CONNECTION: Identified in the inclusive data analysis, this global theme deals with human relationships as articulated by the young people and the overall emergent message that HUMAN CONNECTION is of great value to them. Elements

of this global theme include the organising themes of: “The benefits of connections to others”; “The issues associated with building and maintaining connections with others” and; “Spiritual, cultural and environmental connections to others”.

CONTINUING PERSONAL DEVELOPMENT: this global theme identifies issues which the young people allude to as relevant to their personal growth, another strong theme that surfaced in interview data. Continuing personal development consists of two organizing themes: “Building up communication and life skills” and “Dealing with the label”. This global theme is closely linked to, yet distinct from the next global theme.

COMMUNITY CONTRIBUTION: discusses the varied ways in which young people see themselves as making a contribution to society in the form of “self advocacy, disability activism and helping others” and the importance of “entering the world of work”.

THE DIGNITY OF RISK: explores the significance of a degree of ‘risk-taking’ to the young people.

The analytic process used in respect of the data has been laid out clearly in Chapter 6. To maintain a rigorous and transparent analysis, each global theme with its organizing and basic themes contained therein is illustrated in turn in diagrammatic form. Each theme is described under each of its organising themes using supporting text from the young people’s interview transcripts. Literature relevant to each global theme is cited in the discussion to support, challenge or enhance its meaning.

This section is intentionally rich in quotations from the young people informants as it presents a rare opportunity for their voices to be heard (Freire, 1982) and hence provides direct insight into their concerns as citizens.

7.3 HUMAN CONNECTION

‘Connectivity’ is a vital part of being human (Freire, cited in Khan & Kelner, 2007, p. xxxvi). Whilst it is self-evident that relationships occupy and enrich our lives, the analysis of data showed the myriad of concerns of the young people in respect of relationships. This theme was the most explicit theme within the data set for the young people. The thematic network (Figure 9) illustrates concisely the three key organising themes on which HUMAN CONNECTION is based.

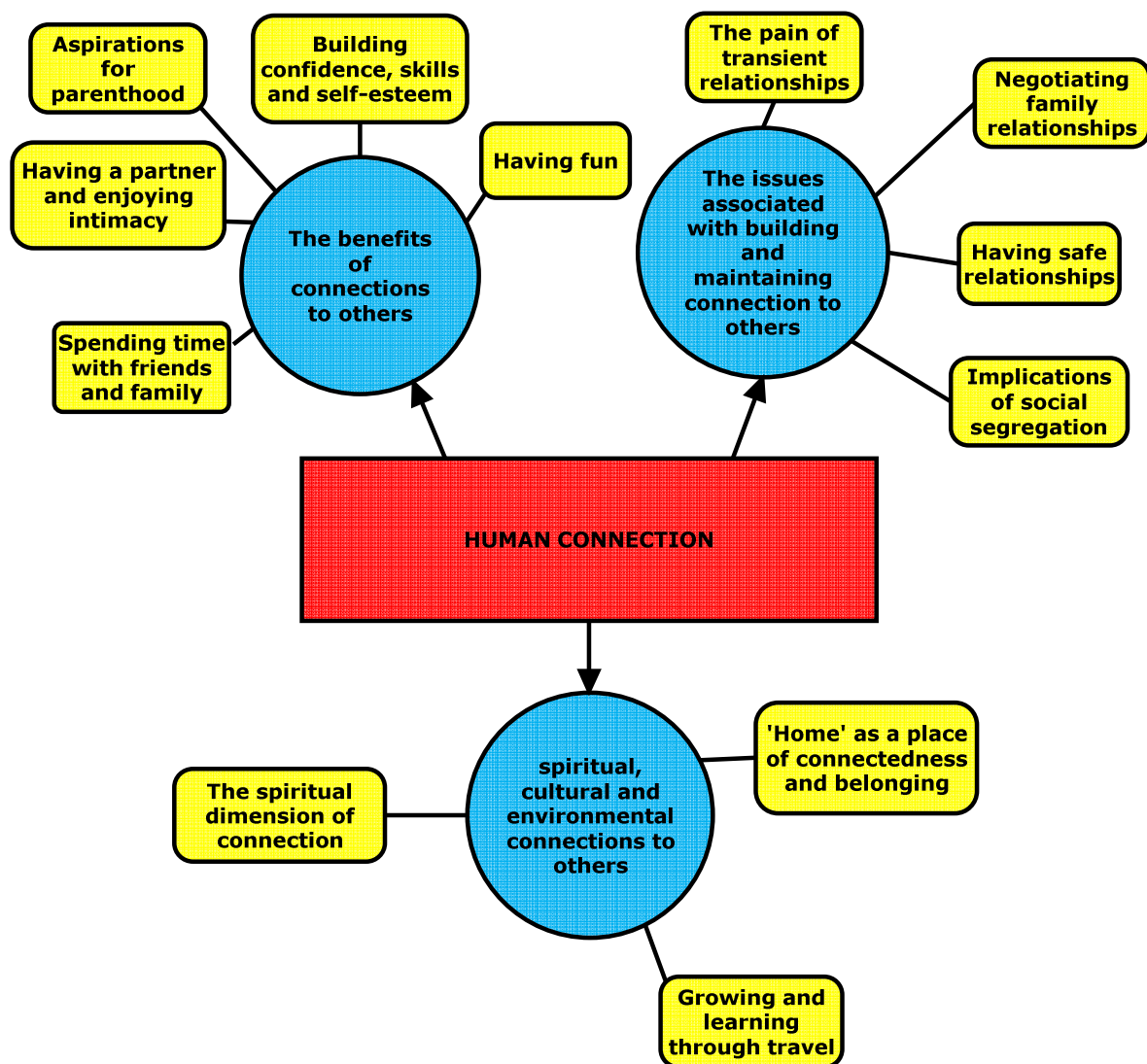


Figure 9. Global theme: HUMAN CONNECTION

7.3.1 The benefits of connections to others

This organising theme relates to the positive impact of different types of relationships which are cited by the young people. Beneficial human connectedness is conceptualised here in terms of how the young people speak positively about the relationships they have and/or have made in the time they were participating in the Circle of Support Project.

The positive features of having a partner are evident: Isabel's pleasure in "spending time" with her "boyfriend Ian" is alluded to in chapter 6. The relationship gives her something that she "look(s) forward to", he features strongly in her future plans,

evidenced by the fact that she is determined to move into a flat with him at some point.

When discussing the Circle of Support Project, for most of the young people, its major attraction was the opportunity to make new friends. Friendship was defined by young people in terms of a 'two-way street' with *others* getting closer to *them* as important as their closeness to others:

Well, when I joined I met new friends, meeting the coordinator and the patron and especially the Team Voice like yourself (Luke).

Coming to know about the project I get to know a lot more friends, a lot more people will get really closer to me...and its came to be a greater joy (Jasmine).

This drive to increase one's social circle and pleasure in connecting with new people are shown to be key issues when discussing quality of life for people with learning difficulties (McVilly, Stancliffe, Parmenter & Burton-Smith, 2005; McVilly & Rawlinson 1998)

In support of this, Luke's mother Emerald articulated some of the benefits of enhanced community involvement in terms of his confidence.

His speech has improved, he's travelling almost independently. He is keen to go out now and socialise...it's an asset, huge asset him wanting to be out there in the community, so it means he's confident...(Emerald, Luke's mother)

Later, Luke indicated the importance of enduring relationships with young people he has met in the course of participating in the Circle of Support Project ; "some of the guys who I am friends with are *real friends who I want to be with in life* " noting the distinction between passing acquaintanceship and the deeper significance of lasting relationships. Katie also tells the interviewer "I hope we will be friends forever" because "that's how friends are *supposed* to be." Katie is forthrightly expressing her view that true friendship is resilient and enduring. Her use of the word "supposed" possibly indicates that an erstwhile 'friend' has not been there for her or has been

lost, hence her emphasis. The young people intuitively went the heart of these issues and prioritised meeting people, making and keeping friends.

7.3.2 Issues associated with building and maintaining connections with others

Much of the data associated with building and maintaining connections with others elucidates the complex nature of human connection; how friendships are found, formed, sustained and the ongoing challenges therein. This organising theme also illustrates the critical importance of family relationships to the young people, the need for communication and ‘renewal’ within these relationships and how people outside the family impact upon this process.

Katie’s work as a co-researcher in Chapter 6 highlights the impact of the loss of a friend upon Isabel. In her comments on the interview transcript, Katie exhorts Isabel to contact her friend “catching up with a friend is a good thing”. There is certain wistfulness to Isabel’s response to the interview questions. She restates that she has not seen her friend Vanessa “for a long time” on three occasions. Isabel reasons that Vanessa has been “busy and stuff” and “she moved town, she moved to somewhere else in another area.” Isabel indicates that Vanessa “works with a company... with people with disabilities” so Vanessa’s relationship with Isabel was probably of a ‘professional’ nature. Demonstrated in this moving encounter is the fact that many people with disabilities develop significant attachments to some of the numerous professionals which populate their social world. If and when the person moves on, there is a palpable ‘gap’, a wound, a loss. This can manifest itself in behavioural changes (reflecting sadness, frustration or anger) often perceived by others as symptomatic of a person’s diagnosed impairment rather than a natural response to loss. This misinterpretation of behaviour is termed “diagnostic over-shadowing” (Riches, 2008). Conversely however, Jasmine chooses to make a clear distinction between personal and professional relationships when she explains her relationship with her Team Coach:

I do have a relationship with Shanti [Team Coach] and that’s quite different than my family and that’s a part of my personal life, from my family to her (Jasmine).

Shanti is not seen as part her 'personal life' although Jasmine did intend to "keep in touch" with her when the Circle of Support Project has ended.

This discussion raises issues about the disabling nature of 'short-termism'; the interfacing of the personal and professional. Where should professional boundaries exist, for example, can a professional relationship become a friendship?

Connections which are essentially 'service relationships' and friendships made within 'service environments' such as schools pose problems of sustainability for people with learning difficulties. Katie talks about her experience at Public School:

(Interviewer) Did you enjoy being in school?

(Katie) Yes I did, the friends, the teachers and the work I was given

(Interviewer) So you made friends in those schools obviously, do you see any of those friends now?

(Katie) No I don't because they are out there working and they have their own lives

The formal environment of the school brings young people together and connections develop over a considerable time frame. When young people leave school they often lack the skills and supports to sustain their relationships; transition planning often 'marginalises' such concerns (Davies & Beamish, 2009). These relationships are inherently fragile and can be lost forever without contact and renewal:

(Interviewer) Are there any old friends from school that you would like to get in touch with?

(Katie) Not now, not really.

In the realm of romantic relationships Katie has already noted Jasmine's point about learning about relationships, her wish to "talk about relationships" more and the need to be able to assert oneself around degrees of intimacy "when you are in love with somebody and you have to say no to that person." Jasmine illustrates that connections in this area are complex, they require self-awareness, negotiation and problem-solving skills which indicate a need for personal development opportunities

beyond straight forward “sex education.” Discussion around sexuality is often denied to people with learning difficulties and, when provided, often takes the form of basic ‘heterocentric’ instruction in the biological aspects of sexual health rather than the social and emotional discourses therein. The ramifications of young people, families and professionals being disengaged from these issues are wide ranging from ‘socially constructed vulnerability’ to high levels of overt and covert control (Brown, 1996; McCarthy, 1998). By silencing such topics the experiential circumstances of young people’s lives are effectively ignored (Fine, 1995). When consulted on possible workshop topics which they could participate in as collective, the young people in the Circle of Support Project voted for ‘relationship skills’ as an important area for discussion and development.

Given that all the young people lived at home with their families the dynamics of these interactions linked to these relationship issues are discourses around the significance of the family to the young people, the complex relationships therein and the impact of ‘others’ upon family interactions.

Family relationships were of critical importance to all the young people, and generally these relationships were represented positively. For most of them spending time with family members was, in itself, a joy. For Rhonda, “being with my family” is one of the most important things she is doing with her life. Ciara talked lovingly about her “beautiful family, beautiful mum.” Luke explained the support he got from his family and their engagement in the Circles of Support Project, for Luke, they are ‘involved’ and he feels the gains are reciprocal:

I enjoyed having people like my family getting involved in the project so they know what is happening, what is on, what event is going to be on (Luke)

All the young people felt empowered by their families in respect of decision-making; that *they* made the decisions in their lives about spending money, going out, who they spent their time with and how they spent their time. Most young people explicated a collaborative decision-making process with their parent/s which seemed to engender elements of both planning for safety and personal development, for example:

When I go out I always let my parents know what I am doing (Luke)

I make the decisions and we discuss it together and she [Mother] just helps along (Katie)

Jasmine articulated the type of support she likes when making a decision:

(Interviewer) Who makes the decisions about when you go out?

(Jasmine) ..I would discuss that with someone who is personal to me, someone who can back me up.....you don't need someone who is bossing you around.

These young people recognised that they needed support but still be at the helm of their day to day life decisions. They emphasised long term, mutually trusting and non-coercive relationships as being of use to them in taking decisions. They also demonstrated maturity in acknowledging their parents need for reassurance that they were safe. The Project Team Voice, Andrew, expressed unambiguous autonomy; "I do as I feel, I go out sometimes as I feel....what I do in life is my choice."

In the above scenarios, parents appear to be providing a skilled and supportive rather than stifling or authoritarian approach. This veers from some research findings that parents of sons and daughters who have learning difficulties are 'overprotective' (for example, Naidoo, 1984).

Although none of the young people indicated that their parents were over-controlling or dominating, Katie and Isabel indicated some of the tensions that can occur in family (particularly parent-son/daughter) relationships. Katie pointed to some discomfort within her relationship with her mother and tentatively broaches this with the interviewer but is reluctant to share any details:

(Katie) ... sometimes I get in the way of things

(Interviewer) What do you mean "get in the way"?

(Katie) I am not sure

(Interviewer) Is that a feeling you have?

(Katie) Yes, sometimes I say things without thinking..

Katie possibly feels she is preventing her mother (a lone parent) from having other relationships or undertaking other activities,

Isabel spoke about family members as being the “most important people” in her life and initially observed that negotiating such relationships can be challenging: “Mum and Dad are stressing me out a bit” but she has also reflected upon the possibility of change; “ I want them to change a bit around so I have a better relationship with my family”. Isabel then shared about how she drew upon support from her Team Coach in taking action to address issues:

(Isabel) That’s what I have been talking to my Team Coach about

(Interviewer) Yes?

(Isabel) Yes, she sorts things out with me

Again the Isabel used the word “with” rather than “for”, the process is participatory emphasising how people outside family relationships can have an important role in facilitating positive engagement with other family members.

Reflective thinking on the part of the young people was powerfully in evidence. Jasmine shared the impact of a segregated education system upon her sibling relationship (Kamlesh is two years younger than Jasmine), but points to the healing power of connecting strategies upon the relationship with her brother:

(Jasmine)..... You see I got a bit ‘looking after’ sort of way in the project and now I can look after my brother a bit more than I would have had through school.

(Interviewer) Why do you think that is Jasmine?

(Jasmine) Because we have been close before and we had to split up and go to high school and it’s really hard to get back and now I did.

As Kamlesh's elder sister, Jasmine saw her place as a caring "big sister" to him. This position and role were soon ruptured when they were "split up" and Kamlesh went to a selective high school and Jasmine attended a 'special education' unit within a mainstream school. This clearly raises questions about holistic societal commitment to inclusion (Roulstone, 2008) and how segregated arrangements of whatever nature can impact on family relationships.

Environments can be segregating but also unifying. Some of the young people demonstrated this when they articulated the meaning of spirituality, culture and home as integral to connectedness.

7.3.3 Spiritual, cultural and environmental connections to others

Even when describing travel abroad with her mother, Katie talks about people rather than scenery or landmarks:

(Katie) Well I have been travelling around countries; Vietnam, Malaysia, Thailand and seeing where my Mum and Dad were born and [Mum] was born in Kulang yes....

(Interviewer) how did it feel for you being in Vietnam?

(Katie) Well I felt good there actually, getting more about where people live and their culture

Jasmine articulates the strength and learning she gains from her faith community connection. She describes her religious mentor who is part of her circle of support:

Gopal G he is from my Hindu culture, I know him from my Hindu background and he has helped me to unfold through my life (Jasmine)

Religious gatherings and celebrations can serve as a medium for meeting people and connecting around religion and popular culture:

....there is another friend I met, her name is Puja and I met her through my Mum because mum was talking to her mother and I met her at this Havan and like again through my culture, in my Hindu culture we do Havans and Pujas [Religious celebrations], and we became the best of friends and we talk together. She is also a fan of Harry Potter (Jasmine).

Future planning on the part of services, for most people with learning difficulties is usually conducted in the discourse of “accommodation” reducing their future lives down to where they will live and how their basic support needs will be fulfilled. For the young people in this study, it was clear that home means much more than this; their current and future accommodation is envisaged in terms of the social connectedness they would experience in the home environment:

(Interviewer) When you say you'd like to live independently some day, what would that mean? Would you like to live on your own?

(Katie) I would want to live with friends and friends could come and visit

(Interviewer) And would you live with other people who have Down syndrome?

(Katie) No, it wouldn't matter, not at all.

Katie does not discriminate as to the intellectual ‘categorisation’ of whom she might live with; she is more concerned about living with ‘friends’.

Notable is that some of the young people used the interview ‘space’ to make statements about what they thought about issues and what they wanted from life. For example, Jasmine uses a question about where she would like to live to inform the interviewer about her aspirations to have a family of her own:

(Interviewer) So you would like a bigger house, why is that?

(Jasmine) So I could fit more children in

(Interviewer) So you would like to live with more children?

(Jasmine) Yes

(Interviewer) Whose children?

(Jasmine) My own children

For Jasmine, where she lives is home and 'home' is about family relationships and having a family of her own one day.

Similarly, Isabel reinforces the notion of home as a place of family intimacy and connectedness, the place where she could enjoy her relationship with her partner. When asked about where her "perfect place" to live would be Isabel was assertive and positive:

(Isabel) I'll be moving into Ian's flat

(Interviewer) You'd like to move in with Ian?

(Isabel) Yes

(Interviewer) So wherever Ian lived that would be your perfect place?

(Isabel) Yes

Both these encounters however raise other issues; each young woman in her own way raised the issue of disability, sexuality and relationships, possibly because there is not much opportunity to raise these issues in their day to day lives. This point was also captured by Anna, one of the Team Coaches:

Everyone has a sexual sidesometimes people with disabilities miss out on that aspect of their lives, it's sort of brushed over, it's like they can't have a relationship (Anna, Luke's Team Coach)

Carl also stated that he would like to "live in Brisbane" and Brisbane is where his sister resides. Unsurprisingly, at the time of the interviews, none of the young people envisaged themselves living in institutional contexts. For the young people interviewed, the material environment was incidental, whilst human relationships in the environment were of fundamental concern.

7.4 CONTINUING PERSONAL DEVELOPMENT

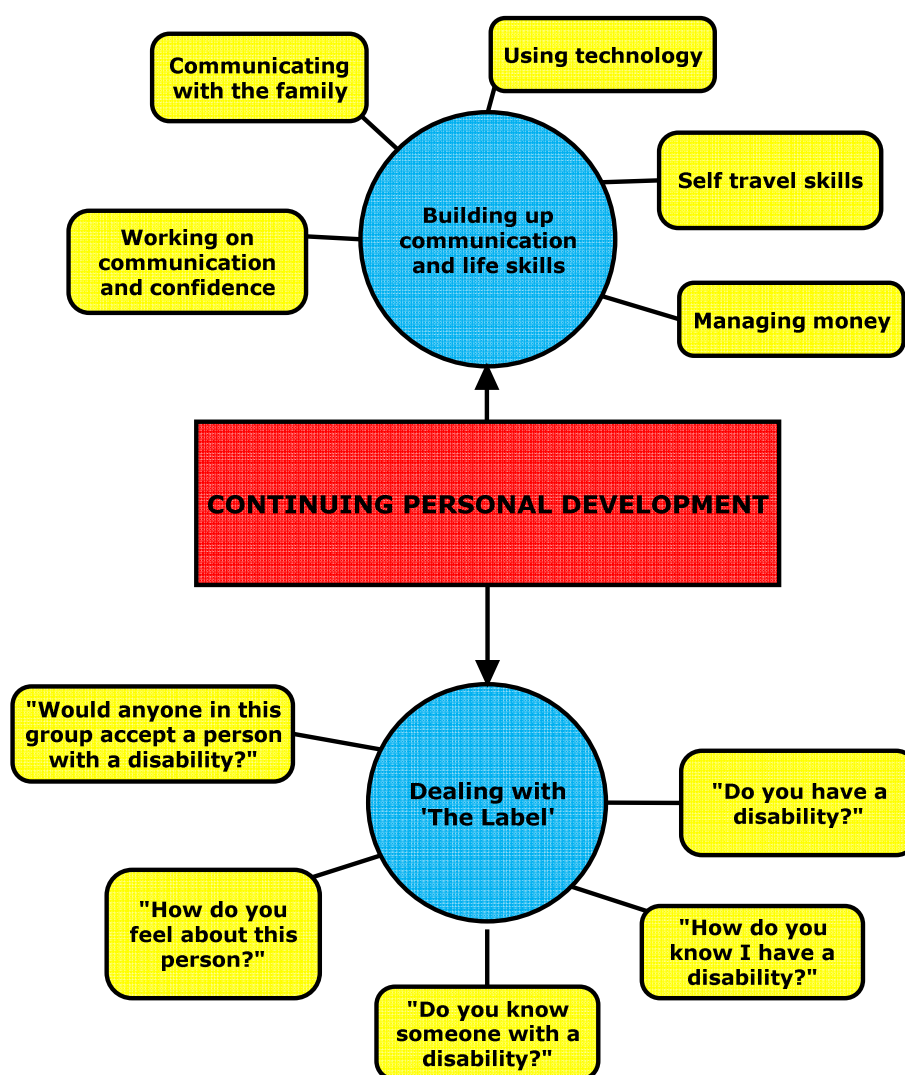


Figure 10. Global Theme: CONTINUING PERSONAL DEVELOPMENT

This global theme identifies areas which the young people perceived as relevant to their personal growth. The notion of personal development as an ongoing and non-static process was embraced. It consists of two organising themes: ***‘Building up communication and life skills’*** which describes the ‘competencies’ they themselves identified as relevant for development or enhancement within the project work and ***‘Dealing with the label’*** which describes processes of dealing with the impact of a stigmatising label. It is illustrated in Figure 10.

7.4.1 Building up communication and life skills

In talking about their existing skills, and the skills they chose to build upon, the issue of communication was viewed as extremely important for the young people.

Communication, in all its forms provides the medium for connecting with others and so is intimately linked with the preceding global theme of connectivity. Many participants commented proudly on their own verbal communication skills; Luke tells us that “I’m a very good speaker to other people and do very well” and Katie describes herself as “decent, well-groomed” and pointedly states “I am communicative”, one of Katie’s goals however was to nurture communication with her mother Susan, and her Team Coach encouraged her to start a “communication book” using her excellent written communication skills. Katie also felt that increasing her level of verbal communication would help her to have a “better relationship with a boyfriend”. Whilst some of the young people demonstrated very clear verbal communication skills, others found verbal communication difficult.

When Katie interviewed Andrew, who has a speech impairment, he described his self-consciousness in telling people about the project: “it’s a bit difficult having a conversation with someone... a bit awkwardsaying how things work and what’s going on.” Andrew however was the only applicant for the role of Team Voice within the project and ironically, participated confidently in most of the university and conference presentations using software.

Carl, attended all the workshops for the project but often said very little whilst he was there. He did however participate in the workshop role play sessions and other activities. He was keen to be interviewed. Interestingly, he had this to say when asked about what he liked about the project workshops:

(Carl) Food

(Carl’s Mum) The food?

(Carl) Yes, and talking

(Mum) And talking, you like the talking?

(Carl) Yes

Carl made a significant point here which also connects to Andrew's situation. People with learning difficulties and communication difficulties are often excluded from environments and meetings where they cannot fully *verbally* contribute (Stevenson, 2009) often before anyone actually asks them whether they would still like to attend. Carl's words also echo the findings in Burke (2005), where workshops provided a 'social inclusion space' where a shared identity could also develop.

In describing the changes that being part of the project had wrought, Jasmine spoke positively about the enhanced connection with her mother, older sister and younger brother through learning different forms of communication:

I have become more sociable with my Mum. I have come a long way since the project, I changed by my sister, I am more contacting her on emails; I never did that before (Jasmine).

Jasmine's observation, "I have come a long way since the project, I changed by my sister" implied that she has grown through the relationship; she is communicating more regularly with her sister which she sees as life enriching. Luke also built on his computer skills with his Team Coach and emailed his brother Jack who often travels outside of the country because of his work.

Jasmine learned to use a mobile phone to call and text her brother who resides in the same household and attends university:

I am and having a few types of contacts with my brother as well and be able to talk to him (Jasmine).

As well as using the project to build on different types of communication skills, many of the participants chose to further develop self-travel skills, Rhonda talks about "getting the train by myself" and having the goal of "getting to Ryde for the meetings" (the monthly Circles of Support Project workshops):

(Mum) What about when you went solo this week?

(Rhonda) I like to sing Karaoke (laughs)

(Mum) No not singing Karaoke, I know you like that, I meant when you went into the city by yourself

(Rhonda) Oh getting the train by myself

(Mum) That's right and what did you say you wanted to do next?

(Rhonda) Go to Ryde

(Mum) Yes, getting to Ryde for the meetings

This emphasis on the importance of self travel skills towards establishing a sense of independence reflects the views expressed by people with learning difficulties in the research of Abbott & McConkey (2006). Luke's mother Emerald articulates the progress made by Luke as he uses his mobile phone and enhanced travel skills to enable him to join his peers with Down syndrome in the city for social events and reassure his parents of his safety:

...he started travelling to the Jet café on his own, so that was pretty exciting, and we got him a mobile phone which was a huge help to him and once he got there he would just ring us and it was great. We could just relax.(Emerald, Luke's mother)

Other skills developed by the young people were around money management and shopping. Carl talked about how he liked to manage his own money, a plan he had embarked upon after discussion in a family group meeting with his Team Coach:

(Interviewer)you manage your own money

(Carl) Yes, everyday, on Sunday night

(Mum) Yes, on Sunday night you get the money out

(Carl) Yes

In a society where money equates to power, access to money and getting the support to manage one's own finances is a significant move forward and vital to 'self-inclusion'. Few of us can spend a day out in the community without spending some

money on travel, food and suchlike. Gaining these kinds of skills brings about enhanced independence and self-esteem and hence they form part of the practice side of 'social inclusion' and social citizenship.

7.4.2 Dealing with 'the label'.

This organizing theme captures the process of how the young people make sense for themselves of their status as a person labelled with an 'intellectual disability' whilst simultaneously exploring what that means for others. This insight is largely given to us by Jasmine when she formulates her own interview questions for both her personal circle of support (Stevenson, 2009), and later, for myself in a recorded interview. It is an important topic and therefore given the status of an organising theme. Jasmine's decision to do this was significant on two levels: firstly, she conceptualised her personal circle of support, not merely as a group of friends or means of practical help or tutelage but also as a context in which to challenge others about the nature of disability labelling and its impact on relationships; Secondly, by questioning the researcher, as previously noted in Chapter 6, she was effectively, challenging the traditional notion of researcher and researched (Oliver 1992, 1998). In essence, she was undertaking her own small but non-the-less powerful 'research project'.

Jasmine's question "Do *you* have a disability?" is confronting. She uses the term disability here as synonymous with 'impairment' and asks us to look at ourselves and ask 'Do *I* have impairments?' We are led to think of the ways in which all our bodies and minds are flawed. The reality is that we *all* have impairments some are invisible, others are not, some carry labels, others do not (Banks & Kaschak, 2003). Jasmine then questions the mechanisms of how we reach a diagnosis of impairment and assign a label "*How* do you know if you have a disability?" How we can know whether we have a disability or not? What must one have or lack to carry the label "disability." Reflecting on this question, Jasmine challenges us to recall that learning difficulty is defined via psycho-medical processes (Mercer, 1973) which are highly flawed (Gould, 1981; Ysseldyke & Algozzine, 1983) and have been/are driven by powerful economic interests (Osgood, 1984). Jasmine is a deep thinker and highlighted the possible need for young people to engage in some discussion of these processes at some stage.

Jasmine's next two questions appeal to the personal situation of the interviewee. Do we have connections with people with a disability and, if so, how do we feel about them? This indicates that she may be curious as to how we view the status of this person in our lives.

Jasmine's final question, "Would anyone in this group accept a person with a disability?" demonstrates the 'vulnerability' that such labelling imposes, and betrays how people, so labelled then become concerned with issues of 'acceptance' and may come to fear rejection or worse (Goffman 1963, 2006).

Jasmine's questions functioned as a device, a gift to give the recipient the opportunity to reflect for themselves about how disability is constructed and, perhaps more importantly, to reflect how that construction might be dealt with by the person who bears the label. When society has the power to assign a potentially oppressive label how does one resist? Clearly this is a personal and developmental challenge that most of the young people are dealing with on a daily basis. Jasmine's actions in placing the problem of disability labelling at the feet of others who do not carry the label perhaps most importantly, could be construed as an act of 'intellectual resistance' or self emancipation.

Marian Barnes (1997), in discussing the empowerment of people with learning difficulties, observed that people who bear learning difficulty labels benefit from a process of personal growth and development which enables them not only to assert their personal needs and the way in which they are met but also to *participate as citizens* within a community, influencing the nature of that community and the resources available to it. Jasmine's questions indicated that part of the personal growth is 'making sense' of the label which she will have to live with all of her life. Some people with learning difficulty labels choose to eschew the label altogether (e.g. Williams, 2002).

The issue of dealing with 'the label' flows into the next global theme.

7.5 COMMUNITY CONTRIBUTION

'Self advocacy, disability activism and helping others' are topics included in the Global theme of COMMUNITY CONTRIBUTION. Self advocacy is often perceived as people with learning difficulty merely verbally articulating their individual and/or group needs and choices. This is a simplistic interpretation and problematic for three reasons: firstly, everyone communicates (Murray & Penman, 1996, 2000) although perhaps not verbally or in a universally recognised sign language; secondly, many people who have learning difficulty labels have difficulty in communicating (Van der Gaag, 1998); thirdly, as Aspis (1997) points out, self advocacy is also a movement via which people with learning difficulties can contribute meaningfully, as equal citizens, to the development of society at large.

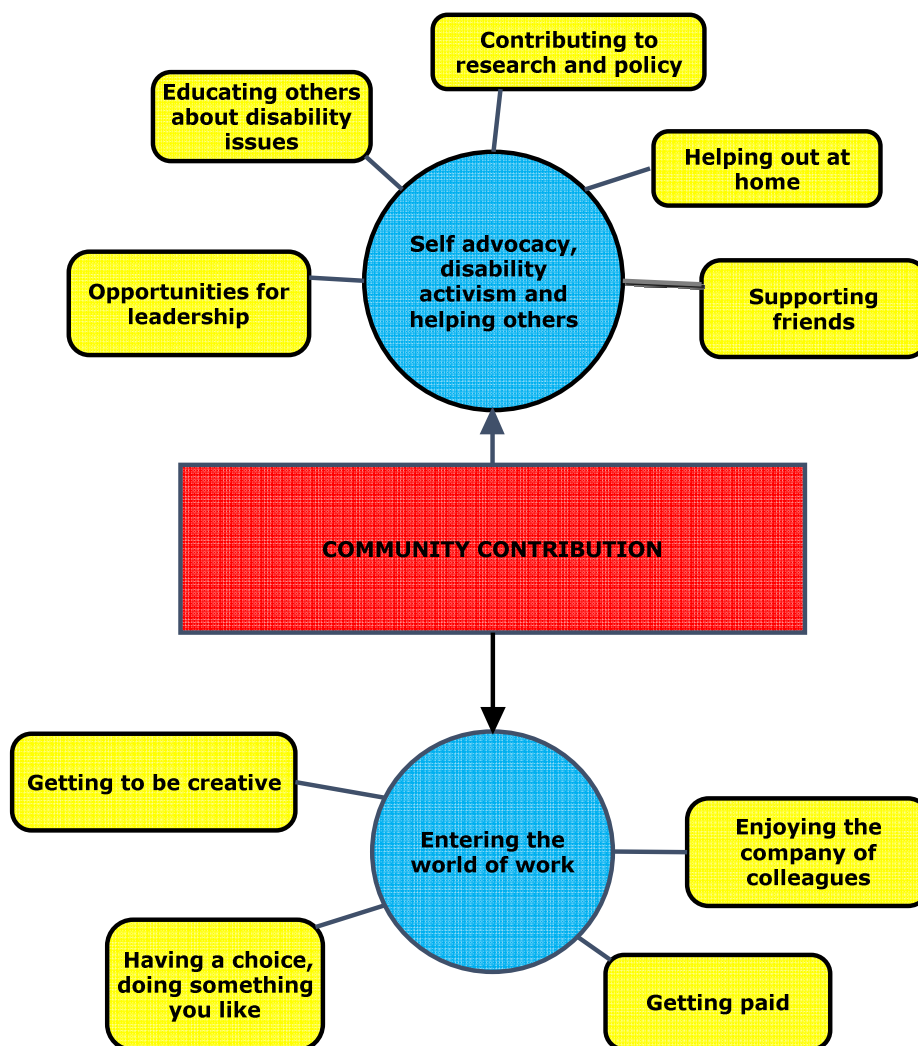


Figure 11. Global Theme: COMMUNITY CONTRIBUTION

This global theme (in Figure 11) also deals with the world of work as seen by the participants, the ways in which they saw helping others as significant and also the unique contributions they can (and did) in the Circles of Support project through teaching others about Down syndrome, disability and other socially relevant issues.

7.5.1 Self-advocacy, disability activism and helping others

Jasmine demonstrates some of the learning that she has gained from her Hindu religious leader when she talks about “what makes a good Team Coach”:

...he's like a spiritual leader to help me on my path so that's what I think about a Team Coach because having a team coach can actually help you in ways that you can see through that particular area (Jasmine).

(Interviewer) ...so a Team Coach is a bit of a leader?

(Jasmine) Yes, leads you into the right places and not the wrong places. What makes a good leader is that a leader can stand up for herself and stand up for others and be like, act good behaviours against her own Team members.

Jasmine was interested in talking in her interview about her spiritual guide who is part of her personal Circle of Support, she believed that leaders also lead by setting a good example and are courageous in their approach to life. This also raises questions of how often people with learning difficulties are enabled to lead, to contribute via offering their ideas and approaches via the self advocacy movement (Aspis, 1997).

Chapter 6, demonstrated how the young people contributed this research process and teaching at universities. In the course of the project, I assisted Andrew in an application to become a member of the NSW Council for Intellectual Disability (<http://www.nswcid.org.au>) he has subsequently served on the board of the organisation. This order of contribution is seen by Steinert (2003, pp.45 - 50) to be the highest level, a priority of the Circle of Support Project and the PAR within was to promote these forms of contribution.

7.5.2 Entering the world of work

Work, particularly the possibility of paid work, was very important to the project young people. Speaking of her (paid) role in the Citizen Educators Project, Jasmine shared:

It gave me a job, the biggest opportunity in my life and that was very important to me (Jasmine)

Jasmine talks about being happy in her work environment at a supermarket, laying emphasis on the notion of team work and interacting with different people:

...I like the music in the background, I like how I can do stuff in like a teamwork as well and I like people coming in and out as well, talking to them (Jasmine)

Social connection and community contribution are almost impossible to separate in many ways. The socially connective aspects of work are clearly described by the young people. Isabel commented on her role at work being made permanent:

Ah It makes me feel happy and it's good to be with more, other people around with me (Isabel).

In terms of the intrinsic value of work itself (at a fast food outlet) however, when asked by the interviewer whether she enjoyed the work itself, her response is sobering, "Not all the time, it's just work." Carl who carries a "dual diagnosis" of Down syndrome and autism was assisted in his interview by his mother. Carl rapidly conveyed the most important aspect of work for him:

(Carl) Working

(Mum) Good, good and what is it about working that you like?

(Carl) Paid!

(Mum) You get paid, what else?

(Carl) Get paid every Thursday

(Mum) You get paid every Thursday

(Carl) and Friday

Carl worked in a sheltered workshop in 'process working' packing headphones for a local airline. When asked about what kind of job he would like to do, Carl reported that it would be "making T shirts" which was an interesting answer and reflected his stylish taste in clothes. The opportunities for challenging and creative *paid* work for the young people however were seen as few and far between. This was reflected in the frustrations of some of the parents and their criticism of some disability employment agencies:

..The whole attitude was that she should be grateful working for Woolworths and packing shelves. Hello, she didn't get the job, she wasn't even going to get paid for it you know (Mary, Ciara's mother).

In terms of their life chances as citizens then, people with learning difficulties continue to be regularly shut out of the mainstream (Deane, 2009) and a distinction between perceived and actual impairment continues to be evident.

7.6 THE DIGNITY OF RISK

For many young people the process of growing up engenders having fun and 'joking around', taking risks. The final Global Theme (Figure 12) embraces the notion of young people having fun, growing up and taking risks and spending time away with parents.

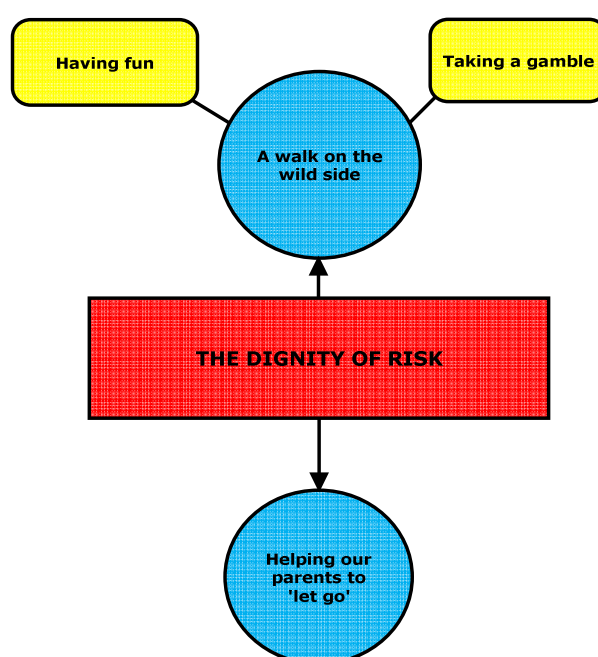


Figure 12. Global Theme: THE DIGNITY OF RISK

7.6.1 A Walk on the Wild Side

The topic of humour is linked to risk taking as risk taking itself is often related to having fun. Humour can also often be irreverent and socially 'risky'. Many of the young people evidenced the importance of humour in the interviews themselves, Carl for example, when asked about what improvements could be made to the project smiled broadly and requested "more food, different food."

Due to her hearing impairment, Ciara's verbal communication skills were limited and, when the project commenced, she had no recognisable sign language with which to be able to communicate with others. Her Team Coach, an expert in both Makaton and Auslan made a great effort to teach her Makaton. Despite her impaired speech, Ciara exhibited her wit and sense of fun throughout her interview:

(Interviewer) Can you remember any signs?

(Ciara) [I] got bored

(Interviewer) You got bored?...

(Ciara) Nods and smiles

(Sister) M is talking about the video you saw with your Team Coach. Can you remember any sign language?

(Ciara) Yes....there

(Sister) I was there? Show me one.

(Ciara) Eat (shows sign for eating in Makaton)

(Interviewer) Drinking?

(Ciara) Cokes! Beer! (Shows sign for drinking) Everyone laughs

When talking about the people in her life that she loves, Ciara lists her family members and again shows her 'off beat' sense of humour:

(Interviewer) Your brother

(Ciara) Ooh David!

(Sister) Anyone else?

(Ciara) Ooh Dad! He find mum!

(Sister) He found Mum?

(Ciara) Yes [laughs]

(Interviewer) Lucky Dad eh? [everyone laughs]

Later, when asked to describe herself Ciara answered “I love fire!” mimicking a character from the film ‘Ice Age’.

Alongside having fun and being irreverently humorous, the issue of risk was raised by Carl who said he would like to go to a casino at ‘Star City’:

(Carl) Green money at Star City

(Mum) Yes, sometimes you get some green money at Star City (\$100.00 bills)

(Interviewer) Ah you fancy getting some green money?

(Carl) Yes

(Mum)..he does like a tippie on the pokies as well (one armed bandit machines).

Both Carl and his mother were clearly comfortable with the notion that Carl liked to gamble occasionally; an activity which obviously engages many adults of all ages. Gambling, in itself, is not an activity which is generally deemed morally ‘appropriate’ or socially desirable. As his mother, Vivienne can make the decision to support Carl to engage in occasional gambling but, for example, how would a support worker respond to this? Whilst it is fair to assume that we should abide by the law, not everything we wish to do (and is legal) is good for us. For example, smoking,

drinking excess alcohol, overeating, gambling and unprotected sex are all activities that are a risk to our health and well-being but which most adults in developed countries are at liberty to participate in. Such activities are often wholly out of bounds to people with learning difficulties.

For many young people, whether they are disabled or not, a degree of thrill seeking' or risk-taking behaviour is generally recognised as a 'normal phase' of development (Sharland, 2006; Steinberg, 2007; McNamara & Willoughby, 2010). Various explanations have been posited for this type of behaviour; cognitive developmental theory explains it in terms of the growing but not yet fully developed capacity to recognise the consequences of actions and the perspectives of others (Steinberg, 2007; Heaven, 1996). Others, who argue from a standpoint of identity development, focus on the belief that young people's risk taking and experimentation are necessary to the process of carving out one's own unique character (Marcia, 1966; Erikson, 1968, 1980).

Within the language of risk there has been an uneasy relationship between the areas of care and control (Sharland, 2006). In the case of young people, some have argued that concerns with care have been subsumed, even 'hijacked', by the latter (Goldson, 2000). Writing specifically in relation to young people with a learning difficulty, McNamara & Willoughby (2010), noted that many such young people can place themselves at increased risk of harm. Certainly some concerns on the part of social care agencies are not purely attached to the (sometimes very real) risk of harm to the individual but also the (equally real) threat of litigation should 'something go wrong.' The safe option in this case is to avoid or restrict any activity which entails any degree of risk which means that people with learning difficulty can lead particularly controlled lives. Using Bordieu's concept of *habitus*, Sharland (2006) advocates that risk taking needs to be an area where social care professionals scrutinise and reflect upon our own judgements about what constitutes acceptable and unacceptable risk. In practical terms, and in relation to people with learning difficulty, Neill, Allen, Woodhead, Sanderson, Reid & Erwin (2008) advocate person-centred planning approaches to positively address issues of risk whilst McNamara & Willoughby encourage an open and supportive dialogue. Within the Circles of Support Project, our values statement acknowledged that all people need to take

risks in aspiring to their life goals, hence a protocol was introduced whereby any new activity which a participant wished to initiate was discussed and the advantages and any possible safety issues addressed with the participant and their family. This does not deal with the issue of more spontaneous risk taking behaviour. Interestingly, when asked about what their concerns were for their sons and daughters, two parents in our study raised concerns about their daughter's being vulnerable to attack or sexual manipulation but other parents expressed concern about their children being marginalised, 'stifled' or over-controlled by others. These concerns will be broached in Chapter 8. This thesis cannot do justice to such a broad and important issue as risk-taking here however it is vital that it is raised here as an area for consideration in any discussion of disability rights and citizenship.

7.6.2 Helping our parents to let go

Rhonda too joked around with her mother and myself during her interview but there is definitely a message to her mother encased in her words:

(Mum)I felt that I needed a little bit of education in letting go

(Rhonda) You are learning it Mum

(Mum) Am I getting better?

(Rhonda) Yes

(Mum) For sure? You don't have to lecture me as much?

(Rhonda) That's what you are like but you are getting better

Whilst most of the young people did not express feelings of being overly controlled by their parents, there was clearly insight on their part that their parents worried a great deal about them. There is a subtle difference. The theme of 'letting go' is explored in literature concerning parents' changing roles in relation to their adult children with learning difficulties (for example, Broughton & Broughton, 2005). However, the issues facing people with learning difficulties in helping parents to adapt to their changing skills and needs is seldom tackled in research. In the Circle of Support Project, a key role of the Team Coaches was to engage with this issue

and support the young person in helping their parent to see that they could take some 'calculated risks' and gain greater independence in some areas. Anna reported that Luke's siblings were supportive in this area.

7.7 Concluding remarks

When I had first transcribed all the interviews in this participatory research, the data presented an almost bewildering range of topics, so diverse in content that I began to wonder whether I should have asked a much more focussed question about a particular aspect of the project or the participants' lives. However, inspired by the participatory data analysis explained in Chapter 6, the tapestry of data was interpreted and grouped into the global themes. The realisation dawned that the young people were expressing the interests and issues that were important to them on the cusp of their adult lives. They were informing me about their concerns and insights as young citizens with learning difficulty.

In her discussion regarding citizenship, disability and issues of political and social engagement, Beckett, (2006 p.15) observed a resurgence of interest in the ideas of citizenship but cautions that unless we ground such discussions in 'real social politics' (and take action accordingly), we run the risk of imprisoning the concept in purely abstract and philosophical discourses rather than moving discussions of social citizenship towards the practical concerns of oppressed groups. The analysis suggested that the concerns of this particular group of young people can be organised into issues which need to be engaged with in respect of their social citizenship and incorporated into an understanding of what social citizenship means to them. This insight is further developed in Chapter 9.

The analysis of the data gathered from the young people foregrounds the next chapter in which the data from the parents of the participants and project staff is analysed and discussed using thematic networks.

8. Findings from parents and project staff

Having explored the concerns of the young people in this study I now move on to consider the interview data elicited via the participatory action research from parents and Team Coaches utilising also my own observations gained via my role as coordinator of the Circles of Support Project.

The lens of the social model (UPIAS, 1976; Oliver, 1990; 1996) is used as a framework to infer some of the effects upon the family of living with a young person who has Down syndrome and those factors which constitute both 'impairment effects' and disablement meaning oppression are brought about via certain social concepts and practices. Also identified from the data are some of the aspects of the Circle of Support Project which parents found to be 'facilitatory' or 'enabling'. The findings constitute three global themes which are explored herein.

I use the same style of reporting as in the previous chapters for transparency and announce the global themes followed by discussion of the organising themes. The reader will appreciate the complexity and interconnectedness within such a discussion. It is vital to maintain clarity and the human connection established in this thesis between the research participants and the reader. Hence, when using quotations, I link the pseudonyms of parents and Team Coaches to the pseudonyms of participants.

8.1 Summary of Global Themes in Chapter 8

THE EXPERIENCE OF LEARNING DIFFICULTY WITHIN THE FAMILY: This global theme (Figure 13) identifies how families in the study felt about their sons and daughters with Down syndrome. It also illuminates some of the diverse challenges they identified as *inherent* in parenting their sons and daughters. These inherent challenges can be seen as 'impairment effects' (Thomas, 1999). Impairment effects are the intrinsic issues which can be said to arise for families from the experience of living with learning difficulty itself as opposed to those challenges families face which are socially constructed (disablement). This is not a simple distinction to make but I attempt to do so here, firstly because it is important not to deny that such challenges

exist for families (Barnes, 1997) and secondly because such clarity makes for powerful argument in later discussion.

THE DIMENSIONS OF DISABLEMENT: following on from the first global theme this global theme describes those socially constructed stressors and barriers to participation which families have encountered as evidenced in the data set.

ENABLING CONCEPTS AND PRACTICES: This theme seeks to interpret what 'enablement' might mean drawing on the language of the social model. It describes the visions, concepts and processes adopted by, and generated within, the circles of support project which parents and Team Coaches perceived as enabling and useful to themselves and the young people in assisting young people to work towards their goals. There are aspects of this theme that point to a need to work holistically towards emancipation and enablement of the family as a whole.

In the following account, each global theme will be discussed in turn. It will be initially presented in diagrammatic form for ease of understanding. The organising themes, for each global theme will be discussed via a description of basic themes which are discussed in turn utilising supporting text from the transcribed interviews.

8.2 THE EXPERIENCE OF LEARNING DIFFICULTY WITHIN THE FAMILY

This global theme is made up of two organising themes: ***The valued family member*** which describes the regard and aspirations that parents had for their son or daughter who has Down syndrome. Secondly, ***The challenges of parenting*** seeks to identify those particular issues associated with learning difficulty which presented intrinsic challenges to families which are *not necessarily* a result of social oppression or disablement as defined by the social model (UPIAS, 1976; Oliver, 1990;1996).

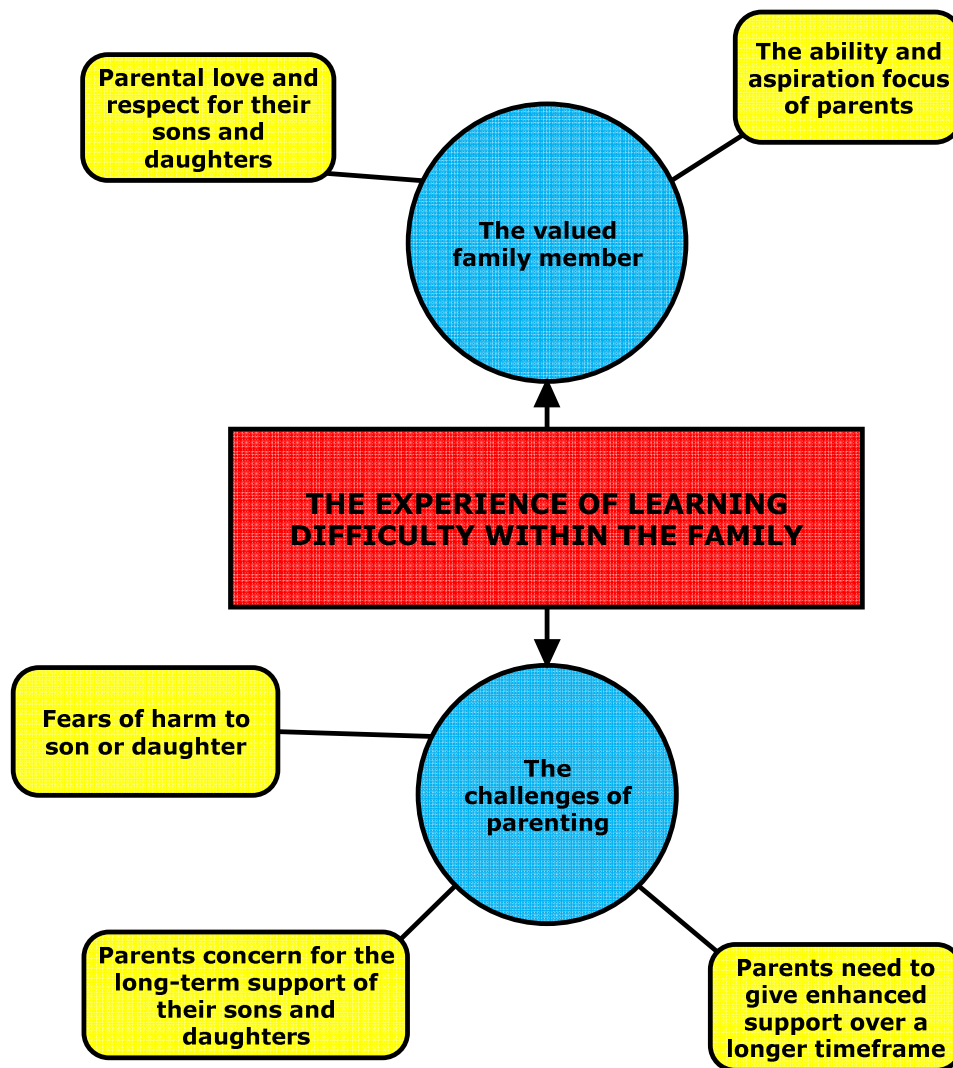


Figure 13. Global Theme: THE EXPERIENCE OF LEARNING DIFFICULTY WITHIN THE FAMILY

8.2.1 The valued family member

The trajectories of parental adaptation to having a child with Down syndrome and the effects of this experience on parental well-being and functioning have been the subject of much research. In reviewing the literature concerning families of children with Down syndrome, Cuskelly, Hauser-Cram and Van Riper (2008) reported a number of studies where families have experienced positive impacts (Scorgie & Sobsey, 2000; Van Riper, 2003; Van Riper, 2007). Parents cited gains in personal resilience, skill development and knowledge of a purpose in life which would otherwise be unavailable to them, as a result of parenting their child with Down syndrome. The limitation of this research in informing this thesis is that, as in many studies, the focus is upon families raising younger children rather than living with and

supporting their young adult children. Cuskelly et al. (2008) shared some incisive insights however, into the nature of having a close family member with Down syndrome which resonate in this research.

Amongst those interviewed in this research project, parents' feelings towards their sons and daughters were, without exception, very positive. There was an obvious and enveloping warmth and love evident when they talked about their children. Mothers spoke with affection about aspects of their adult childrens' characters which had a positive impact on themselves and the family as a whole:

He is a very happy person, he has got a great sense of humour, loves his family, tells it how it is, loves going to work despite things that are hard like crossing the road and the speech problems (Vivienne, Carl's mother).

I would probably go all mushy and say how gorgeous she is, what good company she is (Mary, Ciara's mother).

She has a very well-developed sense of humour (Margaret, Rhonda's mother).

He is charming, he's just a lovely friend, he is very good company, he's quite funny at times (Pamela, Andrew's mother).

Pamela shared some of what she herself had learned from her son and other people with disabilities about the nature of their resilience:

I just absolutely admire people with disabilities. I see people out there going along day by day, whether it's an intellectual or a physical disability, just living life to the full. That's definitely something Andrew has taught me (Pamela, Andrew's mother).

Fathers and mothers were equally loving and positive in respect of their children interestingly both fathers in the study chose to use the word 'blessing' to describe their daughters, again suggesting that there is some higher, spiritually enriching element to parenting their child who has Down syndrome:

I have a child with a disability who is the most loving of my children. I am fortunate that she can do most things...as parents we are very happy with how she has developed...she is a *blessing* in disguise to the family (Rupal, Jasmine's father).

In this one statement Rupal also conveys his appreciation of the love he receives from his daughter and his admiration of her abilities. Rupal appreciates Jasmine's learning difficulty ("I have a child with a disability"), however, as a parent, he has insight into her personal growth. His use of the term 'developed' is carefully chosen. He suggests growth means more than merely reaching targets and achieving "outcomes", it is a complex and multidimensional process and is unique to his daughter as an individual.

Similarly, Rhonda's father Joseph found his daughter to be a "blessing", yet feels the need to qualify what he is saying:

Oh she is a lovely girl, she is such a *blessing* to all our family really. She is such a delight and I'm not lying about this actually, you just get this lovely smile most of the time (Joseph, Rhonda's father *my emphasis*).

In stating "I'm not lying about this actually", does Joseph feel that the interviewer has the preconceived notion that he needs to modify the truth? Does Joseph feel that Rhonda has Down syndrome and therefore, by definition, cannot be held to be a "blessing" or a "delight" by any person outside of the family?

This perspective is reflected in the observations of Cuskelly et al. (2008) who suggested that, although many parents adjust to having a child with Down syndrome and develop enlightened views about what constitutes achievement, they remain positioned in a social context where having a child with a disability can be viewed only as a calamity. The uneasy juxtaposition and interplay of the parents' deep love and attachment to their child who has Down syndrome and the 'personal tragedy' perceptions of the community, in many cases, have rarely been investigated (Cuskelly et al., 2008). Even in the research arena, positive perceptions in families of children with learning difficulties have been hypothesised as the adaptive behaviour of parents (Hastings & Taunt, 2002), which appears to challenge the notion that such positivity is genuine on the part of parents. This phenomenon is linked to the field of stigma and more thoroughly explored in the next global theme the DIMENSIONS OF DISABLEMENT.

Parents were eager to point out the developing skills and capacities of their sons and daughters with an emphasis on their sociability, advancing maturity and independence:

He is becoming more independent, he is quite social... he is quite friendly and talks a lot (Emerald, Luke's mother).

She is very responsible, very dedicated to what she wants to do and she shows maturity, I think in whatever she says and does. She is very respectful, she knows what she wants. She is very clear on her understanding of herself (Heera, Jasmine's mother).

Emerald and Heera both offer positive observations on their children as developing adults; points that are reflected in the writing of other parents who have sons or daughters with Down syndrome (Mardell, 2005, p.194; Kaly, 1998, pp. 74-99.).

Whilst offering their hopes and aspirations for their sons and daughters futures, the parents in this study envisaged a variety of scenarios encompassing lifestyle, work, relationships and types of accommodation. There were cautious hopes that their sons and daughters would find paid work in open employment, if this was not the case already:

I hope that he would get a job that obviously he would get paid to do. Hopefully in a fairly say 'normal' environment (Emerald, Luke's mother).

Emerald's use of the concept of "normal environment" is revealing and is the expression of a desire for her son to experience a life where he is included within the community. Chapter 7 found that the young people themselves very much value paid employment which is possibly symbolic of making a valid contribution to the community. Finding satisfactory open employment as a person with a learning difficulty label is generally difficult (Davies & Beamish, 2009) but this is one area where the diversity of skill, ability and support needs within the population of people with learning difficulty needs to be more fully appreciated. Reid and Bray (1997) stressed the need for people with learning difficulties to have a sense of independence at work whilst at the same time having the 'safety net' of formal

support. As discussed in the previous chapter, in NSW moves have been made to formalise assessment, training, selection and entry into employment for people with learning difficulties with Transition to Work programmes (ADHC 'Stronger Together' policy 2010 p. 23, 31) and specialist disability employment agencies. The danger however, of overly fixed and procedural approaches to work placements for people with learning difficulty is often incompatible with their diverse nature as a group.

The desire of parents to have opportunities which are available to all young people is continued in the area of relationships. Parents acknowledged that the opportunity for formation of romantic relationships is vital. Ciara's mother talked about supporting her to daughter find a life companion:

They all want a soul mate, they all would like a boyfriend or girlfriend but I believe it's a soul mate they want (Mary, Ciara's mother).

Mary, as a practising Catholic, held strong feelings about the fact that in social work training and literature there seemed to be an over-emphasis on 'sex education' alone for people with learning difficulties and lack of corresponding in-depth discussion around the deeper meanings and issues enclosed within the theme of intimacy. This was not an objection to her daughter having a physical relationship (at some stage) rather the observation that sex is only one dimension of intimacy. This also raises issues in relation to culture and sexual orientation which are again often "brushed over" in respect of people with learning difficulties as Fiona, Luke's Team Coach observed. These issues echo the need for further discussions of this complex topic (Brown, 1994; McCarthy, 1998; Fine, 1995).

Parents also raised the need to be pro-active in respect of raising access to possible intimate relationships for their sons and daughters:

I think there should be dating agencies because we have groups for everything, to go to the movies etc. so why can't there be a group for a dating agency? (Susan, Katie's mother)

Recently this is becoming less of a taboo subject and groups such as 'Stars in the Sky' in the UK (<http://www.starsinthesky.co.uk>, 2011) have been established with the

aim of providing opportunities for people with learning difficulties to form romantic relationships.

Isabel's mother supported her daughter's desire to move in with her long-term boyfriend, but also envisaged other scenarios of accommodation which may suit her if this romantic relationship did not endure:

If it was possible for Isabel to marry Ian and be happy safe and secure that would be great, but failing that eventuating, if it's not a reality for whatever reasons, I'd like to see Isabel in a group home situation where she has lots of friends...a house in the community where there is a group of people living and they have got support (Louise, Isabel's mother).

Parents were very clear about the need for community based accommodation environments with support close at hand:

In a perfect world, me personally...I would like to see Carl living in a house about three doors away with maybe a couple of mates he got on well with (Vivienne, Carl's mother).

Parents showed concern that their sons and daughters should be enabled to continue to develop as people and look to fulfilment of their potential. These concerns mirror the concerns and interests of parents of non-disabled children and the concerns of the young people participating in this study.

The analysis of data in this organising theme of the valued family member, highlights that parents in this study have positive regard for their sons and daughters and also that their aspirations for their sons and daughters with Down syndrome corroborate some of the findings from the data analysis in respect of the young people in Chapter 7 as contained in their global themes of human connection, continuing personal development, community contribution and the dignity of risk.

8.2.2 The challenges of parenting

Throughout the course of the interviews, parents offered some of the challenges intrinsic to raising and supporting their sons and daughters, some of which were supported by Barnes (1997 pp.74-75). These can be interpreted as some of the direct effects of impairment upon parents of the young people. It is important to

stress that these “impairment effects” (Thomas, 1999) were not identical for all young people and their families as the support needs of the young people were again, unique to themselves and their circumstances.

Some parents described the rigours of intense support which their sons and daughters needed. Such support is often intertwined simultaneously with encouraging the development of life skills in their sons and daughters. Vivienne shared that “the devil’s in the detail” as she described below the myriad of different tasks that her son Carl requires support with and the sense of guilt she feels when she does not live up to her own perception of her role as a ‘caring’ parent:

...for example, Carl leaves for work every morning at 6.15am and my husband walks him across the road. I find it difficult to get up at that time of day and so if my husband wasn’t around I would find it overwhelming dealing with things. You know there’s a lot of things I feel guilty about that I don’t do well enough like he’s had this rough skin at the bottom of his foot and he told me about three weeks ago and I haven’t made the appointment with the podiatrist. You know I don’t keep on top of things like I should go into [Luke’s] work and see what is happening at lunchtime with the food and try and do that... I should say to him when he gets home from work to have a big glass of water, those caring sort of things get lost in the family life...(Vivienne, Carl’s mother).

Carl, an adult, required ongoing enhanced support from his parents in getting to work safely and in meeting his health needs in terms of his extra physical care and maintaining a healthy diet. This added up to a rigorous daily routine for Vivienne. She alluded to the crucial supporting role of her husband in this process: “....if my husband wasn’t round I would find it overwhelming dealing with things” and also confirmed the multi-faceted nature of family life in which the caring role is embedded: “....those caring sort of things get lost in the family life”. These observations remind us once again of the importance of holistic, family-focussed support arrangements which take into account the particular context and needs of carers.

Another concern articulated by a number of parents was unease for the long term future for their sons and daughters:

You realise that one day you will be old yourself and life doesn't last forever and we are a very small family. I mean there is just me, my husband, my Mum and the three girls here [in NSW Australia]... (Margaret, Rhonda's mother)

Margaret's expression of concern is perhaps particularly pertinent for many migrant parents (of all cultures) whose children are 'first generation' Australians, where there may be a lack of extended family members to share the responsibility of support.

Team coaches also mentioned this as a topic of discussion which parents broached:

...it does come up, "when we go, what will happen?" They do worry you know... (Sundari, Shona's Team Coach)

The number of older parents providing ongoing care at home for adults with learning difficulties is growing (Heller & Factor, 1993; Minnes & Woodford, 2004). A number of studies have shown that older parents correspondingly had a growing concern with future accommodation for their sons and daughters, their need for appropriate emotional and social support and financial provision (Minnes & Woodford, 2004). Roberto (1995) also indicated that parental stress can increase with age as declining health, strength and patience sometimes coincide with an increase in the support needs of an adult son or daughter with learning difficulties. Conversely however, adults with learning difficulties can often be providers of support to their ageing parents (Heller, Miller & Factor, 1997). On this latter point it is important to highlight that 'support' within families is certainly not a 'one way street'. As coordinator of the Circles of Support project, I became aware of many accounts of how the young adults with Down syndrome involved with the project helped out at home with household chores and other tasks. For example, on one occasion, one young woman supported her mother (a lone parent) after she broke her arm, acting, in her mother's words, as her 'carer' for an extended period.

When commenting on her daughter living independently Louise, Isabel's mother comments on a fear of the 'unknown' and having to live with a degree of uncertainty:

I suppose you always wonder as a parent whether they are actually going to cope. And you can't tell until they are actually in that situation (Louise, Isabel's mother).

Other parents articulated a direct concern that their child could become socially isolated:

...she could be marginalised if she does not get the right support around her. This could lead to her leading a reclusive existence... (Rupal, Jasmine's father).

Conversely however, Pamela expressed a philosophical attitude to the long-term future but emphasised the continuing need for her son Andrew, to be "cared for" and valued by others:

I'm not concerned because things work out but I would always want him to be respected and cared for... (Pamela, Andrew's mother)

These observations illustrate that although not all parents fear for their children's future, exploration and early planning of lifestyle and accommodation options might serve to alleviate some parents' worries about the future of their children.

Two mothers expressed concerns about their daughters' ongoing safety. Louise shared that her daughter Isabel had been assaulted in the past whilst travelling home from work alone:

I'll probably always fear for her safety in public because she is a target and she's been a target in the past so that's a concern...even though Isabel's pretty good at yelling or speaking up or seeking assistance but that is probably my biggest fear, even though she travels independently and we let her do all those things, yeah that's probably the biggest, biggest fear of mine (Louise, Isabel's mother)

Heera tells the interviewer:

My biggest fear I think and concern is her vulnerability. Because we can't take away from Jasmine the fact that she has a disability... (Heera, Jasmine's mother)

However, she locates this problem not with Jasmine but firmly with society as she continues....

I don't want to be over-protective of her but I just fear that society, or some people in society because of their misunderstanding, or not understanding or not having that respect might take advantage of her. (Heera, Jasmine's mother).

Studies indicate that people with learning difficulties may be at increased risk of physical attack or abuse (Crossmaker, 1991; Enfield, 1992; Sobsey & Doe, 1991), especially if they have been accommodated in institutional settings. In assessing the research evidence for why people with learning difficulties might be of higher risk from abuse, Focht-New (1996) observes that, lack of imaginative communication technologies and restricted independence and choice are some factors in terms of how we might explain why people with learning difficulties are at higher risk of abuse. In terms of reducing these risks, Focht-New concludes that peoples with learning difficulties themselves must be fully engaged in developing services and solving problems. From the above discussion it is also apparent that involving parents, and their expertise, at an early stage in the lives of people with learning difficulties to discuss how to raise awareness of personal safety issues may also prove productive.

Summary

It was apparent from both my work in the project and the interview data that the young people within the project were loved, valued and highly regarded by their parents. This data draws out clearly some of the intrinsic challenges of parenting a son or daughter with a disability. The young people *do* have various enhanced support needs which extend into and throughout adulthood and these needs place some inevitable pressures upon the family (Barnes, 1997 pp. 74-75). Parents are also aware that their lives are finite and they do not have a crystal ball to predict a secure and fulfilling future with appropriate continuing support for their sons and daughters so there is, for many of them, the fear of the unknown. These observations needs to be put in perspective however Kaly, (1998 p. 20) observes that all parenting is an inherently challenging role. There are many child and adult sons and daughters who, intentionally or unintentionally bring about particular challenges either long or short term to families such as substance misuse, engagement in criminal activity, illness etc. In turn, this does not mean that we stop loving our children (whether they are disabled or not) or deny their value and right to dignity as human beings.

Heera's fears of vulnerability illustrate perfectly how all families are embedded in a social and cultural context (Cuskelly, Hauser-Cram & Van Riper, 2008) which constructs many challenges for parents of young people with learning difficulties. The impact of context on the practical and emotional aspects of life for people with Down syndrome and their families is profound. This discussion foregrounds the next global theme which examines 'dimensions of disablement' in which both parents and team coaches help to describe contextual social oppression and how this is constructed.

8.3 THE DIMENSIONS OF DISABLEMENT

Writing in 1996, Oliver asserted that the social model of disability:

Does not deny the problem of disability but locates it squarely within society. It is not individual limitations, of whatever kind, that are the cause of the problem but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organisation. (Oliver, 1996, p.32).

This global theme (Figure 14.) is concerned with barriers and problems perceived by parents and staff in the project which are socially produced. This is a particularly complex process in respect of people with learning difficulty labels as the very category of 'learning difficulty' itself is assigned by applying tests and other criteria which are socially produced (Mercer, 1973, pp. 2-3 and Rapley, 2004, pp. 43-47). As a theme running throughout this thesis, the history and flaws inherent in the labelling process can be clearly contested and produce different effects, for example, to being 'labelled' with a physical disability. Notwithstanding this complexity, it is still highly instructive to analyse some of the disabling effects of both the categorisation process and disabling aspects of the service culture as they were interpreted from the data.

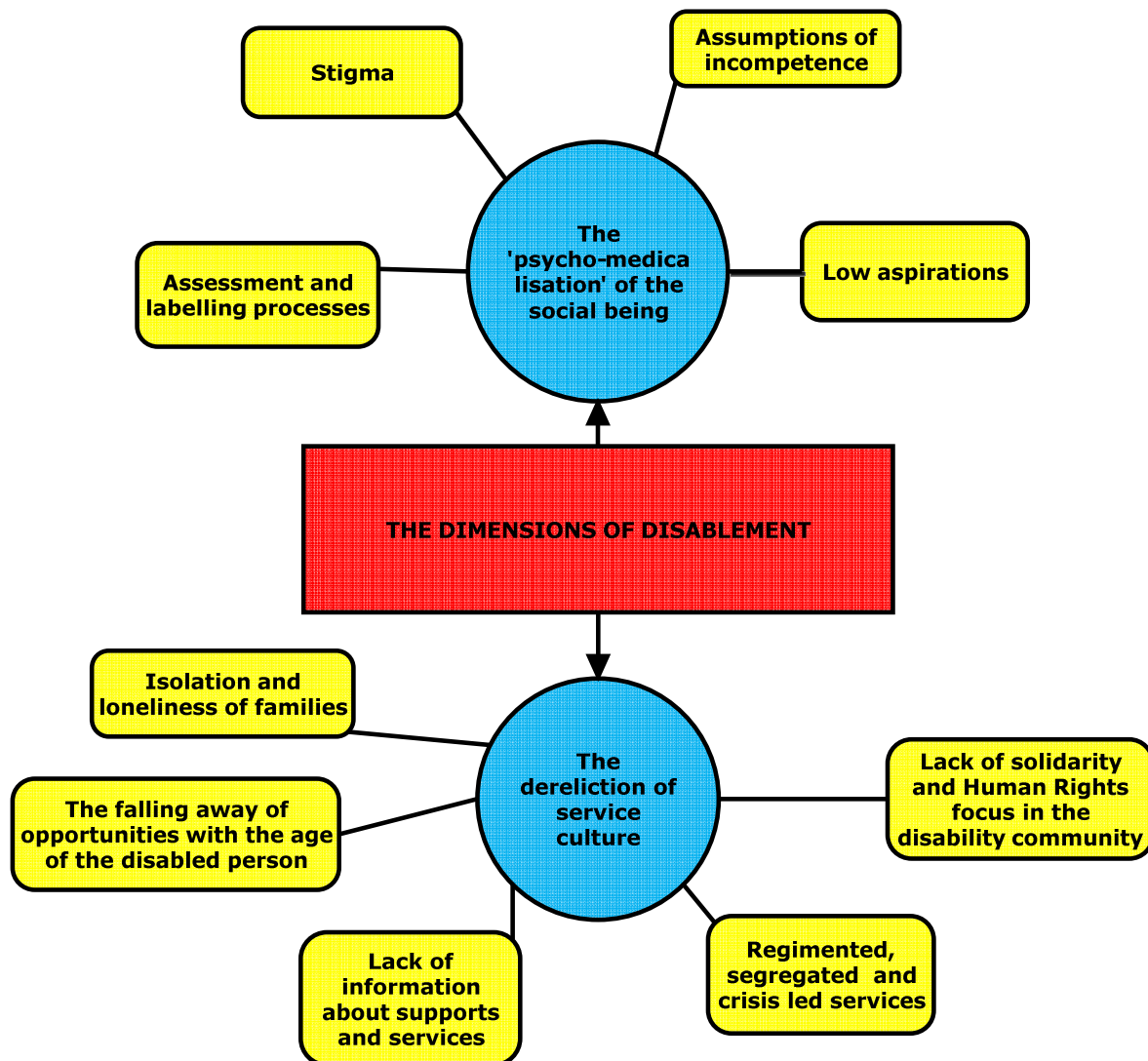


Figure 14. Global Theme: THE DIMENSIONS OF DISABLEMENT

As can be seen from the above diagram representing the topics herein, this global theme is comprised of two organising themes ***the psycho-medicalisation of the social*** and ***the dereliction of service culture***. The purpose of analysing these aspects of the data is to discern, not the more direct 'impairment effects' of learning difficulty itself (some of which have been covered in discussion of the previous global theme) but those features of society which both exist and are lacking which create barriers and stressors for families and individuals. It is pertinent to note that disablement spreads across structures, practices and concepts (Oliver, 1990)

8.3.1 The psycho-medicalisation of the social being

The psycho-medicalisation of the social being deals with the ongoing tyranny of the processes of assessment, labelling and stigma, subsequent assumptions of global incompetence, its exclusionary and ‘life-limiting’ effects and the denial of the personhood, individuality and capacity for self determination. The data indicated that the continuing dominance of the psycho-medical model of disability (Mercer 1973) was evident, not only in the language used by some parents, but in the organisations which purport to advance the interests of people with learning difficulties.

Some parents expressed opinions on the assessments which their sons and daughters had undergone in the process of their post-school training. Within this group some accepted this process as the ‘status quo’ whilst others were incisively critical. One mother talked about how her son had been assessed as unsuitable for open employment by a disability employment agency:

With intellectual disability *you are what other people think you can achieve*. Andrew has been deemed by a certain person to be unsuitable for open employment. It’s made a huge difference to his life just because one person deems him not to be suitable for open employment (Pamela, Andrew’s mother *my emphasis*).

This decision, assigned as a result of testing and assessment processes, has essentially given Andrew a further label (“unsuitable for open employment”) which could limit his future income and employment options. Despite the discrediting of IQ testing (Gould, 1981; Ysseldyke & Algozzine 1983; Smith, 1991; Siegel & Metsala, 1992), it is still applied with voracious enthusiasm to people with learning difficulties. In NSW, Australia, Centrelink and many employment agencies regularly use IQ tests to ‘assist’ in determining entitlement to levels of benefits/pensions and suitability for employment. Groups such as “Access Living” (based in Illinois, USA) have strongly argued that IQ tests serve as an impediment rather than a pathway to employment (Robbins & Smith, 2010). Added to this is the authority granted to the ‘testing organisation’ to firstly conduct the test and thence make decisions about the future opportunities and provision of support to a person based upon the test result. Pamela’s frustration runs parallel to that of self-advocate Anya Souza whose critical perspective on segregatory practices has been discussed earlier in the literature

review of Chapter 2. Souza similarly states that empowerment is the “fight against people who have the power to define who you are.” (Souza, 1997, p.4).

Katie’s mother Susan described to me a scenario where Centrelink had tried to reduce her pension after Katie’s IQ been re-tested and it had increased “by a few points”. Some processes employed by organisations could be said to constitute discrimination and an oppressive assault upon human dignity.

Some staff in the project were aware of the reductive effects of assessment processes. Emma, Carl’s Team Coach, talks about the dehumanising process of ‘tick-box’ assessment:

You know, in my other job it’s about getting a referral form and it’s about their diagnosis and it’s about ticking a few boxes about things they are interested in but you don’t get to know the person like you do here (Emma, Carl’s Team Coach).

In the context of the Circle of Support Project, no formal IQ, ‘risk’ or ‘ability’ assessments were conducted whatsoever, they did not emerge as necessary at any stage in the course of the project. Rather, young people and families continually ‘assessed’ for themselves, their abilities, support needs and the safety and effectiveness of different processes and activities. An emphasis lay on gaining a depth of knowledge of the young person through relationship (Kendrick, 2001) and work with the young person centred upon their unique strengths and developmental goals which they themselves had decided upon.

Later in the interview Emma observes:

All these assessments and stuff, who cares? They are irrelevant if the person is not being valued (Emma, Carl’s Team Coach).

Emma’s frustration with a system she is part of is healthy and reflects her values as a proponent of human rights. Her observations bring into focus the powerful insight of Gillman, Swain and Heyman (1997) whereby ‘client’ assessment processes factors such as IQ, psycho-medical diagnosis (label) and support needs can detract from an understanding of, or ignore altogether, the lived experience of ‘clients’

themselves. In turn, these practices conspire to psychologically distance the professional from the multifaceted and dynamic human being ('client') in front of them. In such a situation it is then much easier to treat this person as an objectified 'case' with fixed support needs rather than a person who is equal to them in human value and who shares the same human rights and dignity (Gewirth, 1981, 1996). Even intentionally 'strengths based' assessment models can produce a similar 'fixity' unless their limitations are acknowledged.

Obviously service providers have concerns about matters such as accountability, fair distribution of resources, productivity targets and so-forth which have held sway in an atmosphere of increasing managerialism within social care services (Parton & Meagher, 2004; Kilpatrick, 2006). This still begs the fundamental question that if services employ processes and strategies, at whatever level, which stifle, humiliate, demoralise and prejudice the opportunities available to the person they purport to serve, we need to more closely interrogate (and perhaps shift) the very bases on which they are constructed and provided.

Stigma linked to the processes of assessment labelling is still very much a feature of the lives of families:

There is always someone watching you from the time you get up to the time you go to bed, everything you do draws stares. Walking through a huge shopping centre you feel the eyes. You get sick of people staring and constantly being the focus of attention. (Pamela, Andrew's mother)

Another mother of a young man with Down syndrome once commented in a workshop "his disability is written on his face" which is a powerful indictment of a society where people with Down syndrome have been segregated and "othered" for decades. Pamela illustrates that the "staring" and 'focus of attention' has a permeating impact upon parents also. In an anthology of stories and verse written by people and parents of people with learning difficulties, Penman (1996) makes a powerful and incisive point about the impact of the gaze of others upon her own son who has learning difficulties in her poem, 'When you look at my Child':

Don't you realise that I can feel
Your need to change him
Your need to be other than he is
To be "improved"
To be more or less or whatever
You are disturbed by
(cited in Murray & Penman, 1996, p.4)

This unsettling stare of others is closely linked to a lingering stigma in respect of people with learning difficulties. Garcia & Magnuson (2000) discussed how culture impacts upon the experience of parenting a child with Down syndrome. This suggests that parents not only have their own feelings for their sons and daughters with learning difficulty but they have the additional psychological and emotional challenges of mediating the perceptions of 'others' and integrating this into their experience, understanding of, and relationship with their child. This 'gaze of others' is closely linked to ongoing stigma (Goffman, 1963, 2006, p.131) in respect of people with Down syndrome.

The application of stigmatising terminology such as 'mongol' and the lack of representation of the positive attributes and abilities of people with disabilities within the media (Barnes & Mercer, 2003) can be seen as a contributory factor to stigma. The need to portray people with Down syndrome leading dignified, successful and included lives is recognised by some disability advocacy groups as being a vital process in combating stigma. In acknowledgement of this, in Australia and growing numbers of countries worldwide, annual 'Down Syndrome Awareness' days are held, together with information and activity aimed at better informing the public about Down syndrome.

There is clearly a need to further explore and question , not only how parents deal with such phenomena, but what the 'unsettling gaze' itself is based upon and how it is manifest even in services which are geared to respond to the needs of people with a learning difficulty.

Low IQ label equals low aspirations?

These labels are, I feel, closely allied to people's expectations of disabled people. The concept being that because they have Down syndrome or Cerebral Palsy or any other disability, little can be achieved by them so that they can be excused from trying (Broughton & Broughton, 2005 p.35)

Flowing from processes of labelling and stigma were some controversial observations concerning the 'learning difficulty community' at large, meaning the families of people with learning difficulties and the specialist disability organisations set up and operated to support them. In this research some criticism was made of the Host Disability NGO for the project and the disability community itself both of which one would expect would be supportive of progressive thinking and action in the area of disability. For example, Mary, Ciara's mother explained, that the Circle of Support Project had supported higher aspirations for their sons and daughters; it had "given them permission" to do so and not given the message that "they are in cuckoo land". Mary's frustration reflected that of many parents who from various agencies appeared to receive the message that being a parent of a child with Down syndrome required a different 'mind-set' in terms of aspiration and expectation. To think otherwise is to be in "cuckoo land", out of touch with 'reality'.

A worker in the Host Disability NGO also intimated that "a lot of ideas never get off the ground because they are squashed before they can get off the ground." Whilst the parents in this study were expressly aspiring for an included life for their sons and daughters, many can be socialised into having low expectations (Ramcharan, McGrath & Grant, 2007 p.67). This data suggests that the negative messages brought about and reinforced by the continuing psycho-medicalised model of Down syndrome can be internalised (Agger, 1991) at an organisational as well as a personal level unless there is an explicit and politically unambiguous agenda which can lead the way forwards.

Other parents identified differences within the disability community. Pamela, Andrew's mother talks about her experience of an unhealthy sense of competition within school:

We shouldn't be doing that competitive thing, very unexpected, it's a real issue and when you see it, it's not very nice..... "my child is doing better than your child", "my child is reading, he's on the next set of books and yours isn't reading at all". You expect to see this in parents of a 'normal' child but you don't expect to see it in parents of a child with Down syndrome but it's there. (Pamela, Andrew's mother)

The internalisation of a traditional mainstream model of schooling which differentiates children according to educational ability (Armstrong and Barton, 2007; Roulstone, 2008) causes dissention and pain even within the disability community. In this instance, Pamela is not objecting to the fact that children with Down syndrome will differ in terms of their level of achievement but rather the devaluing of children within an already socially devalued group. She implies that a sense of solidarity as a collective is sometimes lacking.

8.3.2 The dereliction of service culture

The term 'dereliction' evokes the image of brokenness and decay, lack of progress and renewal and an absence of enthusiasm and energy. This organising theme is primarily concerned with this 'lack', a void in terms of services, ideas and positive practices around people with learning difficulties. This analysis enriches our understanding of the meaning of 'social exclusion' via the data gathered from family members and staff involved in the project.

Regimented, segregated resources

A recurring theme expressed by parents and project staff was the rigidity of services. In looking to future accommodation options for example, one parent still had grave doubts about the traditional 'group home' setting for her son:

When I look at a group home I can't see freedom there, they tend to be very regimented...I wouldn't like him to be somewhere where he has to ask permission to do everything and be limited as to what he can do because someone else is imposing (Pamela, Andrew's mother).

Interestingly, Pamela aspires for her son to have autonomy, free from coercion. Similarly, Margaret, Rhonda's mother exclaims, "I would hate to see her stifled.". She would like to see her daughter "grow and grow and fly and fly away". This reflects a wish for their children to live in environments which allow them to develop their own identity and exercise choice as citizens with equal rights. Being stifled or imposed upon by others (perhaps support staff) who have authority and control over their lives is a genuine fear. Parents talked about the need for someone to be in a supervisory type of role, someone to "keep an eye on things". However there is a considerable gulf between authoritarian control on the one hand and having the caring trusting support of parties concerned with one's well-being. To some extent or another, we all (ideally) have people in our lives who exercise some concern for us, whomsoever we are. This concern with the dual values of 'freedom' and 'well-being' in order to exercise one's human rights as a human agent directly connects such thinking on the part of parents to the philosophy of Alan Gewirth (1996,1982).

Lack of opportunity and low expectations

The previous chapter which was concerned with the analysis of data from the young people indicated the importance placed upon being productively connected to society via paid work. The general lack of work opportunities for people with learning difficulties was a source of great frustration to Katie's mother:

You have lots of people when you are at school. Then you leave school, you go to TAFE, you work really hard... and what do they get at the end of it? Nothing, nothing. It's OK, you have a handful of people with Down syndrome out there who have got good jobs and good luck to them but I can tell you now that it's really hard to try and get these guys a job, a decent job, something that *they want to do*. (Susan, Katie's mother, *my emphasis*)

Susan's frustration echoed the voices of many other parents heard in a large scale study by Davies & Beamish (2009). Data gathered from parents in a large Queensland study, involving the families of 218 young adults (modal age 21 years), underlined the lack of post-school options for young people with learning difficulties and the impact of this issue upon the whole family. In all, 35 categories of work were identified. The most common jobs were kitchen hand, working at a supermarket, and shop assistant (Davies & Beamish, 2009). Of the 53 young people in the study who

had gained open employment, almost half of them earned less than \$100.00 per week.

Mary, Ciara's mother also expressed concerns about the unskilled and unstimulating work offered to her daughter by a disability employment agency:

The whole attitude was that she should be grateful for working at Woolworths packing shelves. Ciara wasn't born to pack shelves, I would rather her volunteer somewhere, do voluntary work where she is appreciated (Mary, Ciara's mother).

This attitude was echoed by some parents in Davies & Beamish's (2009) study as one parent states for example "I believe the wage my son receives is not important- he has a purpose in life/a reason to get up in the morning". Other parents however took issue with the low wage their sons and daughters received for long hours. In one example, one parent related that her daughter worked for 42 hours each fortnight and received only \$49.00 in remuneration.

Parents often provide all the enhanced support required by their sons and daughters with learning difficulties. The absence of wider support networks can produce a disabling effect upon the whole family. Parents sometimes have to give up work and personal activities. This 'disablement' of the family was highlighted by Beamish & Davies (2009) who indicated that research highlighting this was produced decades ago (Ferguson, Ferguson & Jones, 1988) and yet twenty years later many parents and disabled adults remain excluded from society, their rights and status as equal citizens ignored.

Lack of information about resources and services

Families of the young people rarely had contact with services outside of education and training unless they were in crisis. Although schemes do exist for respite care arrangements, free computers, classes and so forth, in NSW at least, acquiring knowledge of these resources seemed to be rather an ad-hoc process, with little proactive engagement from the service sector. Helen, a Team Coach in the project had encouraged a family to access respite arrangements commented that families "didn't have a lot of access to information, or didn't have the time to find information."

The fragmented nature of services in the NSW disability services 'landscape' is a particularly difficult issue for culturally and linguistically diverse (CALD) groups of people with disabilities and their families, especially migrant families. A Victorian consultation report (Kung, 2004) cited "lack of information about services" and "lack of coordination between services" as prejudicial to accessing vital services. This lack of information about existing resources hence forms one of the 'dimensions of disablement' for many families.

Falling away of services/opportunities with age of the disabled person

The first global theme in this chapter 'the experience of learning difficulty within the family', demonstrated that parents of adults with a disability have two interconnected issues to deal with: firstly, as they age the ongoing support needs of their sons and daughters change in nature but do not disappear (Barnes, 1997), their support needs may increase or decrease with age. Secondly there is genuine concern about what will happen to their sons and daughters when they are unable to care for them. One disabling feature of life for many families is that services appear to 'fall away' as the disabled adults get older. Although Katie had no immediate plans to move out of her family home in the near future, Susan, Katie's mother describes her frustration with the diminishing availability of activities and services for her daughter matured:

... it's like everything, a hell of a lot of money for early intervention, hell of a lot of money for the little ones, bit of money out there when they get to adolescence, but what is there for adults? And God help us when they get to older people because there is nothing for them (Susan, Katie's mother).

This again raises the point that there is limited research regarding the ongoing needs of adult family members with learning difficulties generally (Hussain & Edwards, 2009; Clegg, Sheard, Cahill & Osbeck, 2001). Many support services for people with learning difficulties are limited to provision for children and adolescents (Hussain & Edwards, 2009) and studies in rural areas of Australia for example, show a particularly marked absence of access to services (Owen, Gordon, Fredrico & Cooper, 2002). There is a general paucity of adequate transition planning and programs are lacking for people with learning difficulties although plans are afoot to address this in recent government policy documents in NSW (ADHC, Stronger Together, 2010).

Isolation and loneliness in families

Isolation and loneliness in families is obviously not a phenomenon particular to families with a member who has learning difficulties. Indeed, my own experience in working within the Circles of Support project, many of the young people and their families had very active social lives and were well connected with the communities in which they lived. For some people in the study however, this was not the case. Katie's mother expressed her feelings of isolation and raised the reality that she and her daughter needed not just practical but emotional sustenance:

I mean.... it's very hard because I don't have a lot of people to help me support Katie emotionally either.... (Susan, Katie's mother).

This perception was shared by Helen, a Team Coach who shared her experience of working closely with families over a longer time frame:

..... Some of the deeper issues that families shared with you. That was very confronting; the emotional stuff, grief that parents are still carrying, the burn out amongst families. They were really tired and worn out and just needed a break (Helen, Isabel's Team Coach).

In a highly populated and wealthy society, social isolation and loneliness is a socially constructed phenomenon. The data demonstrated the need, not only to work with the whole family but to also pay heed to the support needs and acknowledge the issues facing parents. One area of project development suggested by two parent research participants was some arrangement for parents to get together and offer mutual support and information sharing this way.

Summary

The above analysis demonstrates some aspects of the complex nature of disablement for the families within this research. It could be mooted that the domination of the psycho-medical model in 'diagnosing' and 'treating' disability has ripple effects in the ways services are developed. The medical model manifests a laudible project to identify and treat an illness. However, does such a model translate successfully to people who need long term and flexible support?

8.4 ENABLING CONCEPTS AND PRACTICES

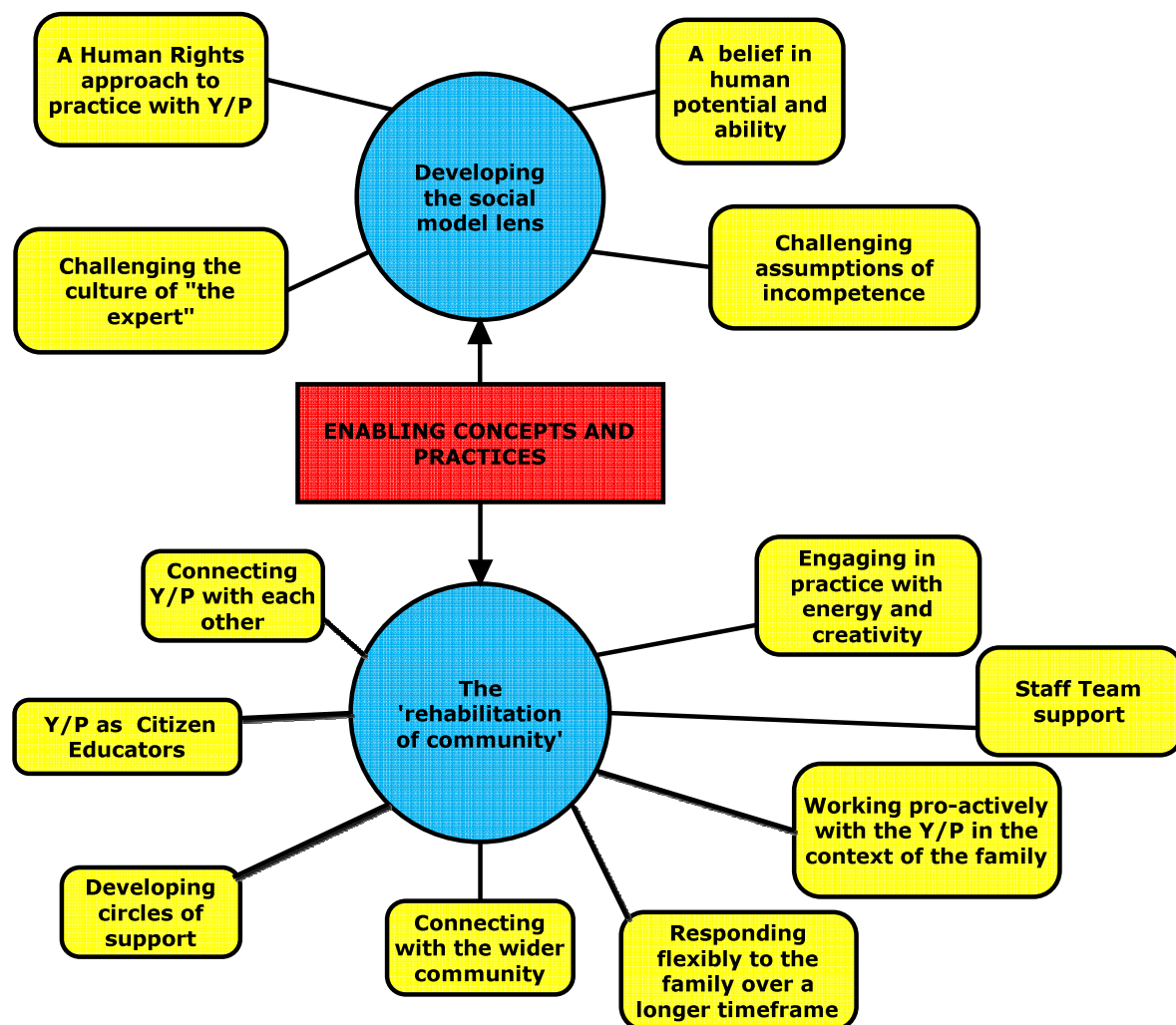


Figure 15. Global Theme: ENABLING CONCEPTS AND PRACTICES

This section focuses upon features of the Circles of Support Project which parents and staff perceived as enabling (Figure 15). This is an important global theme as it describes much of the ‘positive process knowledge’ generated in our action research project. This research however uses the lens of the social model of disability. The notion of enablement used here was derived from the social model of disability as explained in Chapter 3 of this thesis and is reiterated here:

Enablement is....the growth and expansion of opportunities which facilitate the participation of people with impairments in the life of the community on an equal level with others and the removal of physical and social barriers which impede this process.

The social model describes a social relational notion of disability maintaining that disability is socially constructed. The above definition describes forms of 'enablement' as similarly socially constructed. Notably there is, again, an emphasis upon inclusion as (at least) a contributory factor towards enablement. An emphasis upon 'inclusion in the mainstream of activities' obviously unites a social model position with the language of 'social inclusion'.

As explained in Chapters 5 and 6, it is important for the reader to note here that the data gathered in the Voices for Change participatory action research contained commentary on the entire web of Circle of Support Project activity over its three year lifespan (from 2006-2008) including its two 'sub-projects' which blossomed as a result; the making of the DVD and the Citizen Educators Project.

The data was reduced into two organising themes expressing the enabling features of the project work: firstly, ***developing the social model lens*** which relates to data concerned with the conceptual standpoint/s of the project; secondly the enabling practices within the project which flowed from both existing theory and participatory 'learnings' are grouped under the theme ***the rehabilitation of the community*** indicating that the community needs to change and adapt to engage disabled people. Again, the positive practices which parents noted were not solely concerned with actual activity and alluded to a range of factors within the project experience.

8.4.1 Developing the social model Lens

The Circles of Support project was a dynamic and not a static entity. Beyond a concern with observing human rights and ethical practices my approach as coordinator was to 'keep the doors open' to continuous collaborative learning. For myself as coordinator, it was a unique opportunity to implement a constellation of alternative ideas but, more importantly, listen carefully to the young people and their families and let them direct us in what support *they* found useful.

Challenging the culture of the expert

This reflective approach in itself was useful, especially to project staff, myself included. There was no culture of 'the expert'. This for, me was an important attitude

and reminiscent of Illich's critique of the culture of the expert articulated by Finger & Asun (2001):

Experts and the expert culture always calls for more experts. Experts also have a tendency to cartelise themselves by creating institutional barricades- for example proclaiming themselves gatekeepers, as well as self-selecting themselves. Finally, experts control knowledge production, as they decide what valid and legitimate knowledge is, and how its acquisition is sanctioned (Finger & Asun, 2001 p.10).

No fixed method or extensive 'body of knowledge' about the psycho-medical or indeed medical aspects of Down syndrome was required (or applied) on the part of staff at all. PAR in fact is conducted on the basis that locally derived and alternative forms of knowledge are perceived as real and valuable (Mok & Hughes, 2004).

This attitude was evident in the language used by project staff; Sundari, a Team Coach shared that she felt able to work on a "person to person" basis with people in the project. The terms "client" or "service user" were not used, instead the term "participant" describing voluntary involvement with the project (which it was). The term "project participant" also engendered a sense of belonging; a collective 'status' which emerged as of value to the young people. The challenge for project staff was fundamentally to learn about and adapt to the unique and changing wishes and needs of every young person and their family in the project in relation to the pursuit of the young person's life goals. The knowledge required was, in many ways, contextually developed.

A human rights approach

In analysing interview data the language of human rights, the social model of disability and the notion of purposefully 'valuing' people with Down syndrome were apparent. The project Team Coaches articulated 'theories of practical intent' (Alway, 1995) which inspired their practice.

Anna, a Team Coach and an experienced practitioner in the disability field offered her view on the Disability Rights and Choices training which was offered to Team Coaches:

..Disability Rights was good..... I thought that was really good and just kind of focused me to think, OK why are we here? And that is why we are here, to give people their rights (Anna, Luke's Team Coach)

Anna's perception of her work alongside oppressed groups as human rights activity is commensurate with the work of Ife (2001), Ife & Fiske (2006) and the objectives of the Australian Association of Social Workers (2010). However, how often is this usefully re-stated for workers (who may not be qualified social workers) who undertake vital, yet low paid, low 'status' work to support disabled people? Support workers and personal assistants working with disabled people are seldom perceived by policy makers as human rights workers/advocates? Often 'advocacy' is seen as a limited and episodic pursuit, something a person or group might engage in now and again rather than an ongoing process interwoven into daily life.

Advocacy is also a way of working with people, a way of being with people who have a history of oppression and disadvantage. Advocacy is also about seeing potential in people and being proactive about how they might achieve their potential. Many people with learning difficulties have had restricted life opportunities so may not know what is out there for them:

I think there is so much potential there, like I think they are a group of people who have been kind of lost (Anna Luke's Team Coach).

Furthermore, are parents who strive to facilitate dignified and productive lives with their disabled sons and daughters not engaged in human rights advocacy also? If so, this implies a greater depth of vision and purpose than is contained in the reductive label of 'carers' or 'care-givers', a point that Kittay (2001) examines from a philosophical perspective.

Challenging assumptions of incompetence

The history of the oppression of people with intellectual disabilities is apparent in this scholarship of the primary 'othering' and interconnected processes of stigma, labelling and eugenics. Indeed as illustrated in Chapter 2 (Gould, 1981; Yong, 2007) the discourse of eugenics can bring a deprivation of their legitimacy and full value as humans, their potential to contribute to society. It is potentially a limiting and

‘carceral’ label. In the case of people with Down syndrome, their right to life as a ‘category’ of people is constantly held in question (Buckley & Buckley, 2008). There are a number of mechanisms whereby this status can be overturned. In the course of the Circles of Support project as described in Chapter 6, Jasmine (and other young people) participated in research activity and gave presentations at conferences and universities. In these instances, she took on a ‘socially valued’ role (Wolfensberger, 1972) as a researcher and teacher and was able to demonstrate her ability in these areas. More importantly Jasmine was facilitated to be in a position where she could meaningfully educate others about disability first hand. More meaningfully in fact than could a non-disabled academic. The ‘person with a learning difficulty’ became the educator. Her mother commented on the impact of these activities generated within the Circles of Support Project:

...as we reflect on the things that have been happening we can use those things to create more of an understanding in other people of disabilities...because I think it’s starting to put that focus on the positive aspects of ‘abilities’.. (Heera, Jasmine’s mother).

Heera’s elegant use of language here is telling, these processes do not merely raise awareness; they actually “create” fresh understandings and images in the minds of others. The work of the young people in universities and other arenas from which they have been largely ritually excluded allows them to craft these new perspectives for themselves.

8.4.2 Towards the rehabilitation of community

Rehabilitation is a term normally used to describe the process of assisting someone who is physically or mentally disabled (or in the social model sense, impaired), or who has been released from prison to adapt to the community. Through the lens of the social model, disability is socially constructed by oppressive social attitudes and structures. Through this lens, it is the community which requires ‘rehabilitation’; it is the community which needs to move away from the mythical notion of ‘unimpaired’, perfect human beings (Barnes, 2001) and embrace the diverse nature of humanity. Parents and staff provided data which illuminated the practices and processes featured within the Circle of Support Project (itself a kind of ‘service’) which were enabling, healing or positive.

Engaging in practice with energy and creativity

Staff of the Circle of Support Project were key agents of change within families in the three year time span of the project. Whilst some Team Coaches came and went according to other commitments in their lives, the project managed to retain a core of dedicated 'Team Coaches' throughout the three years. As established in Chapter 5 of this thesis, change-orientated social care practice (Healy, 1996) is essentially located within human rights activism which, in this research at least, engendered a belief in human potential and ability and engaged everyone involved in challenging assumptions of incompetence brought about by the labelling processes of the psycho-medical model of learning difficulty. Human rights perspectives appeared to generate energy amongst project staff, as Anna, offering her view on project training around disability rights and choices shared:

....it was just kind of exciting, I felt excited after it. I just thought, "Yeah we have got to keep fighting" (Anna, Luke's Team Coach).

The perception of the project as "exciting" and progressive was a recurrent theme for staff. Emma, having just completed her own research honours degree was drawn to the notion of contributing to the research within the project. She felt the project model was an innovation. Emma wanted to be "part of it because it sounded exciting."

Other staff found fulfilment in working in a non-crisis- driven, long term way with both the young people and families in the project:

..being able to work with the individual in the context of the family, help them achieve their goals, just making someone happy and making friends. It seemed exciting, making a difference really (Sundari, Rhonda's Team Coach)

Sundari's simple desire to make "someone happy", be "friends" and "make a difference" is a far cry from some of the mechanised 'assessment, intervention, outcome' framing of managerialist social work tasks. It is an approach more in keeping with social work as an expression of a love of humanity (Morely & Ife, 2002) and illustrates a desire for positive social connectedness on the part of staff.

Passionate engagement of staff was also valued by the families, as Heera noted, Jasmine's Team Coach showed great 'enthusiasm' in "getting the Jasmine's circle of support going". Part of the role of the coach was to take enthusiasm and energy into the family and this was facilitated through valuing the Team Coach's unique abilities and creativity. Vivienne also commented positively about the impact of the person-centred planning process undertaken by Emma.

The dynamic nature of the Circles of Support project provided space for creative thinking as a collective rather than a fixed, procedurally driven activity. This factor, in itself, appeared to promote high levels of initiative and creativity in the staff group. For example, as coordinator I put together a manual for staff (which was refined and developed throughout the project) in order to give staff some initial basic guidance in the person-centred planning and Circle of Support processes contained in the project plan. Emma, Carl's Team Coach remarked however:

I found the manual to be useful. I haven't probably used it to the letter, no definitely not, but I found it useful as a guide I kind of adapted and used a few things (Emma, Carl's Team Coach).

Similarly Shanti explained the diverse nature of young people who have Down syndrome and the need for flexibility of approach:

....what I liked about the role was it was just sort of, you went on a more person to person level. What might have suited one participant might not have suited another and you went with whatever approach worked. And if nothing worked you had the manual to fall back on so we kind of had that flexibility...(Shanti, Jasmine's Team Coach).

Shanti's final point is challenging to any formal notion of social work; "the manual" was something to "fall back on". This highlights that the project work was driven significantly by the initiatives taken by young people and families themselves rather than any form of procedure. Similarly, Sundari, shared that "there is no timeframe" indicating that the pace of the work was also unique to each family. Sundari's own journey was transformative as she became increasingly aware of the unique character of participants within the project:

Just the abilities and strengths being so varied amongst participants [of the Circle of Support Project]...When I started I was scared, everyone is so different...(Sundari, Rhonda's Team Coach)

Along with person and family centred approaches, creative thinking on the part of staff is critical where working with any oppressed and marginalised group. An interesting paradox emerges here: given the extent of categorisation, segregation and oppression that has marred the aspirations of people with learning difficulties and their families historically outlined in Chapter 2 of this thesis (in a field highly populated by 'experts' and 'specialists') the ability to *not* make assumptions of incompetence and think in a manner which was unfettered by stereotypes was useful.

Staff team support

All the Circle of Support Project Team Coaches interviewed for the research valued the fact that they were part of a team. The monthly team meetings and project development day provided for them a sense of belonging to the project. Feedback, ideas and emotional support were forthcoming from the team approach:

....everybody has been really supportive of each other and if there has been any kind of little issue that has come up there's been other Team Coaches that will jump in and give their opinions and feedback (Emma, Carl's Team Coach).

As project coordinator I gained much from the feedback at these meetings about progress with families. On a deeper level, the togetherness and connectedness of the team also helped to embed a culture and shared vision for the project for all of us which was important in the very early stages of a new endeavour. Andrew, the project Team Voice was also present at these meetings and his representation of the young people ensured that we kept discussions on track.

Working with the young person in the context of the family

Staff in the Circle of Support Project worked over an extended time period with the young person and their entire family. All the Team Coaches commented on the importance of "rapport" and having time to build a relationship with the young person and the family in order to ensure constructive engagement.

Parents repeatedly stressed the need for staff to work around the needs of the family as a whole:

They have to listen to the family, they have to listen to what works and not push their ideas onto the family because what works for one family may not work for another family. They have to be flexible (Mary, Ciara's Mother).

...she was quite happy to go along with us and work flexibly and do things the way Jasmine wanted (Heera, Jasmine's Mother).

This was not always an easy task for staff. The necessary complexity of this practice approach and the need to be adaptable and flexible were articulated by Anna:

..it's not like a normal job when you go into the workplace where you go "OK this is what we are going to do" so you turn up when they want you to turn up , to their house or wherever and you deal with whatever is going on in their life (Anna, Luke's Team Coach).

Anna demonstrated her acute sensitivity to the closeness and intensity of the mother – son relationship and the importance of practical and moral support for Emerald:

Emerald had worked so hard with Luke for so long, since he was a baby, she was at a point where she needed someone to help....I think having someone else there kind of took off the pressure and got her to sit back a little (Anna, Luke's Team Coach).

Because all the young people were living at home the practices of the project were probably most aptly described as family focussed *and* person centred. The two approaches are certainly not mutually exclusive. Barnes (1997) make the point that people with a learning difficulty are embedded in their families, whilst Kittay (2001), a mother of a young woman with learning difficulties herself also stressed the deep interconnection of parent and child, even when the child becomes an adult. Good practice, it seems, fully acknowledges these issues.

The close involvement of families in plans and action for the young people was a highly productive element of the project work. Emerald's enthusiastic support of Anna's (Team Coach) work with Luke is exemplified in the following description of

work Anna has undertaken with her son in terms of managing his money. Emerald illuminated the detailed process:

....like they go into the shop and they give the assistant a five dollar note....they don't know whether to expect change...they have to watch what the cost of a thing is.. so she (Team Coach) got him to write down how much money he was spending every day...he would have his money for his train and he would have his money for his drink or whatever he would buy for his lunch so he had that little thing each week he would do (Emerald, Luke's mother).

This descriptive account indicates not only Emerald's intimate concern with her son's development of life skills but also evidences a high level of communication and understanding between parent and Team Coach along the way. By keeping Emerald informed and part of all the work she undertook with Luke, Emerald's position as Luke's main support person was respected and there was continuity of support for Luke in terms of his work on his goals.

Connecting with the wider community

One of the issues with the social inclusion agenda is the gap between the rhetoric which abounds in agency policy documentation and the scholarship and practice of inclusion in everyday life. In the project two basic forms of connection were advanced: firstly via the Circle of Support as discussed here, which aimed to enhance discussion and relationships in families and those people in the young person's immediate network; and secondly, through building relationships with other people/groups in the community. Both were vital components of the project process. This latter feature of our work happened at both an individual and agency level.

This connective practice was intertwined with aspects of development as outlined in Chapter 7. Building up social skills, money management skills and confidence ran concurrent with community connection. These subtle 'connecting' skills are apparent when Emma describes a night out with Carl and his friend:

He gets his own drinks and we go and sit down and watch the football together, then there is a meat tray raffle and he goes up and buys his own tickets, then at the end of the night we have started to use the courtesy bus so what we trying to do is build up his relationships with the people who are at the club, the local people....so it's just building up his profile I guess in

the club so people know who he is. Yes, building up those relationships so that he will be able to go independently (Emma, Carls' Team Coach).

From Emma's account we can see that Carl has the opportunity to exercise his money skills and connect with people in the course of a 'normal' community based activity. Emma was able to analyse the different steps and skills Carl could strengthen in the course of this activity and envisaged how he could then eventually enjoy a night out independently.

The second form of connecting practice was concerned with other agencies within the community. The story of the Citizen Educators Project has been told in chapter 6 and is hence added into this global theme as an enabling practice.

Personal Circles of Support

It is important to recognise that not all the people in the Circle of Support Project chose to form circles of support as described in Chapter 2 and contextualised in Chapter 4. Some families embraced the concept wholeheartedly and sought to continuously increase numbers in their circles, others preferred to keep the circle (at least initially) comprised of close family members. Other parents rejected the idea and need for any notion of a formalised circle in which case participants placed emphasis on working with their Team Coach on development of skills and attended the project workshops for example. For those who did seize the idea, the concept of an intentional circle was interpreted differently by the different families in the project. Interestingly the two families who were the greatest proponents of the 'metafamily' circle and who established a pattern of regular gatherings were migrant families whose children were first generation Australians. Both Rhonda and Jasmine's families were also active members of faith communities; Christian and Hindu respectively.

Margaret, Rhonda's mother outlined some of the ways in which the circle had impacted on her immediate family:

I think its brought us a lot more closer to each other because through the circle of support meetings and things like that a lot of things have been talked about, discussed that we don't

usually sit and discuss as a family....we have got more understanding into each other which I think is great (Margaret, Rhonda's mother)

This also illustrates that the rigours of family life often do not naturally facilitate focussed discussion about the young member who has learning difficulty and their future needs. Margaret articulated the circle of support as a device which had a number of interwoven positive impacts:

....a tool for giving Rhonda the opportunity to have more people in her life than just the immediate family. And I'd like to think that those people who have been supporting Rhonda will be there long-term. May be going in and out and in and out depending on circumstances in their lives but I'd like to think that it could carry on with these people for all of *her* life. So that she's got more people supporting her in life and she is also learning skills to make her more independent. And at the same time she is making new friends and socialising (Margaret, Rhonda's mother).

Margaret saw the circle as a flexible, practical tool that could accommodate changing circumstances:

...you just have to realise that it is very flexible. It's not solid or strict or whatever, you know like people come in when they can, they do things when they can, then they might drop out then they might be another period when they do things. It's been good to open up our home and let strangers, basically, come in and get to know them and know that there are a lot of people out there who are caring and want to work with our daughter (Margaret, Rhonda's mother)

Heera explained one of the strengths of having a Circle of Support as a mechanism to increase awareness and building capacity in communities:

..even with the Circle of Support, not every one of them has had a person with a disability in their own life. So just coming here and listening to other people talk about disabilities, listening to Jasmine herself, that is in some way 'spreading the word'...(Heera, Jasmine's mother).

Certainly in terms of this research project, there was a mixed response to the idea of a more formalised circle of support however, the deployment of the idea of a circle was generally appreciated by families as a potential future support mechanism.

Summary

This global theme has illustrated that the project had a number of interwoven concepts and processes which proved enabling for the young people and their families in varying ways. The identified enabling concepts and practices in the project are interpreted as supporting the families and the social citizenship of young people and are integrated into the modified service model discussed in Chapter 9.

8.5 Concluding remarks

Although it is evident that there is considerable crossover and intertwining of themes, flexible use of the social model lens facilitated the development of three candid global themes present in the web of the interview data gathered in the 'Voices for Change' participatory research. These global themes provided fertile ground for further discussion in the next chapter. A number of key issues were penetrated via this analysis. The first global theme confirms that regardless of the presence of any impairment, families see their sons and daughters who have Down syndrome as complete and valuable family members and human beings, their aspirations for them are geared towards the achievement and enjoyment of their human rights and engagement in active adult citizenship. Different perspectives were expressed but on this broad theme, there was a high degree of consistency in the data. Sitting alongside this however, is parental realism about the effects of their sons and daughters impairment as they perceived and explained these in terms of their various enhanced support needs which are manifest and present over an extended timeframe, if not lifelong.

The second global theme however demonstrates that in day to day life a significant feature of socio-cultural oppression appears to stem from the continued application and ramifications of the psycho-medical model which labels, limits and places emphasis on the perceived deficiencies of their adult children. The body of data informed us that this model and the assumptions that flow from it can have impact on their sons' and daughters' social status, work prospects and relationships for example. At a more abstract level the psycho-social model appears, in itself to inhibit the realisation of citizenship rights and processes somewhat. This model possibly manifests itself in the form of a 'dampening' and regimenting effect on services for people with disabilities which, from the perspectives of the parents in this study at

least, seem to evaporate away with the increasing age of their adult sons and daughters.

With regard to the third global theme concerning what concepts and practices families reported to be enabling within the Circle of Support Project an interesting paradox emerges: in a field highly populated by 'experts' and 'specialists', the ability to support participants and their families unfettered by the boundaries of categorisation and stereotypes was useful. Staff in the participatory research similarly appeared to value team support, supervision and 'back-up' but be energised and emancipated by an approach to work which was based on human rights, both flexible and responsive to the needs of the family and not procedurally bound.

The findings from Chapters 6, 7 and 8 all hold implications for theory, practice and disability research. The following discussion endeavours to examine some of the issues raised in more depth.

9. Discussion

*O chestnut-tree, great-rooted blossomer,
Are you the leaf, the blossom or the bole?
O body swayed to music, O brightening glance,
How can we know the dancer from the dance?*
(WB Yeats, from 'The Tower', 1928 p. 26)

The Voices for Change participatory research journey was a dynamic and vibrant process which has added to the body of knowledge within disability studies on a number of levels. Describing Yeats' 'dancer and dance' is complex however. The discussion is structured as follows:

9.1 Structure of the discussion

Theoretical considerations

Analysis of data from the young people has identified some of their concerns, interests and aspirations as citizens which have contributed to theorising in respect of social inclusion and social citizenship. A further outcome of the research was the identification of some aspects of social oppression using the lens of the social model, particularly from the views expressed by parents. Discussion of these issues challenges 'psychological' and individualised interpretations of the experience of parenting and supporting a son or daughter with a learning difficulty (Olshansky, 1962; Heiman, 2002).

Threads from the findings are drawn together and woven within relevant theory. I relate the findings to the earlier literature reviewed regarding human rights (Gewirth, 1981;1996, Ward and Birgden, 2007; Ward and Stewart, 2008) social citizenship (Beckett, 2006), the social model (UPIAS, 1976; Finkelstein, 1980; Oliver, 1983; 1990; 1996) and social inclusion (Buckmaster & Thomas, 2009) in order to demonstrate what the research has added in terms of new knowledge in these areas.

Developing a practice model

This research was practice based and sought to promote practical outcomes which will bring benefits to people living with disability. PAR is generally conducted to address problems at a local level (Fals-Borda & Rahman, 1991; Mok & Hughes, 2004). With regard to recommendations for practice therefore, I outline how the participatory research informs the structure of a revised project model aimed at supporting the citizenship of young people with learning difficulty. Accordingly, the new enhanced, theory based model is named the “Citizen Engagement Project”.

Developing flexible and responsive research

The implications of this study in terms of its participatory research process are significant. I review the ‘findings’ from the participatory research process itself documented in Chapter 6 and consider questions around whether the research is emancipatory. This includes deliberations in respect the EDR principles (Barnes, 2002; Stevenson, 2010) explicated in Chapter 5 of this thesis and investigates how they have been met in this research. Emergent from this debate are a number of considerations for the non-disabled researcher in relation to undertaking projects with co-researchers who have learning difficulties.

Policy implications

Although the findings of PAR are always context specific, considerations are made in respect of what messages from this research have to offer future social policy.

Finally, the limitations of this research are fully acknowledged.

9.2 Theoretical considerations

The findings of this research contribute to theory in respect of our understandings of citizenship, disablement and enablement. Throughout this thesis, primacy has been given to the participatory activity and voices of young people in the research process. Congruent with this approach, I construct a theoretical framework of inclusive social citizenship from the voices of the young people in this study. I seek to define and locate this framework within a human rights based model. This evidences that the co-researchers in this study are able to make a contribution to theory around social citizenship.

9.2.1 Problems with the concept of inclusion/social inclusion

The review of literature in this thesis exposed the multiple dimensions of oppression in relation to people with learning difficulties which have been perpetrated over the centuries. Politically, people with learning difficulties are largely perceived as an 'excluded' group. The language and politics of 'social inclusion' have been deployed to bring them into the mainstream of society.

Subsequently the 2008 Convention on the Rights of Persons with Disabilities seeks to reiterate and reinforce the human rights of disabled people with an emphasis on their 'inclusion and participation' in society (UN Enable Website, Guiding Principles of the Convention). Legally then, inclusion is a human right of people with learning difficulties.

As identified in Chapter 2 of this thesis earlier, academics have identified a number of theoretical and practical problems with the concept of 'social inclusion'. Social inclusion lacks a clear definition and coherent theoretical 'core' (Buckmaster & Thomas, 2009; Armstrong, Armstrong & Spandagou, 2010 p.31). Largely because of these factors, problems of interpretation can occur at both theoretical and political levels. For example, 'social inclusion' limits its scope to those people who are (somewhat arbitrarily) deemed 'excluded'. Depicted is a scene of the passive 'excluded' being (arbitrarily) 'included' by a benevolent and charitable majority. Steinert (2003, pp.45- 50) develops a conceptual framework of participation in his discussion of social exclusion. His use of language suggests that the term 'participation' is preferable to the term 'inclusion' as it engenders a more pro-active and less passive stance on the part of the 'excluded' individual.

Additionally, whilst social inclusion generally emphasises participation in the community and is thereby linked to social citizenship, crucially there is no *theoretical* linkage to rights as there is with the status of citizenship (Buckmaster & Thomas, 2009). Other questions arise: Do all the problems encountered by people with learning difficulties relate to 'social exclusion'? Can such problems be solved by 'social inclusion'? If there is no clear definition of social inclusion, how can we know this? One can of course argue that social inclusion means different things to different

people but, by the same token, inclusion can end up meaning “everything and nothing at the same time” (Armstrong et al, 2010 p. 31). Finally, in connection with the above discussion, social inclusion as a ‘stand alone’ and unexplicated concept does not furnish ‘the excluded’ with any means whatsoever of establishing clear accountability at the level of government. This can mean that the excluded (and their supporters) are constantly in the position of lobbying for ‘inclusion’. Crucially, ‘social inclusion’ does not intrinsically suggest or require that the ‘excluded’ have a role in defining for themselves how they might wish to be included.

Locating the notion of ‘inclusion’ within a well-buttressed human rights and social citizenship framework rather than as a free-floating notion in its current vague, under-theorised state (Buckmaster & Thomas, 2009) strengthens its meaning and political efficacy. The following discussion develops this argument.

9.2.2 The application of Gewirthian human rights theory

The work of Gewirth (1981,1996) is important as he has, as discussed in Chapter 2, used deductive logic to identify two broad absolute human rights; those of ‘freedom and well-being’ and from this he has established the Principle of Generic Consistency (PGC). These are terms which are open to much interpretation (necessarily so) but provide a foundation for discussion of human rights theory and social citizenship.

So, in developing a visual model of core and surrounding layers, what are the elements of this theory? Firstly, Gewirth’s post-Kantian theory of human rights forms an important core. Gewirth (1996, p.13) argued that human action is the basis of human rights:

...for it is with actions that all moralities or moral precepts deal, directly or indirectly. All moral precepts tell human beings how they ought to act, especially toward one another, whether within or outside of institutions; or, as in the case of the virtues, they tell what kind of person one ought to be.... (p. 13).

The context of action also has necessity as:

All human beings are actual, prospective or potential agents. No human being can evade the context of action, except perhaps by committing suicide; and even then the steps he takes for this purpose are themselves actions. (p 13).

Gewirth then goes on to argue that ‘purposiveness’ or ‘intentionality’ are required by the agent in that the agent acts to achieve some desired end. Additionally, in order to have agency, humans need the freedom or voluntariness to act on their intentions. ‘Freedom’ for example can include access to relevant information, being able to consider all possible alternatives, being able to plan strategies to achieve the goal without unjustified interference (Gewirth, 1996 p. 13; Ward and Stewart, 2008). Agents also need well-being to achieve their goals. These include the entire individual and social/community factors impacting upon the individual, for example, their physical and mental health, education, living conditions, emotional and social support and so on (Gewirth, p.13, Ward and Stewart, 2008). Gewirth subsumes all these factors under the concept of ‘well being’.

9.2.3 The relationship between Gewirth and the social model

The constituent components of ‘well-being’ will, of course, shift and change according to the characteristics, circumstances, culture and historical position of the individual. One powerful assertion of Gewirth’s thesis is that absolute human rights are not culturally relative. From this we assert that cultural traditions which discriminate and inhibit the freedom and well-being of some humans on the grounds of race, gender, religion (or other variables such as physical or intellectual impairment) cannot be permitted to restrict the application of human rights. With regard to disability there is an important link with the materialist perspective. Gewirth draws on the work of Marx to explain ‘historical variability’ in that the “number and extent of [the worker’s] wants , as also the modes of satisfying them, are themselves the product of historical development” (Marx, Capital, 1867, Vol. 1). Importantly, this renders Gewirth’s thesis of human action as the basis of human rights as compatible with the social model of disability which is also developed from a Marxian materialist perspective as outlined in the literature review of this thesis. Gewirth’s theory is also

one of 'practical intent' in that he places the necessary features of freedom and well-being at the heart of state and organisational governance (Gewirth, 1996, pp.106-252). Disablement can therefore be said to be social oppression as it constitutes structural and attitudinal factors which impinge upon the freedom and well-being of people with impairments-whatever the nature or context of that impairment. The social model is notably non-specific about historical context or the exact nature of what we might term 'disability' for precisely this reason.

9.2.4 Linking Gewirthian theory with human rights objects and policies

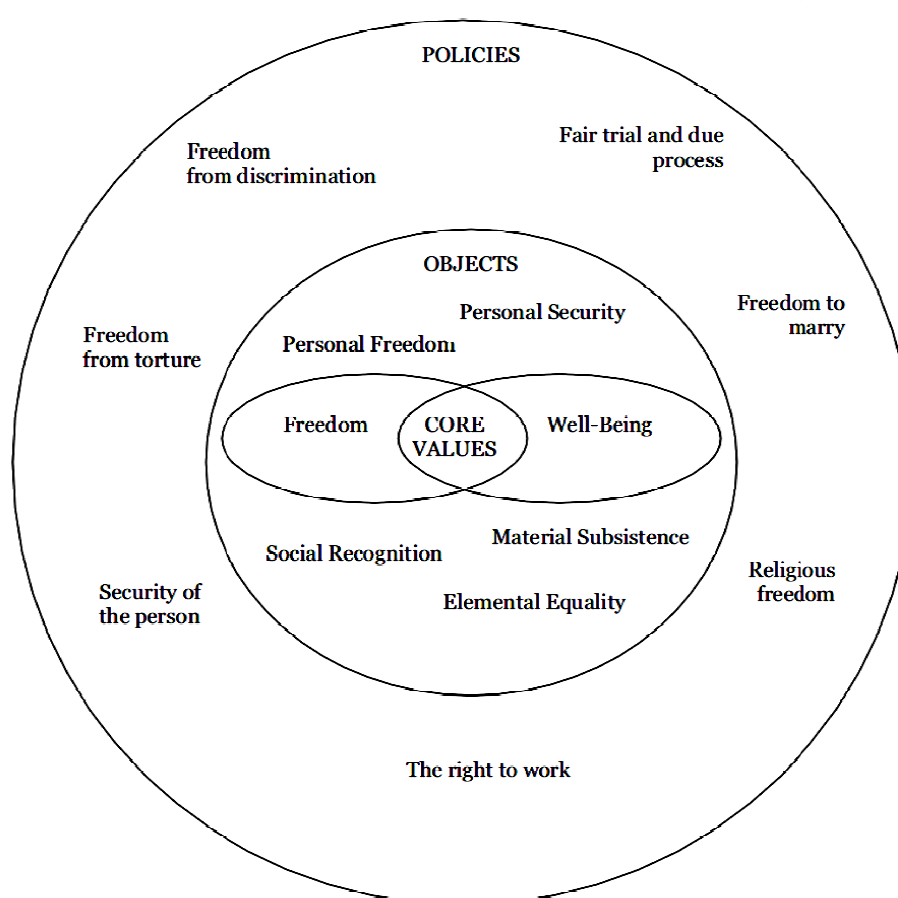


Figure 16. The structure of Human Rights. Reproduced with authors' kind consent.

The above diagram was produced by Ward & Birgden, 2007 and is cited in Ward & Stewart (2008, p.302). Ward & Birgden (2007) developed the above model (Figure 16.) which charts a movement from core values using the justificatory theory of Gewirth (1981, 1996, 1998) through to pragmatic human rights objects and thence through to policies. They drew upon the work of human rights authors including Li,

(2006), Orend, (2002) and Rescher (1993) and argued that there are corresponding duties to respect the stated rights. Ward & Birgden (2007) thereby made strong theoretical links between Gewirth's justificatory theory and the various conventions on human rights.

Later, Ward & Stewart (2008) applied this model of human rights to people with learning difficulty and argued that it has resources to connect the perceived gap between human rights and human needs. In so doing, the authors argued that this offers ethically defensible practice guidance. They discussed how the above model can all be employed by professionals when called upon to work with individuals with learning difficulties and their families in making important life decisions.

The robust and well argued theoretical structure created by Ward & Birgden (2007) has great value in respect of the findings of this research when we consider it together with the observations of Beckett (2006, p.195) in respect of citizenship.

9.2.5 Why is the concept of citizenship important?

Citizenship as a concept been raised in Chapter 1 of this thesis and problems with defining citizenship and social citizenship have been identified by many (Kymlika & Norman, 1994; Saloojee 2001; Buckmaster & Thomas, 2009). It remains however, an important, if contested, notion on a number of levels. In accordance with the human rights theory developed here, Gewirth straightforwardly argued that a citizen is a 'rights bearing agent' (Gewirth, 1996, pp. 68-69). Gewirth stated that this thought dates back to Aristotle (Politics, 1.2.1253) who held that:

...to be fully human is to be a member of a polis, a civitas, a political community, and thus to be a citizen, a civis : "man is by nature a political animal" (cited in Gewirth, 1996, pp. 68-69).

If we accept this argument then human rights are inseparable from all civil and political rights. This notion of citizenship demands an integration of human rights with issues of 'governance' defined as the act or process of governing (derived from the Greek term 'steer'). Governments are therefore concerned with law-making, the policies, services and professional practices which flow from such laws and their

impact upon social groups. Beckett (2006) opined that a universally agreed set of non-culturally specific human rights is unlikely but she conceded that 'individuals would still remain the 'citizens' of a state' and hence issues of governance are matters which disability scholars need to engage with. Arguably we therefore need to continue to engage with human rights theory and citizenship in an integrated, dynamic and practical way.

Beckett also identified social citizenship, the exercise of one's rights as a citizen in their social context, as a "process" (2006, p.195) rather than a fixed status; people are diverse, dynamic and entities within diverse and shifting environments. So, what processes constitute social citizenship for participants of co-researchers in this research?

9.2.6 The contribution of findings from the young people to social citizenship theory

From this participatory action research, four global themes emerged from an analysis of the data from and by the young people. Their concerns as citizens were explicit in the following global themes (i) engagement with human connection; (ii) the need for continuing personal development; (iii) the importance of community contribution; and (iv) the dignity of risk. Positioned together, these themes can be said to capture some of the processes of social citizenship (Figure 17.) which were important to young participants and co-researchers in this research. In Figure 17, the four global themes (in red) explored in Chapter 7 are made up of organising themes (in blue). Brought together, they can be said to form a dynamic matrix of citizenship processes. Most importantly, these processes were identified by the young people themselves through active participation in this research project which, in itself, is a citizenship practice.

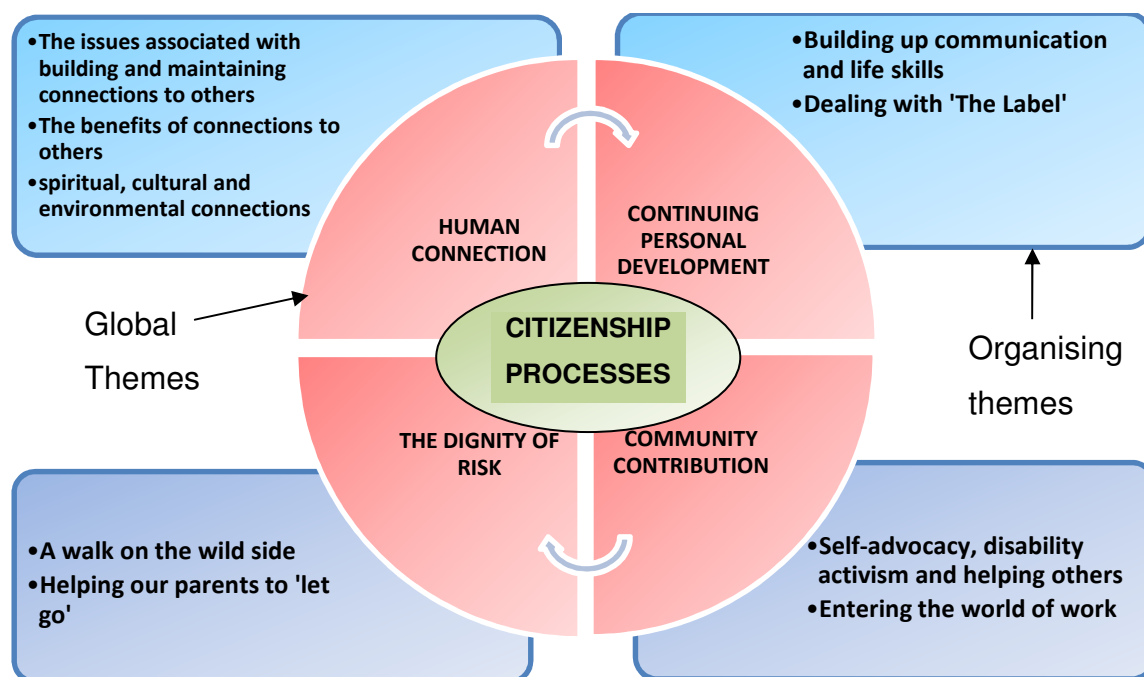


Figure 17. Global themes and organising themes as dynamic and interconnected citizenship processes.

It is important to assert that the above four global themes as illustrated in Figure 17 do not comprise an exhaustive list of the constituent elements of social citizenship for the research group. It also must be noted that these are dynamic processes; intertwined, shifting and changing and specific to each person and their circumstances. Brought together however these themes can model some of the processes of social citizenship which the young person informants and co-researchers held to be of some significance. In effect, when a young person is positively engaging in these processes or addressing concerns within these domains, this can be seen to indicate a positive and active manifestation of human rights and therefore active social citizenship.

Theoretically then, can these processes be embedded into a rights-based theory of social citizenship, to extend its meaning and practical application?

9.2.7 Integrating social citizenship processes identified by co-researchers into a human rights framework

Taken together these can be interpreted as social citizenship processes and can be integrated into a framework building on the work of Gewirth (1981, 1996; Ward & Birgden, 2007; Ward & Stewart, 2008) shown in Figure 18.

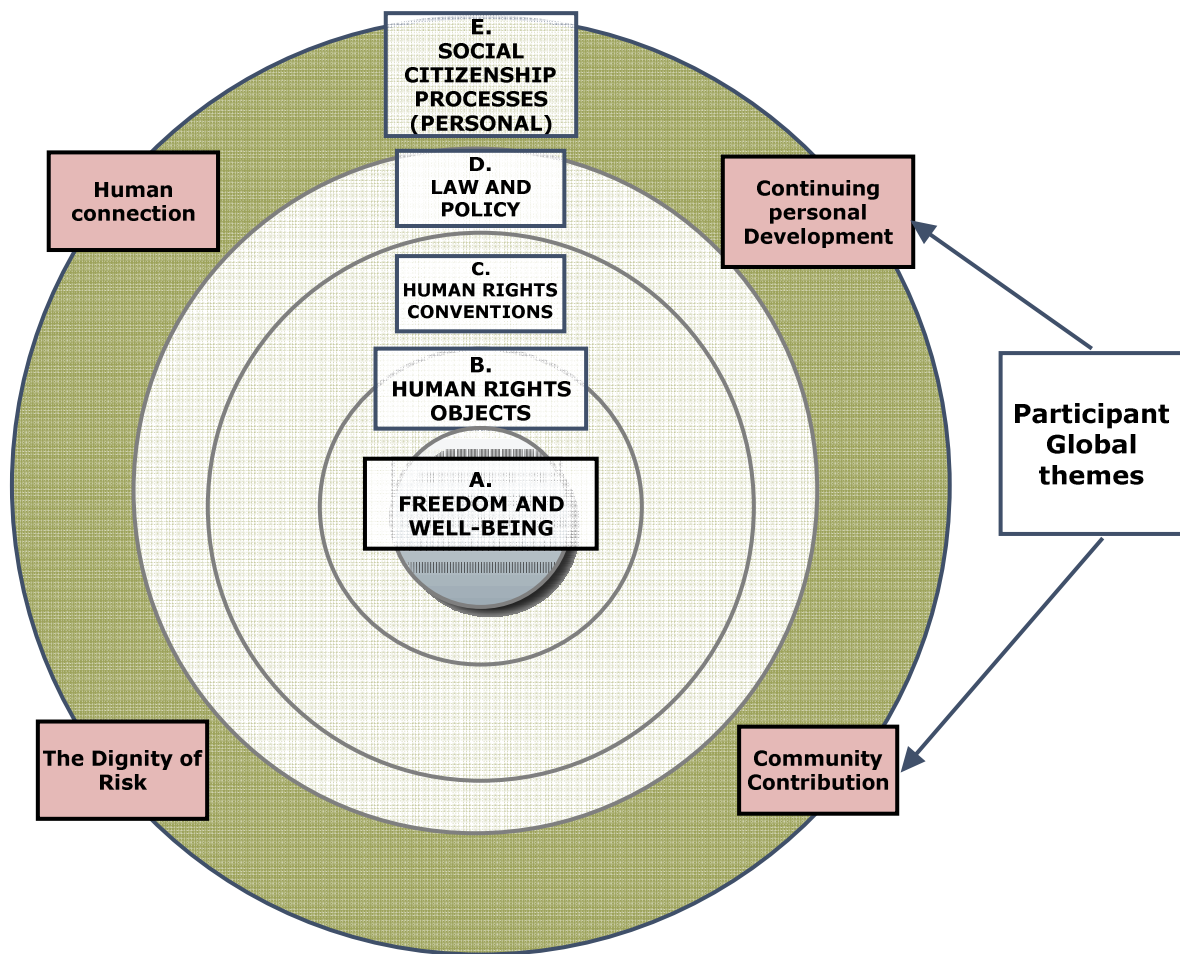


Figure 18. Framework of Social Citizenship theory for young people involved in this research

The importance of this model, building on the work of Ward & Birgden (2007) is that social citizenship processes defined by the young people have an explicit theoretical core consisting of the following:

- A. Freedom and Well-Being as the necessary conditions of human agency, as defined by Gewirth (1981, 1996) and identified as core values;
- B. Human Rights objects (Orend, 2001 p.125), these in turn support the Human Rights Conventions
- C. Human Rights Conventions (e.g. 1948 Convention on Human Rights and the 2008 Convention on the Rights of Persons with Disabilities).
- D. Human Rights Conventions form the basis of law and policy (D).
- E. Represents practices and areas of engagement of social citizenship. These are informed, in this research, by the global themes in Chapter 7 of the thesis.

Human rights are at the heart of social citizenship. It is this engagement in social citizenship processes by the young people which forms both the active *expression of their human rights* and, simultaneously helps to protect human rights and ensure the achievement of the core values of freedom and well-being. In other words, a dynamic and reciprocal process occurs between all the elements of this model with high integration between the layers. For example, in contributing to the community via the self-advocacy movement, the collective voices of these young people have the potential to influence law and policy, in turn, law and policy can be formulated to help support these practices. Policy makers, law makers, practitioners and the young people are engaged in a wider 'community of support', which drives participatory (even emancipatory) action. I will illustrate how these processes can be applied in practice when I go on to explain the Citizen Engagement Project.

I have argued that social inclusion needs to be theoretically integrated within a human rights framework and cannot be a meaningful concept when positioned outside of such a framework. Importantly, a social citizenship approach does not *necessarily* draw on the language of 'social inclusion'. Instead, 'social citizenship processes' accommodate what might be termed as inclusive processes such as 'community contribution' and 'positive social connection' within a much clearer and well defined rights framework. Most importantly, stepping towards the emancipatory ideal, Emancipatory Disability Research, in this instance has enabled this group of young people with learning difficulties to define some aspects of what they see as social citizenship processes *for themselves*.

9.3 Grief and disablement

The findings from the data gave many insights into the nature of disablement in the lives of the families who participated in the research and this is my next area of focus. The following discussion focuses on the issues of grief and 'disablement' in the area of learning difficulty. It raises issues and invites the reader to question assumptions sometimes made about the experience of parents of people with disabilities.

The review of literature in Chapter 2 of this thesis exposed the multiple dimensions of oppression in relation to people with learning difficulties which has been perpetrated over the centuries. The dominant and well funded intertwined discourses of eugenics and the psycho-medical model in defining and controlling their lives have contributed to the devaluation and disenfranchisement of people with learning difficulties. They have formed stigma and 'assumptions of incompetence' which are challenging to change. The individualised and personal tragedy discourses of disability however are essentially challenged by applying the social model of disability (UPIAS, 1976; Finkelstein, 1980; Oliver, 1983; Abberley, 1987). As has been explained throughout this thesis, the social model is employed as a strategic device which acknowledges impairment but defines disability as oppression which is socially constructed. Whilst the individual complexity of disability cannot be denied, a socio-political analysis of disability by individuals and in certain groups can prove to be highly illuminating, multi-faceted and sometimes personally transformative as expressed by Hervey (1991):

I think I went through an almost evangelical conversion as I realised that my disability was not, in fact, the epilepsy, but the toxic drugs with their denied side-effects; the medical regime with its blaming of the victim; the judgement through distance and silence of bus-stop crowds, bar room crowds and dinner-table friends; the fear, and, not least, the employment problems (Hervey, 1992 p. 2, cited in Barnes and Mercer, 2003 p. 12)

Hervey illustrates how impairment (in this case 'epilepsy') is present in his life but how disability is wrought through the debilitating side effects of the drug regime, the medical model which pathologises and individualises the person who has epilepsy and the painful stigma created by the insensitivity of other people who have little awareness of the implications and effects of epilepsy. Through a social model analysis, Hervey is able to extricate the impairment 'epilepsy' from the assigned disablement brought about by society. Interestingly, as demonstrated by Hervey, separating 'impairment effects' from disablement (social oppression) is never a simple process and clearly the complexity of what may be seen as 'impairment' and disablement produces a thousand grey areas. Ultimately only the individual themselves can establish (for themselves) what constitutes 'impairment', 'impairment

effects' and disablement (social oppression). It is useful however to meditate on what emerges in findings from the small 'collective' involved in this research.

9.3.1 The disablement of the family

The young people participating in this study were all resident at home with their families and so the data from parents illuminated much about both their position as a loved one and issues surrounding the support required and provided. Staff involved in the project and working directly with the young people and families also had insights and experience to make a valuable contribution to knowledge in this area. The global themes of 'THE EXPERIENCE OF LEARNING DIFFICULTY WITHIN THE FAMILY' and 'DIMENSIONS OF DISABLEMENT' which were fully explored in Chapter 8 can now be assembled to illuminate and model how social oppression can impact upon the inherent challenges of supporting a young adult with learning difficulties.

This gives us a different lens through which to view and critique psycho-medical approaches which have evolved in relation to how we might understand the feelings and responses of parents of children and adults who have learning difficulties.

The social construction of parental 'grief'?

In their review of relevant literature, Kearney & Griffin (2001) identified that research describes a welter of negative parental reactions following the initial impact of a diagnosis of severe impairment in a child. In some quarters there is the assumption that parents experience a grieving process when a child with a disability is born. A theory of unresolved grief, of ongoing 'chronic sorrow' (Olshansky, 1962) associated with giving birth to, raising and supporting a child (later an adult) with learning difficulties still influences professional bodies of knowledge in the area (Krafft & Krafft, 1998; Mallow & Bechtel 1999). There seems to be a certain flawed logic in embracing notions of grief in this area however. A defining feature of 'grief' is that it is a process usually associated with absence, the actual death or loss of someone. It is something of a conceptual leap to assert that we can actually grieve for a person who is here with us; a person whom we essentially love and appreciate. Considering the findings of this research, is it not possible that societal factors some of which are mentioned in the 'Dimensions of Disablement', have enormous impact on the emotions of parents/main support people?

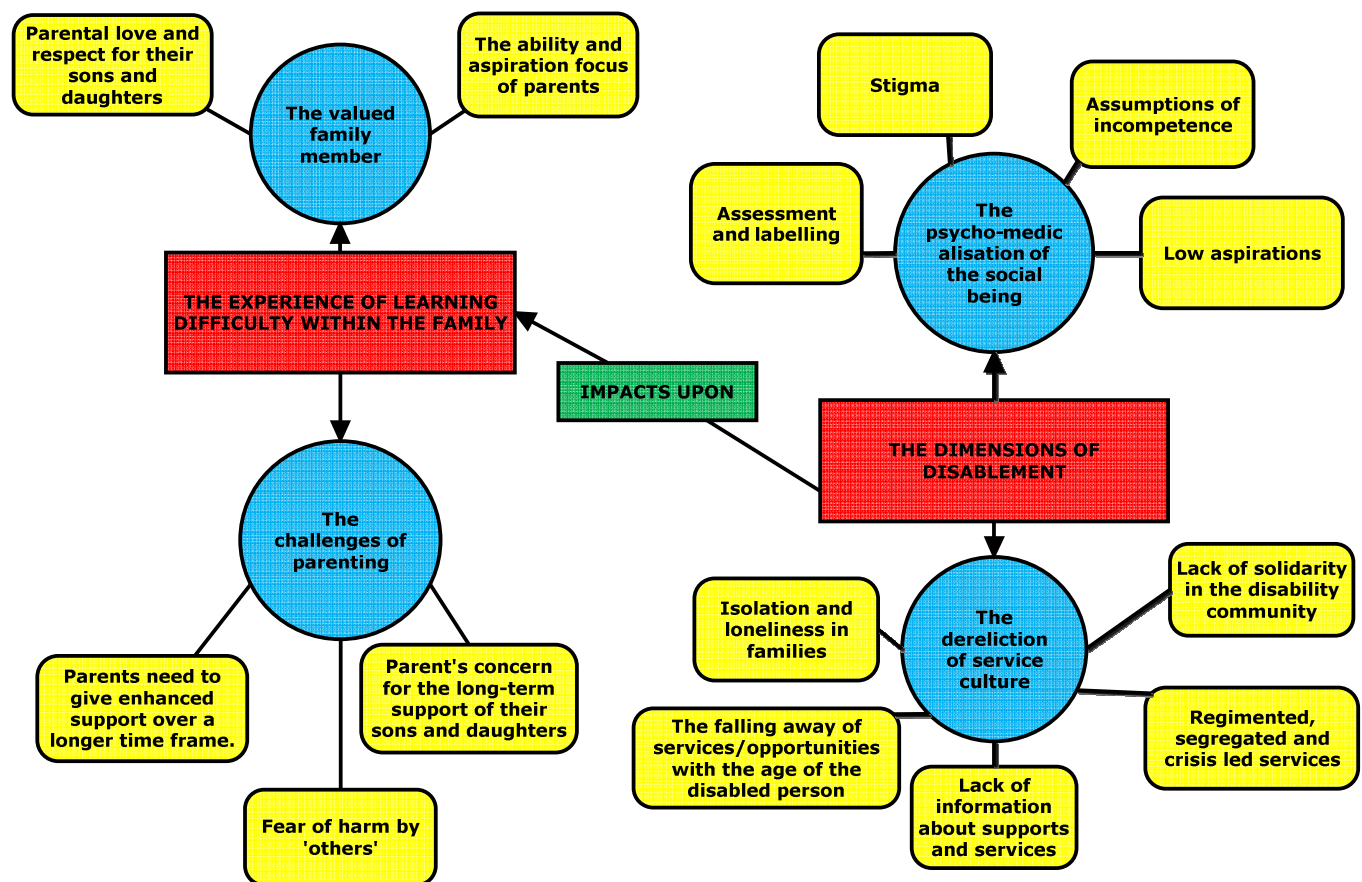


Figure 19. The social construction of parental grief?

Figure 19 unites the global themes THE DIMENSIONS OF DISABLEMENT and THE EXPERIENCE OF LEARNING DIFFICULTY WITHIN THE FAMILY to provide an example of how disablement (UPIAS, 1976; Finkelstein, 1980; Oliver, 1990, 1996) can impact on the family. Viewed this way disablement can be clearly seen to provide a number of challenges to families in addition to the impact of the effects of the impairment (Thomas, 1999). I will not repeat the descriptions and discussions of the organising themes (in blue) and basic themes (in yellow) here as this has been accomplished in Chapter 8. Figure 19 presents a powerful image and is reminiscent of the view of Koch (2008) discussed in Chapter 2 of this thesis, who concludes that the “deck is stacked” for parents raising and supporting their children and adults who have ‘special needs’.” It is reasonable to infer from the above diagram that grief and ‘chronic grieving’ processes (which are complex and unique to the individual in any event) may be at least in part, socially constructed rather than an innate feature of being a parent of a child with a disability. Studies such as those of Brown (2007, p.7) reveal “recurrent grief” amongst mothers of young people with learning difficulties as

a complex relationship between emotional and social factors. Other authors contend that grief and loss need to be revisited in relation to disability (Sapey, 2004). There is certainly a reassessment needed in terms of what 'grief' means and a need for definition and specificity, in terms of what individuals are possibly grieving for or about. The issue requires much more research as parent authors such as Kaly (1998), Murray & Penman (1996, 2000) along with Green (2007) remind us not to make assumptions about how parents may feel about their children with disabilities. For parents, there can be a myriad of socially constructed stressors at play which they often have (or feel they have) little or no control over. If any of us lived with a person we loved that had to exist in a society which devalued and excluded that person, a society in which there is a constant fight for their inclusion in the mainstream of activities, a society which will probably deny that person many of their citizenship rights, these challenges would undoubtedly make life difficult and depressing at times. Furthermore, a diagnosis of 'chronic grief' in a parent can lead to a referral for various models of grief counselling. Guided by the psycho-medical model, such counselling could individualise problems, ignore contextual social oppression and tacitly reinforce the notion that the presence of impairment is an overwhelming 'tragedy' for the person themselves and the family (Oliver, 1990;1996), this view is shared by Kearney and Griffin (2001).

Summary

This observation on the findings of this study will stand more detailed and rigorous exploration but there is certainly enough evidence presented here to underline the need to fully acknowledge and address, from a community perspective, the dimensions of disablement, not only of the person with learning difficulty, but of the family as a whole. The use of the social model lens here not only underlines the need to "couch *disabled peoples'* experiences, narratives and stories within their environmental and cultural context" (Barnes, 2001) but also the *experience of those close to them*. The example here, although limited, constructively challenges highly individualised models of 'parental grief' brought about by the (assumed) tragic absence of a mythical 'perfect' son or daughter. In the words of Finkelstein (2002):

A good model can enable us to see something which we do not understand because in the model it can be seen from different viewpoints... it is this multi-dimensioned replica of reality that can trigger insights that we might not otherwise develop (Finkelstein, 2002, p. 13).

What has been most notable in my own experience as a social work practitioner in the UK, coordinator of the Circles of Support Project and in the course of the Voices for Change research in Australia is the overall strength, resilience and sheer tactical skill demonstrated by many parents in the face of a disabling society and the enduring nature of their feeling for, and commitment to, their children as evidenced in the data analysis in Chapter 8. The positive message in using the social model lens, is that “disablement” can be impacted upon via the development of various enabling social mechanisms. From a service perspective we can learn to culturally ‘frame’ learning difficulty in a different way and cultivate supports and attitudes that will enable, rather than disable, people with a learning difficulty and their families. This brings me to the next area for discussion.

9.4 Implications for practice: The Citizen Engagement Project

One of the perennial challenges facing social workers, social work agencies and policy makers is the translation of theory into strategy and thence into practice. It is not the aim of this thesis to prescribe a ‘new dogma’ of practice in relation to people with learning difficulties. Flexibility and responsiveness have been emphasised as a hallmark of both the approach to the EDR process documented herein and the theoretical considerations thus far. However, effective leadership in the provision of services for people with learning difficulties calls for this approach to be incorporated into a social citizenship paradigm requiring vision, energy and a sense of direction.

Commensurate with the practical and participatory thrust of this thesis and the EDR emphasis on producing research findings of practical benefit to disabled people, it is appropriate to discuss the final project model which emerged from the research. The model developed here consists of five domains of practice which can be said to assist the promotion of social citizenship alongside young people with Down syndrome/ learning difficulties. For this reason I have re-named the practice model, initially conceived of as a Circle of Support Project at the beginning of this research, the **Citizen Engagement Project**.

In Chapter 8, I identified some of the processes within the project which families and staff identified as positive under a global theme of ENABLING CONCEPTS AND PRACTICES (section 8.4 of this thesis). The basic themes which emerged in the

analysis around positive conceptual thinking and critique of the psycho-medical model of learning difficulty included: a conscious human rights approach to practice; a belief in human potential and the need to challenge pervasive “assumptions of incompetency” made by both professionals and laypeople which are created by the labelling of people with a “learning difficulty”, which is itself a (flawed) social construct (Gould, 1981). This powerful label can subsequently place limitations on the aspirations society has for them and correspondingly on the aspirations they are allowed to have for themselves (Aspis, 1997; Souza, 1997). Practice and processes at play within the Circles of Support Project which parents and staff found to be positive included: staff energy and innovativeness; working with the young person in the context of the family; responding flexibly to the family; developing circles of support; encouraging connections with community organisations; gaining opportunities for those young people who were interested to become researchers and educators; and connecting the young people with each other (via workshops). How can these enabling processes be incorporated into a new model of support?

9.4.1 The theoretical basis of the Citizen Engagement Project

The Citizen Engagement Project is undergirded by an understanding of the history of the oppression of people with learning difficulties and an awareness of powerful discourses which can continue to perpetrate their oppression as described in Chapter 2 of this thesis. This understanding has been shown to be critical, to this group and other oppressed groups in analysing their continuing oppression and in avoiding repetition of past mistakes. For example we could not begin to work alongside Australian Aboriginal people without first having some understanding of the mechanisms and impact of colonialism in Australia. To counter oppression, a commitment to universal human rights, grounded in the core values of freedom and well-being (Gewirth, 1981,1996; Ward & Birgden, 2007; Ward & Stewart, 2008) is essential. The model explicated in section 9.2 of this thesis can be applied. The lens of the social model (UPIAS 1976; Finkelstein, 1980; Oliver, 1983, 1990, 1996) is employed as a practice tool to identify disablement, enablement and hence serve as a vector for the realisation of human rights. The social model is used to re-frame the experience of people with learning difficulties and their families as they participate in the project identifying barriers to participation and enabling supports. These

foundational features of the project will, of course, have implications for staff training, as will the following domains of practice:

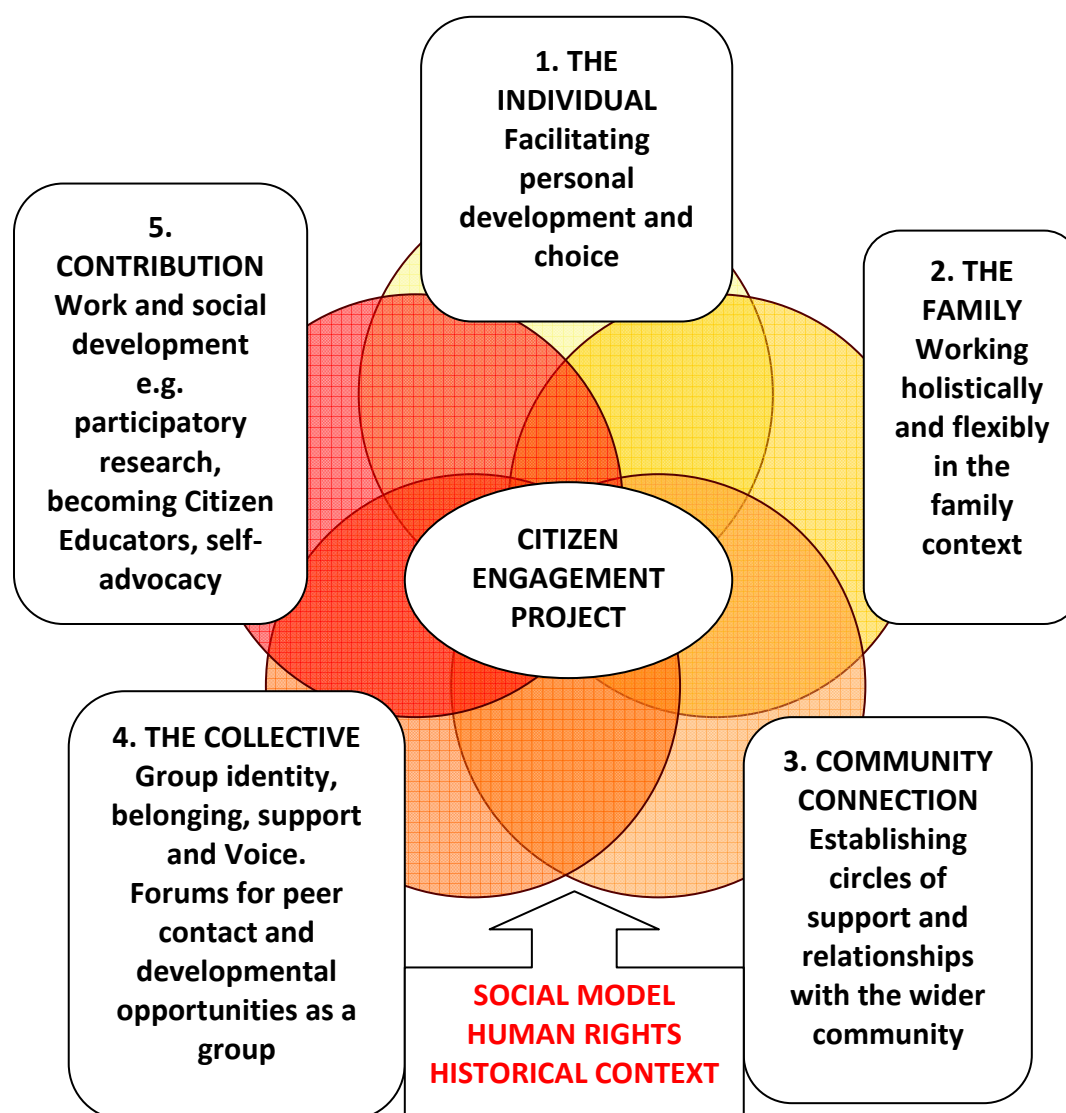


Figure 20. The foundation and practice domains of the Citizen Engagement Project

9.4.2 The practice domains of the Citizen Engagement Project

The term ‘engagement’ is used in this model to describe a stronger and more reciprocal relationship between the individual, their human rights as a citizen and the society in which they live. Figure 20 illustrates the foundational basis of the Citizen Engagement Project and the five domains of practice which are now discussed:

1. THE INDIVIDUAL: Facilitating personal choice and development

This domain of practice draws on the global themes of “Continuing personal development” and the “Dignity of risk” discussed earlier in this chapter and in Chapter 7 of the thesis. Exactly what a participant perceives as personal

development is a matter for them to decide. For example, 'personal development' could mean learning a new skill, learning more about oneself, taking a course or having a new experience. Many new experiences entail a degree of 'risk taking' which needs to be countenanced and discussed by the participant, their family and the practitioner. To some extent the paternalistic veto on some experiences can be an unintentional disablement via automatically assuming that the young person does not have the ability to be safe because of their impairment. Any 'risk', skill or support assessment process needs to be participatory, avoidant of labelling, and fluid.

It is very important that words such as 'mentorship' and 'training' are avoided if possible in this process as such language can imply an unequal power relationship and can reinforce the 'competent mentor' training the 'incompetent client' with learning difficulties which can be disabling and infantilising. The activist social work approach (Healy, 1996, pp.2-3) explicated in 5.1.4 of this thesis is applicable.

2. THE FAMILY: Working holistically and flexibly

This was an approach emphasised by the young people themselves, parents and staff as vital. The research established that young adults with learning difficulties generally need various kinds of enhanced support in organising and living their day to day lives. Most of this support is traditionally provided by the family, often a parent or parents will have the role/s of being a main support person. Outreach work is a key feature of practice; engagement takes place in the home or community environment.

As well as support with the practical rigours of their role, parents often benefit from emotional support and the opportunity to talk through complex issues. These can include areas such as the need to support their sons and daughters' developing adult rights and freedoms together with any concerns about their safety and well-being. This work is key as often there are practical and emotional issues to be explored and addressed by families before (and during) working towards a young person's life goals. Again, a flexible and holistic approach which genuinely acknowledges and embraces the family situation is a cornerstone of the project strategy.

3. COMMUNITY CONNECTION: Establishing circles of support and relationships with the wider community

This domain of practice has been drawn directly from the analysis of data from the young people and has been carefully explored earlier in this thesis. The circle concept needs to be available for implementation, flexible and adaptable, remain 'dogma free' and chiefly responsive to the needs and circumstances of families. For example, some young people and their families may not wish to have a 'circle of support' in terms of a regular meeting with people sat in a room together. They may feel a sufficient support network without needing anything more formal or they may wish to have an 'inner circle' with family and identify 'satellite' members. Circles can vary in membership, disband and re-connect if need be, with the agenda of the participant and family circumstances. Even the deployment of the idea of a circle of support within families can stimulate some valuable thinking, discussion and awareness which can be made use of at any time. Connecting with the community also engages the project workers pro-actively and creatively in the generation of opportunities for engagement and involvement in the wider community (McKnight, 1990).

4. THE COLLECTIVE: Group identity, voice, belonging and peer support

The monthly workshops in the Circle of Support Project were shown to fulfil a number of functions meeting emotional, developmental and self advocacy needs although other collective activities can be beneficial with the concepts of group identity, voice, belonging and peer support as objectives. Importantly the individual and group are not polarised, rather the group decides together the content and direction of the workshops.

5. CONTRIBUTION: Working in the community and participating in social development

This domain of practice is wide-ranging. Contribution can occur via a number of means in terms of offering help and support to those at home, working either voluntarily or in paid employment in the community or, at a more political level participating in research (as did some co-researchers in this study), becoming 'citizen educators' or participants in governance and decision making forums. The primary message in here is that everyone can make a contribution to society.

Summary

Figure 20 illustrates how all the identified areas in the Citizen Engagement Project have the potential to overlap and relate to each other. Participants in the Citizen Engagement Project exercise autonomy and choose which areas they wish to engage in. They can move in and out of the different areas according to their wishes, needs and individual circumstances. It may be for example that even if a participant is not living with their family or does not even have (or wish to have) contact with their family they can be facilitated to participate in the other areas.

Together, these five domains of practice help to both ‘unpack’ and apply the notion of inclusive social citizenship at a local level as determined by the participatory action research conducted in the Circle of Support Project.

If this project were to be implemented, further participatory action research cycles would be beneficial to enhance the scope and nature of the Citizen Engagement Project both theoretically and practically. This point leads us into the final section of this discussion chapter which seeks to address principles of Emancipatory Disability Research and where the research in this thesis stands in relation to these.

9.5 Implications for research

9.5.1 Was the Voices for Change doctoral research emancipatory?

This section reviews each of the EDR principles (Barnes, 2001) documented in Chapter 5 of this thesis, as I endeavour to assess whether this research was genuinely ‘emancipatory’.

Control

The overall research question was derived from the ‘summarising statement’ of the young people consulted in the course of the Circles of Support Project, so their concerns were paramount. In the Voices for Change research, my strategy was to flexibly and responsively move along through the research journey facilitating participation of co-researchers in as many research tasks as possible, giving over control and power to them at every opportunity. All my co-researchers were engaged in other training and/or employment besides the research project. Not all of them wanted to engage as co-researchers throughout. Via this flexible approach, as

explained in Chapter 6, co-researchers were able to engage in the formulating their own interview questions, become interviewers, data analysts and participate in dissemination of findings. Whilst self advocates such as Aspis (2000) and Harrison, Johnson, Hillier, & Strong (2001), have argued that researchers should share their skills with people with learning difficulties, Williams & England (2005, pp.30-40) raised pertinent questions around the issue of control. Self-advocate England argued:

How do we, as self-advocates, manage to do research? It depends on what research we are doing. We need support to do it, but we can take the challenge. Support is important. I like to have back-up, because if we are stuck we should always have someone there to help us. Everyone's different; it's according to what you need. When we get support, does this mean we are not taking the lead? (Williams & England, 2005, p. 31).

Possibly England's comments above apply to any social science researcher. What non-disabled researcher is truly 'in control' of their research project? Do we experience a loss of control if we are facilitated to undertake research? As a non-disabled researcher, all my research activity has taught me that all researchers are, to varying extents, at the mercy of ethics committees, access to funding, time constraints, other investigators, personnel such as research assistants, mentorship and statistical expertise, training, available research equipment such as computers and software, access to relevant literature and often, the politics of the organisation/s within which the research takes place. Do we not all need support? Do we not all need to compromise, fit in with our specific context in order to see a research project through to completion? As academics self-nominating as 'researchers', perhaps we need to have the humility to accept that we have limitations and are *interdependent* beings within any context. Where others help us with the barriers we face, we ourselves are *enabled* to undertake the task. Where unassailable barriers exist, the process 'disables' us.

If disability research is conducted only by disabled people, then a kind of 'separatism' could be perpetuated. This attitude runs counter to the express wishes of the co-researchers in this project. Andrew argued the case for our co-operation and commitment ("all hearts contains in the research") in his report in Chapter 6. The

voices of people with learning difficulties incisively articulate the universal need to co-exist and operate constructively alongside other inhabitants of a community whether we are disabled or not (Martin, 2006). Oppressed groups (whether disabled or not) are often by definition, disengaged and disadvantaged in terms of access to funding, initiatives, research environments; people with learning difficulties particularly so. Researchers who work alongside and support people with disabilities to access the academe and benefit from this association are engaged, in good faith, in a process of human rights activism, not charity or parasitism (Healy, 1996; Stevenson, 2010).

There are enormous caveats to these arguments of course; the non-disabled researcher does not carry a learning difficulty label. The non-disabled researcher does not share the historical backdrop of oppression and susceptibility to stigma and discrimination which is attached to co-researchers in this study. An awareness of these factors is critical and the distinction is therefore relevant to make. It is perhaps important that the 'ideal' of complete control remains intact in EDR for all these reasons but is perhaps seen as an aspiration to guide the integrity of the research rather than a fixed and exclusory requirement. As Barnes (2001) notes, EDR is a "process" itself and not a static ritual.

Accountability

This research was conducted within the Host Disability NGO by myself as an active member of staff there. In my time therefore, I was accountable to the organisation itself. Membership of the Circle of Support reference group brought about a high degree of accountability also. Problematic from this perspective however is that, like many organisations run for the benefit of people with learning difficulties, most of the staff were non-disabled. Throughout my time working in the Host Disability NGO as the project coordinator of the Circles of Support Project, there was only one person with a learning difficulty on the governing board which is a clear indication that the organisation itself was still closely bound to its 'parent support' roots. The only disabled people on staff were an administrative assistant and Andrew who was the Team Voice of the Circles of Support Project. So, whilst most of the staff were parents of disabled people, there was little direct accountability organisationally to people with Down syndrome themselves. The initial research plan and papers were

published on the Host Disability NGO website along with some of the software presentations by the (consenting) young people. Further accountability to disabled people was achieved via the research steering groups of which four were held over the timeframe of the research. A large meeting involving parents, staff and co-researchers was held in 2010 at which broad research findings were shared. When this thesis is finalised an accessible version of the findings will be made available to participants and will be posted on the Host Disability NGO website. I am currently engaged with the Host Disability NGO as a consultant on their state-wide project.

In my own view most 'accountability' arose from the participatory research process itself. Whilst working closely together regular dialogue could occur, the voices of the co-researchers could be heard, and their parents were aware and involved. The co-researchers became people with whom I had a working relationship rather than research 'subjects'.

Practical outcomes

Whilst the issue of control is controversial, debate seems to centre around this principle of the paradigm at the expense of the other six principles of EDR which are equally important. The issue of practical outcomes is extremely important. The literature review, for example, identifies the ongoing tendency to subjectify people with learning difficulties in research (Annison, 1999; Oliver; 2004) without necessarily producing corresponding '*practical* outcomes' for people with learning difficulties (EDR Principle 3). Whilst no researcher (disabled or otherwise) can guarantee how their research findings might be used in the future, they can work on projects which are at least initiated in consultation with disabled people, include them as far as possible and *intentionally and explicitly* seek to produce knowledge and working practices which can be applied to overcome barriers and challenge social oppression. The Voices for Change research had two major practical outcomes:

(i) As described in Chapter 6, the Citizen Educators Project blossomed as a result of the co-presentation activity in the research. This constituted an innovative and empowering self-advocacy and teaching role for young people with learning difficulties. This approach has the potential to be further refined to enhance teaching and student learning about learning difficulty and disability issues in many contexts.

It also has implications for how community engagement can be fostered by universities.

(ii) The Voices for Change research findings helped to produce a revised and evidence-informed project model termed the Citizen Engagement Project described earlier in this chapter.

The research had other outcomes which were of direct benefit to the co-researchers. For example, the participation of co-researchers in academic research processes brought about an increased confidence and self esteem which was evident in feedback. Co-researchers were paid when possible for their input. The co-researchers were given access to learning about research. Subsequently, evidence of their growing ability to conduct research and reflect on the process then produced knowledge about the some of the possible support needs of people with learning difficulties have when participating in research.

The social model of disability

The use of the social model compels the non-disabled researcher to consider the cultural and political context of learning difficulty. It was important that the co-researchers in this context had the opportunity to be self-directed and identify their own concerns in the participatory data analysis. Following their lead, the data for the young people was analysed in terms of their broad concerns as citizens. Disablement as experienced by people with learning difficulties and their families is complex and multifaceted as evidenced in Chapter 8 of this thesis. The lens of the social model of disability was used to identify what features of the Circles of Support were enabling hence adding to knowledge of how an 'enabling environment' can be constructed to support participants towards achieving their personal goals and citizenship rights.

The problem of objectivity, the need for rigour and choice of methods

The theoretical framework for the research presented in Chapter 5 served to clearly demonstrate my ontological and epistemological positioning as a researcher. Chapters 5 and 6 also serve to detail the research method and process in a transparent and rigorous manner. The methods used in this project were appropriate to the group and the tasks concerned. A flexible method of data analysis was chosen via observing and noting the abilities of a co-researcher.

The role of experience

This thesis has contextualised the entire research project in examining the dimensions of oppression of people with learning difficulties in Chapter 2. The use of PAR as a means of engaging young co-researchers engendered a rich and positive environment. The participatory process itself exposed enabling practices and disabling barriers to participation in both disability and academic institutions. Earlier discussion in this chapter in relation to the “social construction of parental grief?” has served to further identify disablement in the lives of the families involved and challenged notions of “learning difficulty” as an individualised, personal tragedy.

9.5.2 Concluding thoughts on the positioning of the non-disabled researcher in EDR

As a non-disabled researcher engaging in research with people with a learning difficulty over a four year timeframe, EDR provided some clear guidance regarding the ethics of this field of inquiry. Participation in the research was essentially facilitated by myself. In terms of the emancipatory nature of the research it can reasonably be concluded that some elements of process and findings were emancipatory.

It could be argued that the notion of ‘control’ requires some reconfiguration in respect of people with learning difficulties. If this is not permissible, then EDR for many people with learning difficulties is probably impossible and potentially represents an exclusionary paradigm for all but the least disabled and most privileged of people within this group. If the notion of control is ‘relaxed’ somewhat then the other (equally important) features of this paradigm, such as the use of the social model, become accessible to people who have learning difficulties and their supporters.

This research ‘style’ could be recognised as perhaps another step on the road towards truly emancipatory research (Zarb, 1992) and part of the EDR “process” (Barnes, 2001). With these points in mind, I offer the following reflections regarding the positioning of the non-disabled researcher in research alongside people with learning difficulties in the emancipatory research paradigm:

- i. Due to the history of exploitation and subjectification in research of people with learning difficulties, their participation in research aimed at social development in their favour is *as important as the findings*. To exclude people with a learning difficulty from a process which purports to promote their social inclusion is inherently contradictory. This is in keeping with the principles of social model of disability and the 2008 Convention on the Rights of Persons with Disabilities.
- ii. The non-disabled researcher roots her practice in human rights advocacy and in a theory of human rights which embraces both the inherent dignity common to all human beings but also fully recognises our common fragility and vulnerability. The researcher accepts that these rights are reciprocal/common to all of us and that the defence of even one person's human rights is a defence of the dignity of humanity at large.
- iii. In the context of social research, EDR is an activity which is both motivated by and explicitly moves towards the realisation and enjoyment of the human rights of people with learning difficulties.
- iv. The non-disabled researcher is a dynamic 'research conduit' and opens herself up to learning from people with learning difficulties in their roles as both research informants and co-researchers. It is important that research practice works pro-actively to overturn and not mirror current social barriers. The research process is a learning experience for all and therefore flexible and responsive to the 'voices' (either verbal or non-verbal), needs and abilities of one's specific co-researchers.
- v. Research outcomes appear to be improved when there is the opportunity to build genuinely caring, trusting and ethical relationships with co-researchers through regular contact over a reasonable timeframe.
- vi. Research methods which involve or emphasise assessment, labelling and make assumptions of incompetence are potentially further disabling to people with learning difficulties. Whilst some of these practices may be unavoidable

arguably all these factors need explicit consideration in disability research planning.

Writers such as Walmsley (2004) advocate research training, pre-planning and role definition which are desirable, appropriate and achievable in some research situations with specific groups of co-researchers with learning difficulties who have the time and space in their lives to do this. Opportunities for participatory action research learning difficulty studies, however, are (so far) quite rare, not least of all due to the continuing dominant status of the medical/health paradigm in the allocation of research funding and corresponding demand for large scale disability studies (Oliver, 1998) often associated with the 'health/medical' paradigm. Furthermore, it is difficult to generalise about such a diverse group of people and thus be prescriptive as to exactly how individuals can, and should, be involved in research processes. Arguably, opportunities for small scale participatory projects need to be embraced. Learning difficulty 'research methodology' is still developing, and, beyond the establishment of an agenda which underlines the need for ethical integrity, an over-proliferation of 'rules' could be counterproductive to some researchers and disability groups getting involved in developing innovative research practices and adding to our knowledge in the area.

Above all, in accordance with EDR principles, non-disabled researchers need to acknowledge and own the 'political nature' of their work. This way, we protect everyone's rights to participation in research production, not just our own.

9.6 Implications for policy

Together with other authors, this thesis has identified weaknesses with the concept of social inclusion. As a basis for policy it is arguably under-theorised and needs to be unpacked. Rather than leaving this task solely to academics and government policy writers alone, this research suggests that people with learning difficulty and their families have a clear role to play in defining issues around their citizenship and inclusion. Participatory action research approaches to informing inclusive service development could prove a positive way forward.

In this vein, future policy makers may wish to bear in mind the philosophy and structure of the Citizen Engagement Project as a useful constellation of strategies via which to pursue inclusive social citizenship (Buckmaster & Thomas, 2009) for young people with learning difficulties. With appropriate consultation and modification, these strategies may well assist other groups within and outside of the disability field.

9.7 Limitations of this research

The strengths of this research are that it was planned and implemented within a project being conducted by an established Host Disability NGO. The research was guided by the principles of EDR.

There are a number of limitations to this study. It is difficult to conduct PAR within the constraints of a traditional PhD format. The doctoral research was not driving the project itself as the Circle of Support Project had been planned prior to my appointment as coordinator. Likewise, although I came into the project as a co-ordinator with a social model lens, the Circle of Support Project was not set up to be driven specifically by the social model and the exigencies of rigorous qualitative research, therefore there were some constraints on doctoral inquiry from the outset. Had the academic research been planned at its inception, the co-researchers could perhaps have been even more involved, for example in making the application to the university human research ethics committee.

The data collected in this research was largely interview-based although my subjective observations as coordinator of the Circle of Support Project have formed part of the findings. Future researcher-practitioners might consider harvesting data derived from more participant observation. For example the workshops, circle of support meetings, presentations and research meetings were all fertile ground from which to organise data collection.

The research was a small scale study undertaken in Australia within a particular community using the social model. As such, it is not directly generalisable to other settings without several caveats. Implementation of the Citizen Engagement Project model and further cycles of participatory action research will continue to edify the model and maintain a context for social action and social change.

10. Conclusion

Social inclusion is now an integral feature of global government policy frameworks in respect of people identified as belonging to 'marginalised' groups (Fawcett, Goodwin, Meagher & Phillips, 2010 p.159). Controversially however, pertinent issues have been identified by academics and policy makers in respect of how we might define and interpret calls for 'social inclusion' in relation to human and civil rights, policy and practice for people with learning difficulty. As a 'stand alone' concept, 'inclusion' can mean everything or nothing. It is currently vague and politically malleable. It can even be interpreted as a variant of traditional charitable, benevolent models in relation to oppressed groups. Theoretical strength and coherency is particularly important when matters of accountability are at stake for governments, legislators, policy makers and institutions with 'social inclusion' agendas.

Internationally, the social model of disability has supported progressive policy change in respect of disabled people since its inception. Its application in respect of people with learning difficulties has been slow to gain momentum, particularly in Australia. Further embedding of the social model lens is warranted in this country as a strategic device to progress the participation of disabled people in Australian society.

This thesis has striven to remain true to the ideas of inclusion (as a facet of human rights theory and practice) and the lens of the social model in utilising Emancipatory Disability Research methodology within an action research project. A contextual notion of social citizenship is defined in respect of the co-researchers involved. Through participatory research within the EDR paradigm, the young people involved consistently identified *for themselves* that human connection, continuing personal development, making a contribution to the community and the dignity of risk were some essential conceptual components of their notion of social citizenship. The abstract nature of these terms ensures that diverse forms of social citizenship can be accommodated within each conceptual field. Theoretically, these processes were then incorporated into a Gewirthian model of human rights (Gewirth, 1981, 1996) drawing on the important work of Ward & Birgden (2007) and Ward & Stewart

(2008). In this model, 'social inclusion' is located within a model of social citizenship and linked cohesively and coherently to human rights core values which form the basis of ethical governance and practice.

Via the use of the social model, we can also identify those social processes and perspectives which can be said to be individualising, disabling and which therefore need to change and *can* be changed.

Findings from parents and staff informants yielded valuable commentary on the myriad of processes and practices which can 'environmentally' support and enable the young people's social citizenship and this knowledge can be applied practically in developing service models as shown in the Citizen Engagement Project.

My overarching conclusion is that social work is political activity grounded in human rights. Legislation, policy and practice need to explicitly and coherently support this approach. As social workers and social researchers we can (and arguably must) engage flexibly and responsively with those individuals, families and communities in society whose citizenship rights have been denied. No discourse of diversity is adequate without a corresponding acknowledgement of both our common humanity and the potency of collective action. We are all of equal value. We all share the same human rights. Let us work alongside each other to realise them.

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Appendices

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Appendix 1. Letter of approval from Human Research Ethics Committee



The University of Sydney

NSW 2006 Australia

Human Research Ethics Committee

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22 March 2007

Professor B Fawcett
Faculty of Education and Social Work
Room 337, Education Building – A35
The University of Sydney

Dear Professor Fawcett

The Human Research Ethics Committee considered Ms M Stevenson's correspondence dated 5 February 2007. After considering the additional information, the Committee at its meeting on **20 February 2007** approved your protocol entitled **"Voices for change: Participatory Action Research in partnership with young adults with Down Syndrome in New South Wales, Australia"**.

Details of the approval are as follows:

Ref No.:	02-2007/9747
Approval Period:	February 2007 – February 2008
Authorised Personnel:	Professor B Fawcett
	Ms M Stevenson (PhD Student)

The HREC is a fully constituted Ethics Committee in accordance with the *National Statement on Ethical Conduct in Research Involving Humans* - June 1999 under Section 2.6.

The approval of this project is **conditional** upon your continuing compliance with the *National Statement on Ethical Conduct in Research Involving Humans*. We draw to your attention the requirement that a report on this research must be submitted every 12 months from the date of the approval or on completion of the project, whichever occurs first. Failure to submit reports will result in withdrawal of consent for the project to proceed.

Chief Investigator / Supervisor's responsibilities to ensure that:

- (1) All serious and unexpected adverse events are to be reported to the HREC as soon as possible.
- (2) All unforeseen events that might affect continued ethical acceptability of the project are to be reported to the HREC as soon as possible.

- (3) The HREC must be notified as soon as possible of any changes to the protocol. All changes must be approved by the HREC before continuation of the research project. These include:-
- If any of the investigators change or leave the University.
 - Any changes to the Participant Information Statement and/or Consent Form.
- (4) All research participants are to be provided with a Participant Information Statement and Consent Form, unless otherwise agreed by the Committee. The Participant Information Statement and Consent Form are to be on University of Sydney letterhead and include the full title of the research project and telephone contacts for the researchers, unless otherwise agreed by the Committee and the following statement must appear on the bottom of the Participant Information Statement. *Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, University of Sydney, on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or gbriddy@usyd.edu.au (Email).*
- (5) The HREC approval is valid for four (4) years from the Approval Period stated in this letter. Investigators are requested to submit a progress report annually.
- (6) A report and a copy of any published material should be provided at the completion of the Project.

Yours sincerely



Associate Professor J D Watson
Chairman
Human Research Ethics Committee

cc: Ms Miriam Stevenson, [REDACTED]

Encl. Advertisement "Call for Research Participants!!"
Participant Information Statement
Participant Consent Form
Parental, Guardian or Advocate Agreement

Appendix 2. Recruitment of Participants Flyer



The University of Sydney

Faculty of Education and Social Work
University of Sydney A35
NSW 2006.
Australia

CALL FOR RESEARCH PARTICIPANTS!!

- ✦ Are you involved as a participant, family member, team coach/facilitator, volunteer or Team of Champions member in the [REDACTED] Project?
- ✦ Are you interested in being involved in research within the project?

Miriam Stevenson, the project coordinator and a PhD student at the University of Sydney, is planning participatory action research based within the [REDACTED] project. For more information please contact her on her university email at mste8601@usyd.edfac.edu.au.



Appendix 3. Participant Information Statement



The University of Sydney

Faculty of Education and Social Work
University of Sydney A35
NSW 2006.
Australia

ABN 15 211 513 464

PARTICIPANT INFORMATION STATEMENT

Research Project

Title of study

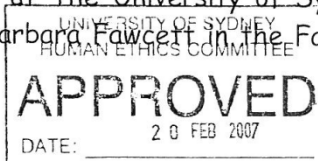
'Voices for Change': Participatory Action Research involving young adults with Down syndrome and their families.

What is the study about?

You are invited to take part in a research project which looks at how young adults with Down syndrome can be assisted in achieving their personal goals. We are hoping to learn whether or not circles of support can help participants do this. You are being approached as a possible participant in this research as you are working with us in the [REDACTED] Project at [REDACTED] NSW.

Who is carrying out the study?

Miriam Stevenson, the coordinator of the [REDACTED] Project is conducting the study. It will form the basis for her degree of Doctor of Philosophy in Social Work at The University of Sydney under the supervision of Professor Barbara Fawcett in the Faculty of Education and Social Work.



What does the study involve?

If you decide to participate you will be asked to work with Miriam on planning the research and give your opinion on the work you are doing by participating in group discussions and short interviews. We will also record some interviews and discussions and may videotape some of these. The reason why we might videotape some of these is so that we can look at how groups interact together in making decisions

and solving problems. I plan to discuss the results in my PhD dissertation and in journals so that others might learn from the work we have done.

How much time will the study take?

The research will take place over about 2 years. You will be invited to participate in group discussions and/or be interviewed every six months to talk about what you find good and what is hard about being involved in a circle of support. The interviews and focus groups will last about 20 minutes each so you will not get tired, you will be provided with refreshments at the interviews and will be able to take breaks whenever you need to.

You may wish to be part of the 'Voices for Change' research steering group who meet more often - about every three months.

Can I withdraw from the study?

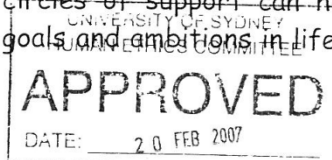
Being in this study is completely voluntary - you are not under any obligation to consent and your position in the [REDACTED] Project will not be affected at all. You may also choose not to be involved in some parts of the study but still participate in other aspects. Any information you give for the study, which is recorded by me, can be destroyed/erased if you choose to withdraw from the study.

Will anyone else know the results?

All aspects of the study, including results, will be strictly confidential and only the researcher will have access to information on participants. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

Will the study benefit me?

Hopefully you will find the study interesting and taking part will be fun. It is an opportunity for you to have a say in how you think circles of support can help people get support in achieving their goals and ambitions in life. It is my hope that some participants will



Page 2 of 3

be able to help me to present the findings of the research at conferences and meetings if they so wish.

Can I tell other people about the study?

Yes you can, the study is not a secret. You will not be named in any articles which are written about the study, every effort will be made to ensure you are not identified.

Where can I get feedback about the study?

All participants will receive regular feedback throughout the study via the monthly [REDACTED] Project Newsletter and the website. There will be a report written which will be published in the [REDACTED] Newsletter and on the [REDACTED] website.

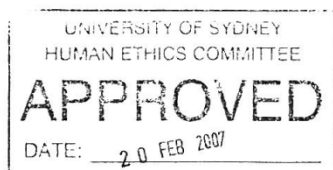
What if I require further information?

When you have read this information Miriam Stevenson will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Miriam Stevenson on email mste8601@usyd.edfac.edu.au or contact the [REDACTED] office on (02) 96834333

What if I have a complaint or concerns?

Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 4811 (Telephone), (02) 9351 6706 (Facsimile) or gbriody@usyd.edu.au (Email).

This information sheet is for you to keep.



Appendix 4. Parental, Guardian or Advocate agreement



The University of Sydney

Faculty of Education and Social Work
University of Sydney A35
NSW 2006,
Australia

ABN 15 211 513 464

PARENTAL, GUARDIAN or ADVOCATE AGREEMENT

I

Agree that my son/daughter/friend.....

Has given his/her informed consent to participate in the research:

Title: **Voices for Change: Participatory Action Research with Young Adults with Down syndrome in NSW, Australia.**

In giving my consent I acknowledge that:

1. I have read the Information Statement and the time involved for my son/daughter/friend's participation in the project. The researcher/s has given me the opportunity to discuss the information and ask any questions I have about the project and they have been answered to my satisfaction.
2. I understand that I can withdraw my son/daughter/friend from the study at any time without prejudice to my or my child's relationship with the researcher now or in the future.
3. I agree that research data gathered from the results of the study may be published provided that neither my son/daughter/friend nor I can be identified.
4. I understand that if I have any questions relating to my son/daughter/friend's participation in this research I may contact the researcher who will be happy to answer them.
5. I acknowledge receipt of the Information Statement.
6. My son/daughter may/may not be videotaped for research purposes (please circle)

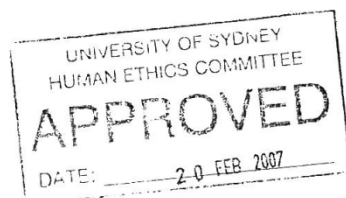
Signature of parent/guardian/advocate.....

Your relationship to the participant

Your contact details.....

Date.....

If you have any queries concerning this form or any aspect of the research, please
do not hesitate to contact the researcher Miriam Stevenson email:
mste8601@usyd.edfac.edu.au



Appendix 5. Participant Consent Form



The University of Sydney

Faculty of Education and Social Work
University of Sydney A35
NSW 2006,
Australia

ABN 15 211 513 464

PARTICIPANT CONSENT FORM

(Participant retains copy of this)

I, Name (please print), give consent to my participation in the research project.

TITLE OF PROJECT: Voices for Change Participatory Action Research with Young Adults with Down syndrome in NSW Australia.

In giving my consent I acknowledge that:

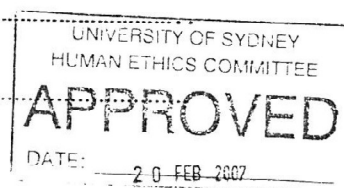
1. The things I will be asked to do in the project and the time involved have been explained to me, and any questions I have about the project have been fully answered.
2. I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researcher.
3. I understand that I can leave from the study at any time and I do not have to give a reason. My relationship with the [REDACTED] Project and Miriam will not be affected, now or in the future.
4. I understand that my involvement is strictly confidential and no information about me will be used in any way that reveals my identity.
5. I DO/DO NOT consent to being videotaped for the purposes of research.

Signed:

Name:

Date:

Page 1 of 2



If you no longer want to be in the study please fill this in and give/send to
Miriam or contact her on mste8601@usyd.edfac.au

I do not wish to be in the study any longer

Signed:.....Print name.....date.....



Appendix 6. Young Person Interview Guide

VFC -Participant interview

1. Imagine you are talking on the phone to an old friend who you have not seen for a long time. How would you describe yourself?
2. What do you feel are the most important things you are doing with your life at the moment?

If you could 'wave a magic wand' -

3. What would be your perfect job?
4. What would be the perfect place to live?
5. What are the other things you would like to have in your life?
6. What made you want to join the Project?
7. When did you join the project?
8. Who is your Team Coach?
9. What work have you done with your Team Coach?
10. Who are your 'Team of Champions' (the important people in your life) right now?
11. Has anything about your relationship with anyone in your family changed? If so, how has this happened?
Any more changes you would you like to see?

12. What about your friendships- do you know any more people since you started the project? Have you done any work on your friendships?
13. Do you have any more skills than you used to have? Have you learned anything new?
14. Has your week changed at all since you joined the Project?
15. Have you made any moves towards any of your goals since you joined the project?
16. Have you achieved any goals?
17. What do you think about the workshops with your peers at [REDACTED] Leagues Club (*reminder about the workshops*)?
What did you think about them?
Is there anything else we could cover in the workshops that might be useful or fun?
18. Who makes the decisions in your life about when you spend money?
19. Who makes the decisions in your life about when you go out?
20. Who makes the decisions in your life about who you spend time with?
21. Who makes the decisions in your life about what you do with your time?
22. What could we do in the project to make it better?

23. Is there anything else you would like to tell us about what it's like to be in the Project?

Thank you!

Appendix 7. Parent Interview Guide

Parent Interview- 'Voices for Change' Research Project

1. How would you (briefly) describe your son/daughter to someone who did not know him/her?

Prompts

We recognize that this will be dependent upon who you might describe them to so consider-

How might you describe him/her to a service provider?

How might you describe him/her to an old friend you haven't seen for 10 years?

2. What are your hopes and dreams for your child? What kind of future would you want for them if money and other resources etc were no object?

3. What are your fears (if any) for your son or daughter for the future?

Prompts

What do you see as the barriers to your son or daughter achieving their goals?

4. What is your understanding of the aims of the [REDACTED] Project?

5. What influenced you in supporting your son/daughter to become part of the project?

6. How long has your son or daughter been involved with the project?

7. Who is the team coach?

Prompts

How would you describe your relationship with the team coach?

What qualities do you feel make a good Team Coach?

8. What work has the team coach done with your son or daughter?

9. What work has been undertaken with the family as a whole?

10. What impact, if any, has the project had on you as a parent (i.e. has anything changed about your attitude to parenting your son or daughter, your relationships or

your lifestyle etc)?

11. What impact, if any, has the project had on other family members (i.e. has anything changed about their attitude, relationship with your son or daughter?
12. In your opinion, what has worked out well?
13. Is there anything you feel could be added to the project to make it better?

Prompts

Is there anything you were not happy

Anything missing or anything that failed to meet your expectations?

14. Is there anything we have not touched upon that you would like to add?

Appendix 8. Team Coach Interview Guide

Team Coach Interview questions April 2008

1. Could you tell me about:
 - a) Your educational/professional qualifications
 - b) Your work experience prior to starting the project
2. What do you think 'drew' you to the [REDACTED] Project?
What factors/experiences/beliefs influenced your decision to apply for the job?
3. a) What did you feel about your preparation in terms of training and written material for the role of Team Coach?

b) With the benefit of your experience now, what other training and resources would be useful to Team Coaches?
4. Could you describe for me the work you have done with each of your participants and their families?
5. On reflection, what issues emerge for coaches and families in forming Teams of Champions/Circles of Support?
6. What did you enjoy most about the work?
7. Which aspects of the work were most challenging for you?
8. What did/do you feel about the kind of support you get from:
 - a) The coordinator
 - b) Your peers (other project staff)Would any other forms of support help you?
9. What are the key things you have learned, so far, in your time as a Team Coach?
10. Do you have any dreams or visions yourself for the future of the project? If so what are

they?

11. Is there anything else we haven't touched on that you would like to say?

Appendix 9. Example of Katie's coding of transcript

(JG) Yes I really enjoyed it	
(MS) And are you looking forwards to doing some presentations?	
(JG) Yes I am and that will help me through my office skills as well	Goals - knowing how to do things
(MS) Yes a lot of things are about confidence aren't they? What about your friends, the other participants. Have you made any friendships there; is there anyone in particular that you like?	
(JG) Not really but it does bring me closer to them as I said before because the first time when I went they were really new to me and now I am a bit more used to friends. I can actually sit with them and have a friends bonding time. And they show me where to go and stuff like that.	Getting your friends involved.
(MS) So do you think you have any more skills than you used to have?	
(JG) Emailing, how to use the camera which I never knew and that came as a surprise to me through that I am going to make a movie so that's new to me and I really want to learn that. And also writing. I am improving in my writing skills. I'm improving in my reading as well. I'm reading things that are of interest to me by heart. My crime scene books that I am reading.	Another way of communicating with your friends.
(MS) Do you borrow them from the library?	
(JG) Yes	
(MS) So have you achieved any of your goals since you started the project?	
(JG) I have to say yes, I can do emails now which I never did before; my dad has set me up with a computer and everything.	Confidence in learning new things you never done before.
(MS) Do you have your own computer now?	
(JG) Yes my own computer and now all my emails are coming to me, my (family) background emails and my Australia emails- that means friends and family and my cousins. The other skill is that I can take people out now because I never did that, because I never did that, because I'm only 19 and I not able to take people out as I am only very young. But I came to this skill from my sister and my brother and from my friends in the circle of support and through the training to work program that I am doing	
(MS) So it's quite important for you to be able to take people out.	
(JG) Yes	
(MS) So what do you think about the workshops at Ryde?	

Appendix 10. Example of Jasmine's coding of transcript

19.08.09

Ri

<p>Interview with LUKE Collins (AKA Bond) 20th March 2008; Venue: Home in [REDACTED], Sydney, Time: 3.06pm, Time taken: 32mins 24secs, Present: [REDACTED] Miriam Stevenson, Emerald Collins, LUKE Collins</p>	
<p>(Andrew) Imagine you are talking on the phone to an old friend you have not seen for a long time how would you describe yourself?</p>	
<p>(LUKE) easy-going, I am a good person to talk to and I would talk about what I would do in my job I'm a very good speaker to other people, and do very well.</p>	
<p>(Andrew) what do you feel are the most important things you are doing with your life at the moment?</p>	
<p>(LUKE) well, I like doing horse riding, and I enjoyed myself at every [REDACTED] workshop that I participate in.</p>	
<p>(Andrew) if you could wave a magic wand what would be your perfect job?</p>	
<p>(LUKE) I would like to work in the (an) office because I love filling and all the other tasks as well and I would like to be more independent in my job.</p>	
<p>(Andrew) what would be the perfect place to live?</p>	
<p>(LUKE) I would like to live here with my parents at the moment and when the time is right high would probably move to Hornsby (suburb on the Upper North Shore).</p>	
<p>(Andrew) what do the things you would like to have in your life?</p>	
<p>(LUKE) I would like to go out shopping and doing things myself and be more independent in life.</p>	

to say just question a?	
(Andrew) has anything about your relationship with anyone in your family changed?	
(LUKE) well I am still with my family they still support me and we have all got involved with the project.	
(Miriam) like everyone has been involved in the project?	
(LUKE) yes	
(Miriam) and how has that felt for you?	
(LUKE) very happy and I enjoyed having people like my family getting involved in the project so they know what is happening, what is on, what event is going to be on.	
(Miriam) and so have your family been more involved in your life?	
(LUKE) yes they have I now have my own washing bag in my room so that I can help mum do the washing and with dad I went to meet [REDACTED] which was a big one with Dad because I haven't been to a game before. With [REDACTED] she said I am getting very independent with what I do in the project and my brother [REDACTED] he does his own thing and he like he is very supportive and get himself involved as well. And [REDACTED] says it is so great to have me involved in the project and to meet new people.	
(Emerald) and so you are on to part b now?	
(Andrew) any more changes? You would like to see?	
(LUKE) well I would like to see some more participants in the project for the whole of next	

Appendix 11. Luke's presentation at the Australian Catholic University

Myself, My Life

About me

- I have two brothers and a sister
- On the weekends I love going out with friends. I am in a social club called the [REDACTED] Club
- I love going horse riding
- I love dancing and singing
- I also love watching wrestling

- My favourite music is Abba, Tom Jones and Rob Thomas
- I go swimming each week
- I used to compete in the Special Olympics
- I work 3 days a week with [REDACTED] Partners, an accounts firm in the city

The Project

Some of the goals I achieved:

- Travel independently on the bus and train
- Learned budgeting skills
- I now contact my family and friends independently using email and mobile phone
- I have a great job!

I want social workers to know

- I have the same dreams and goals as everyone else
- I want to be independent
- Go out with my friends
- Have choices and make my own decisions about my life
- I want to be listened to and understood
- I want to be treated fairly and with respect

The type of person I want to work with

- Listens to me and understands me
- Is supportive and trustworthy
- I want them to encourage me
- I want them to treat me like an adult

My job at E Partners

- I have my own work station, phone, computer and work email - I sit with the other accounts staff
- I have good IT skills and do some data entry
- I open and distribute office mail
- I check the electrical appliances are off when they should be

Colleen – my workplace support

- Colleen is a great example of a good support person.
- She sets me clear tasks
- She sometimes works beside me to check my work
- She gives me confidence in myself
- She helps me to understand things
- She is a good listener and respects my opinions
- She makes sure I am not left in what is going on and introduces me to new people after they arrive.
- She supports me out, leaves me the space to organise it all

SAME AND DIFFERENT

We are now going to do a fun exercise.....!!

Find the same and different sheet in your pack

- Write down 3 things about yourself which you think are the same as most other people
- Write 3 things about yourself which you think make you different from most other people

- What did we find..... That most things we have in common with at least some other people- whether we have an intellectual disability or not!

Appendix 12. Isabel's presentation at the Australian Catholic University



WELCOME

- Thank for attending this workshop
- A big thank you to The Foundation for Young Australians in providing "The GIG 2007" at this wonderful place
- I am proud to be a part of this event as an

ABOUT ME

- My name is
- I am 22 years old and was born on Australia Day in 1985
- As you can see, I have Down Syndrome
- But I am a young Australian, just like you!

MY FAMILY

- I live with my mum, dad & three brothers but I have my own mobile home on our property
- Mum is a nurse and a TAFE Teacher
- Dad is an Electrician
- 21 & is working in Western Australia
- 19 is 1 Year 12
- 15 is Year 10

MY WORK

- I have been working at McDonalds for eighteen months
- I work four days a week
- I get two trains & a bus to and from work each day (and walk 3km home)
- My tasks include cooking, deli choices prep and dining room duties plus cleaning (yuck)
- I love my work most of the time

WHAT I LIKE DOING....

- I love listening & singing to music
- I love animals
- I like reading
- I love dancing with the
- I love cooking
- I like swimming
- I like ten pin bowling
- I love spending time with family, my friends, & especially my boyfriend,

MY ACHIEVEMENTS



- I have represented Special Olympics in swimming & ten pin bowling at State level
- I was a Torch Bearer for Special Olympics in 2002
- I am very good at maths, reading, writing
- I can travel around Sydney using trains
- I can understand bus timetables
- I am a member of Mermaids which is a dance group for people with disabilities

MY ACHIEVEMENTS

- I do my own housework in my mobile home
- I make my own breakfast & lunch and sometimes dinner
- I iron my own clothes and help Mum with the ironing and folding, and meals
- I do my own grocery shopping
- I am good with money

MY GOALS FOR THE FUTURE

- To work at McDonalds for ever
- Make more friends
- To become more confident
- Not to stutter when I get nervous
- Improve my computer skills
- Learn how to SMS on my phone
- Get better with sewing

MY GOALS FOR THE FUTURE

- Learn to accept that people are trying to help me, not criticize me
- Build a good network of support from friends, family and professionals so I can live independently as much as possible
- To live away from home
- To maybe marry K
- Just to be happy and safe

CONCLUSION

- I think I am just like other young Australians
- I just need a little bit more help with things
- I have the same feelings and needs
- I just have one extra chromosome
- So what !!!

Appendix 13. Extract from co-researcher presentation at Sydney University

Getting started on the analysis

Miriam applied for money to pay three co-researchers to do some of the data analysis. Ni came on board to give us support.

Working On Campus

Thanks to the Sydney Uni for finding a room for us. It was good to be on the campus with other students.

Coding Transcripts

We chose the transcripts we wanted to analyse. We started coding transcripts from project participants and their parents.

From the transcripts we looked for what was important to us. We highlighted or underlined words and sentences and put them in our own words in the comments column. There were interesting answers from participants and parents.

as' Work

did some typing about doing the research was like on the laptop. We had a recording device and I interviewed about the research, and he interviewed me as well which was good.

**Key Themes:
Independence skills**

- Budgeting /money skills
- Travelling independently
- Shopping skills
- Emelling/phoning skills

**Key themes:
Friendships/relationships**

- Making new friends
- Ability to stay in touch with friends.
- Friendship is built on communication to keep friends.
- Going out with friends in the community and having fun.
- Aspects of having a boyfriend.

Key theme: Making a Contribution & GETTING INVOLVED!!

- Importance of paid work and having a job that you like.
- Helping and assisting people at workshops.
- Helping our families.
- Working together as a group/team.

Other things that we found are important ,

- Importance of culture
- Understanding of culture and religion of other people in the community.
- Public speaking and advocating as people with disability about our equal human rights.
- Opportunities to educate and lead people

Parent transcript: the interesting and important things to us

- Our parents love us and respect the things we are achieving.
- Our parents want us to have full lives, be healthy and be as independent as possible.
- Our parents are still learning themselves to let go but still give us the right support.

Miriam: Data Analysis Using Thematic Networks

- Based on Toulmin's 'Argumentation Theory' (1958) adopted by Attridge-Stirling (2001).
- Basic themes
- Organizing themes
- Global themes
- Works with the Participatory Disability Research Paradigm (Barnes, 2001; Stoyekwin, 2010) and the 2005 Convention on the Rights of Persons with Disabilities which move away from paternalism and stress full participation.

Thematic networks