University of Leeds

SCHOOL OF SOCIOLOGY AND SOCIAL POLICY

DISSERTATION/PROJECT

Student ID number	200517753
Name	Donna Clifford
Degree programme	MA Disability Studies (Distance Learning)
Module code	SLSP 5606M
Module title	Dissertation Project
Dissertation Title	Social barriers experienced by Parents with Learning Difficulties: identifying strategies towards future empowerment.
Word count	15,720

Disabled students with additional support needs agreed by Disability Services should tick the appropriate box

I have been assessed as having:

Dyslexia		
Dyspraxia		
Other (please specify)		

School of Sociology and Social Policy

The University of Leeds

'Social barriers experienced by Parents with Learning Difficulties: identifying strategies towards future empowerment '

By: Donna Clifford

Submitted for the Degree of Masters of Arts in Disability Studies.

September 2011

Abstract

This dissertation project seeks to explore how societal barriers and labelling of disabled people, affects the everyday lives of parents with learning difficulties. Issues relating to a lack of access to relevant information, and a paucity of effective support for parents with learning difficulties, initially inspired the project. These constraints were brought to my own attention by people with learning difficulties themselves. A comprehensive literature review carried out within this study, defined the lack of access, discriminatory support systems and negative attitudes that still compromise parents' own attempts to be seen as 'capable' and 'responsible' adults.

The project explores how 'labelling' can impact upon an individual's own identity and self esteem. Using societal and economic barriers as a benchmark, it investigates how negative attitudes and stereotypes synonymous with 'learning difficulties', often affect the interactions between disabled parents and non-disabled professionals. By adopting an emancipatory approach to research, the experiences of labelling and societal barriers were collated here as a marker with which to validate or refute existing research. This process, by engaging the views and opinions of parents with learning difficulties, inspired further suggestions for

strategies to support both parents' personal autonomy and their future self-empowerment.

The findings here offer an insight into how parents are experiencing ongoing support that can, at best, build upon their own strengths. A collaborative support network of family, friends and external agencies, can help to facilitate parents' own 'success'. However, despite this, many parents are still regularly compromised by issues relating both to labelling and negative societal attitudes. Further compounded by the ongoing economic and cultural barriers affecting disabled people per se, the perpetuation of oppression among disabled parents is still evident here, and can seriously compromise attempts by parents with learning difficulties to engage with professionals within the field. Thus it effectively dis-empowers parents and reduces them to nothing more than second-class citizens and a voiceless minority.

The dichotomies underpinning the application of medical and social models of disability are intrinsic to the social care systems that affect the lives of parents and their families. Shifts towards a more 'inclusive', 'comparative' society, do not always manifest themselves away from the rhetoric of legislative speak. Practices adopted by professionals within the field of child protection and disability are not always motivated by the fundamental

belief that disabled people are the true 'knowers' of disability, despite the best intentions to engage people in their own life choices and steer them towards self-governance.

The study raises questions about how parenting links to wider societal issues such as poverty, perceived 'abuse', negative attitudes and power imbalance between disabled parents and non-disabled professionals in particular. It is hoped that findings, presented to parents in an easy read format, could provide the basis upon which parents themselves can support and engage with further research, subsequently building their own pathways towards expressing their individual or collective voice in the future.

<p align="center">***************************</p>

Contents

Appendices

****

Chapter 1: Contextualising the Issues

Introduction

This project will identify social barriers that affect the opportunity for disabled parents to be seen as parents first, with "the same responsibilities as other parents, but [with] specific needs which must be addressed if they are to have an equitable service and opportunity" (Gilsham,2010:unpaged). Furthermore, it will examine negative attitudes that often prevail, relating more to 'urban myth' and the historical stereotyping of disabled people, than to everyday reality. It will highlight how preconceived ideas, synonymous with the concept of 'disability', can often compromise the attempts of disabled parents to assert themselves effectively when accessing 'support' services. Most importantly the project highlights the inequities that exist for disabled people when accessing non-disabled societal 'norms'.

Research states that between 40-60% of parents with learning difficulties have their children removed from their care (Booth and Booth,1998). However, "there are no reliable estimates of the number of parents with learning difficulties. Their true prevalence is unknown and probably

unknowable" (Booth and Booth, 1998:1). Does this high removal rate therefore suggest that parents thus labelled, are in some way inherently 'deficient', incapable of providing adequate parental care? Or rather, are parents with learning difficulties often compromised by inequalities relating to the availability of appropriate support networks and prevailing attitudes synonymous with 'learning difficulties' and disabled people per se? It is accepted that many parents with learning difficulties often face additional social barriers such as, "severe poverty, unemployment, poor housing, difficult neighbours and harassment" (Gilsham, 2010: Cooke and Richards,2008) but, do these constraints make them any less able parents?

Research Background

During my own career, working as a crisis advocate within the field of 'learning difficulties', generic social 'barriers' were brought to my attention by a number of disabled people. Social barriers are the disabling restrictions imposed upon 'vulnerable' groups of people (often from minority or oppressed social groups), by wider society that does not take into account their needs (Sheldon,2004). Whilst working closely with and directly supporting people with learning difficulties, a number of specific 'barriers' to parenting were identified by various individuals. For parents with learning difficulties, common barriers often appeared to be linked to

lack of access, both to information and support networks. Further barriers

were also identified; these were often experienced through parents' own

interactions with professionals, both within the field of learning difficulties

and child protection (Booth and Booth, 1994).

Through my own further research, and within this project's literature review

(Chapter 2), these barriers were further validated by existing studies within

the field (Booth and Booth, 1994: Booth,1990: Tarleton,2006:Leaviss et

al,2010). However, empirical evidence also suggested a paucity of

'disability led' research, research that included the voices and experiences

of parents with learning difficulties (Booth and Booth:1994). This was

something that as researcher, I felt needed to be addressed here in line

with an emancipatory research design. To adhere to an emancipatory

research design, one that "seeks to be accountable to disabled people"

(Hollomotz,2011:19) and ensures that disabled people have some control

over the research process (Zarb,1992), parents' subjective insight and

experience needed to be an intrinsic part of the research process itself.

Research findings also suggested a level of 'silence' surrounding parents

with learning difficulties. This related both to their input in "the tradition of

social policy research" (Olsen and Clarke,2003:xi) and in their identification

with the 'label' of learning difficulties. This was often influenced by the

"negative effects of historical prejudices associated with learning difficulties" (CHANGE, 2010:36). These issues will be expanded upon in Chapters 2 and 3, relating specifically to self-identity and the project's research methodology.

Key Definitions

The project will explore and synthesise two parallel, but intrinsically related research strands, namely the label of l*earning difficulties,* relating this to the following criteria:

1) That [individuals] have a significant intellectual impairment, IQ below 70 (but this can vary between 70 and 85)

2) That their adaptive and social functioning is compromised due to the presence of intellectual impairment.

3) That these indicators were present before adulthood. (Cooke and Richards, 2008).

The research will link *learning difficulties* with the socially accepted 'norm' of *'parenting',* a common social marker for an 'ordinary life' (Kings Fund Centre,1980), "one of the most private, intimate roles that we undertake and yet [the] one subject[ed] to the greatest public gaze and scrutiny" (Olsen and

Clarke,2003:xi). It will synthesise the two, thus highlighting the *social barriers* that affect *parents with learning difficulties*.

Social barriers will be the markers facilitating our understanding of the findings, linking this to the personal *ontology and epistemology* of the disabled parent participants. This means that parents' subjective understanding of their place, identity and autonomy within the world, both as parents and disabled people, will be at the heart of the research process. And *barriers* themselves will underpin the whole of this research project too.

Social barriers here are defined as:

    1) Negative attitudes: "presumption of incompetence"

        (SCIE,2005:unpaged).

    2) Absence of explicit 'standards' relating to parenting.

    3) Poverty:

        lack of *financial* support for people with learning difficulties

        lack *of practical* support

        lack of *social* support.

    4) Paucity of specific information relating to parents with

        learning difficulties (I would add here, that this

        information also needs to be easy read and relevant

        to parents' own requirements).

5) Low socio-economic status.

6) Unemployment.

7) Social isolation or exclusion (SCIE,2005,unpaged).

Historically*, individualised models of disability*, those that ascribe labels relating to a person's individual impairment, link intrinsically with the formation of our modern social and healthcare services (Finkelstein,1998). *Labelling* people with 'learning difficulties' as an example, is "an acknowledgment of the individual's deviation from non-disabled norms" (Hollomotz,2011:158), subsequently, people are then treated differently. Stigma relates to the way 'difference' is judged by society at large. It can affect the way a 'devalued' individual perceives themselves and how this, in turn, can impact upon a person's self esteem (Goffman,1963). Goffman states that :

> "First impressions in social encounters are
>
> important in helping to construct a social identity,
>
> which conveys anticipations and expectations on
>
> the parts of others".
>
> (arasite.org/undated/unpaged).

Subsequent chapters will explore the intrinsic link between stigma and self identity, combining existing empirical research with the participants' own

experiences and highlighting the effect upon their interactions with wider society.

To explore the issues relating to learning difficulties and parenting, this project will implement a 'social model' framework of disability. It will differentiate between 'labelling' of individuals, prioritising instead the economic and societal factors that contribute to the creation of 'disability'. It will make a clear distinction between:

> *'impairment'* : "lacking part or all of a limb, or
>
> having a defective limb, organism or mechanism of
>
> the body" (Hollomotz,2011:14)

and

> *'disability'* : " the loss or limitation of opportunities
>
> to take part in the normal life of the community on
>
> an equal level with others due to physical and
>
> social barriers" (Thomas,1999: 15).

This research study will aim to show how specific groups of disabled people such as parents with learning difficulties, are often encountering "complex and sophisticated oppression" (Barnes,1996:43) within their everyday lives. It will highlight how services aimed at 'supporting' parents,

often compromise and fail them, due to their ascribed 'label' as 'disabled' parents, and how this means that they "are uniquely disadvantaged in their ability to challenge the identity forced upon them" (Dowson,1997:104). Chapter 2 will highlight how disabled people, as a marginalised social group, have a history of oppression (Barnes and Mercer,2005; Atkinson et al,1997). It will contextualise the place of disabled people within society, and will identify models of disability too.

Research Questions

By utilising the *social model of disability* as a framework, the project will thus explore the following key research questions:

1) _What does the 'label' learning difficulties mean?_

Research methods will attempt to explore this question from the perspective of disabled parents. It will also ask, what do people ascribed with this label, think that 'learning difficulties' means to other people? It will explore identity and how this is linked to a collective voice, could this help support parents with learning difficulties?

2) _What barriers exist for parents with learning difficulties?_

This question will highlight social and economic barriers. Various authors have defined barriers that exist within society that can compromise the interactions of disabled people (Booth and Booth,1994; Leaviss et al,2011; SCIE,2005;Dowson,1997). The seven barriers highlighted by SCIE (2005) will be the benchmark for debate. Discussions will highlight how barriers can lead to unequal power relationships and can often result in the oppression of minority groups such as parents with learning difficulties.

3) *What strategies can parents suggest, based on their own experiences that could inform the work of professionals and other people who support them?*

This question will use social barriers as a benchmark to change. It will define the hurdles that need to be overcome, and by involving parents here at this developmental stage, it will validate the voices of parents as the 'experts' within the field (Priestley,1997). By defining strategies from a parent perspective, it will challenge "bureaucratically organised [….] top-down power, based on authority and delegated through […] institutions and agencies" (Weber cited by Reeve,2004: 239).

Aims and Objectives

The overall aim of the research will be to explore the barriers facing parents with learning difficulties within their everyday lives. It will look at how the

label of learning difficulties can further compound socio-economic challenges facing parents labelled in this way. It will endeavour to gain insight into the issues, by listening to and engaging with parents themselves. Throughout the research, the social model of disability will underpin the findings and methodology, contextualising the issues facing parents within a historical and sociological framework.

The objectives of the research are defined as thus:

a) Conduct a content analysis of relevant literature. This will identify key themes.

b) Recruit a sample of 8 parents with learning difficulties. It is not essential for the parents to be actively parenting their children. It is their life experiences and defining barriers that will be of importance here.

c) Speak to parents to gain insight into how they would prefer to approach the research. Ascertain how often they are able to attend group meetings or one to one interviews. Prepare a presentation for participants in easy read format. This will enable the parents to understand what the research is about. Prepare an easy read consent form, ask parents to sign this.

d) Conduct semi-structured interviews or focus group meetings. This will provide the empirical evidence that will validate current research within the field.

e) Analyse field data and produce transcripts of the interviews with parents. Analyse the data; code and link the data with the seven barriers identified by SCIE (2005). Produce a draft of dissertation to be submitted to Professor Colin Barnes on the 18th July 2011.

f) Revise dissertation in line with Professor Barnes' feedback.

g) Submit dissertation for assessment on the 1st September 2011.

h) Disseminate summary of research findings in an accessible (easy-read) format for all parent participants. Aim to do this by December 2011.

Project Synopsis: Chapters 2-7

Issues relating to the three key research areas of parents with learning difficulties, labelling and barriers, will be expanded upon in Chapter 2, in line with existing empirical research. The Methodology underpinning the research will be explored in Chapter 3. This section will define the choice of qualitative research, underpinned by emancipatory principles and participatory design. It will introduce the parent participants and how their feedback will be analysed and linked to barriers. Chapters 4 and 5 and 6 will, in turn, address the key areas of labelling, barriers and strategies for change. Findings here will be validated by empirical research carried out with parent participants themselves. Chapter 7 will collate and present overall findings, alongside recommendations for future research development.

Conclusion

This introductory chapter has given a brief overview of key research areas. It has defined seven barriers that may exist for disabled parents who themselves, are often facing negative pre-judgments, relating to a label associated with their individual impairment.

The following chapter will take an in depth look at labelling and the seven common barriers facing parents with learning difficulties. By considering existing empirical research, it will highlight, (by expanding upon the social model of disability) how 'learning difficulties' is a randomly applied label, created and insufficiently understood by an often 'disabling' wider society. It will explore how this affects the identity of parents. It will aim to assert, that this lack of knowledge around parents' own needs, is creating and reinforcing inequalities for disabled parents and simultaneously perpetuating discrimination. It will endeavour to explore some of the strategies that have been implemented to counteract oppression within this area.

****

Chapter 2

Learning Difficulties, Labelling and Barriers to Parenting

Introduction

This Chapter will develop some of the concepts previously introduced. By utilising existing literature within the field, it will define three areas of research. *Disability and Labelling* will begin by exploring how labels and historical connotations relating to 'learning difficulties', can have an impact upon the attitudes and interactions of disabled parents within wider society. It will expand upon the application of the Social Model of Disability (Oliver,1983), highlighting some of the issues that face people with learning difficulties when engaging with this model. *Learning Difficulties, Parenting and Barriers* will explore the social and economic barriers identified in Chapter 1 (SCIE,2005) by utilising current research within the field. It will consider how these barriers can impact upon disabled parents. And finally, *Parents with Learning Difficulties: Strategies for Change* will identify potential strategies that could support parents with learning difficulties in the future.

Learning Difficulties, Disability and Labelling

Disability is itself a form of social oppression; it is "the restriction imposed on top of our impairments by the way our society is organised" (Sheldon,2004:69). Alison Sheldon states that "all disabled people" are subject to it (Sheldon,2004:69) and it is thereby further fuelled by oppressive practices and perpetuated by negative attitudes (Barnes and Mercer, 2004: Campbell and Oliver,1996). To explore the issues relating to learning difficulties and parenting, this project will implement a 'social model' framework of disability (Oliver,1983). It will differentiate between 'labelling' of an individuals' accredited impairment, prioritising instead, the economic and societal factors that contribute to the creation of 'disability' and the ongoing oppression and discrimination of disabled people per se.

Attitudes and Stigma

For people with learning difficulties, the dynamic between impairment and disability is often further compounded. Not only are learning difficulties often hidden (not visually apparent to others), but learning difficulties are very poorly understood (Hollomotz,2011). Historical prejudices relating to the fear of 'feebleminded parasites' (Atkinson et al,1997) are still apparent in today's society. It is therefore hardly surprising that people with a hidden impairment such as learning difficulties, often aim "to 'pass' as 'normal' to avoid the

negative consequences of stigmatisation" (Hollomotz,2011:121). *Stigma*

relates, not predominantly to the individual and their accredited impairment, but

to "negative qualities attributed to certain social identities by others in the

society" (Walmsley and Johnson,2003:68). Therefore people with learning

difficulties, have traits attributed to their impairment (by wider society), such as

'child-like, vulnerable, incapable, passive and different ' (Meekosha,2006; Booth

and Booth,1994; Hollomotz,2011). These associations and negative

assumptions about the label learning difficulties, can negatively impact upon

how an individual perceives themselves, it can also affect their own autonomy

and an individual's self-identity (Goffman,1963).

Prejudices relating to labels also influence the attitudes of other people towards

them. In their recent study CHANGE (2010) acknowledge that :

> "the negative effects of historical prejudices associated
>
> with learning disability, seem to be the motives that
>
> determine a woman with a learning disability to avoid
>
> her identification as a person who is part of the
>
> vulnerable group of people with learning difficulties"
>
> (CHANGE,2010)

Therefore labels link with an individual's self identity and self esteem. By constantly witnessing their own perceived 'deficit' or 'otherness' through the eyes of other people (Goffman,1963), disabled people can often begin to "regard themselves as inferior" (Walmsley and Johnson,2003:68). For disabled parents, who engage with support services, often at "crisis point" (Choppin,2009:31), these labels and negative assumptions often account for "discriminatory treatment and prejudicial judgements about their ability to cope" (Booth and Booth,1998:2). The threat of having children removed from their care, often influences many mothers and fathers to avoid asking for help when needed, or, as many mothers report, succumbing to interventions such as "involuntary sterilisation" (Olsen and Clarke,2003:12) offered as an intervention to counter their perceived 'incapacity' to parent their own children (Gillespie-Sells et al,1998; Wates and Jade,1999).

The labelling of disabled people, classifying and grading 'disability' by medical conditions and 'deficit', has become synonymous with 'need' and 'care', emphasising the 'vulnerability' of the individual (Hollomotz,2011). This medical model of disability ascribing labels relating to individual impairment links intrinsically with the formation of our modern social and healthcare services (Finkelstein,1998). The roots of this medicalisation hark back to the days when people with learning difficulties were isolated, hidden away in long stay 'hospitals', treated appallingly, systematically abused and

assumed to be 'retarded' or 'lunatic' (Atkinson et al,1997). Initiated by the

Mental Deficiency Act of 1913, institutionalisation of people with learning

difficulties was commonplace, linking intellectual impairment with "social

evils" and determining it as one of the root causes of "economic burden"

(Atkinson et al,1997:38). Hierarchies of staff within institutions led to wide-

spread abuse of disabled people, who were graded and classified as 'idiots'

through to 'real social menaces' (Atkinson et al, 1997). Fear motivated non-

disabled society to control 'feebleminded' people from 'breeding', taking into

account here the women with learning difficulties, who were "presumed to be

more immoral and fertile than other women" (Atkinson et al,1997:41).   It is

this grounding in eugenics and medical based social oppression that gives

historical context to the way in which attitudes and labelling link with today's

modern, supposedly more inclusive social and healthcare systems.

Dowson thereby (1997) asserts, that:

> "social care services not only have enormous influence
>
> over the quality of life for people with learning
>
> difficulties [but they also] largely determine the
>
> significance of the label[s] [themselves]" (Dowson,
>
> 1997:104).

Despite all of this, people with learning difficulties are finding their own pathways with which to challenge the barriers and labels that perpetuate their oppression. Goodley (2004) states that the social model is not prescriptive and should be adaptable enough to encompass the various "forms of activism" (Goodley,2004a:pp.118-119) utilised by specific groups of disabled people. The self advocacy movement for instance (People First, undated), very much aligned to the thinking underpinning the social model of disability (Oliver,1983), has been a move towards the politicisation of people with learning difficulties. It has been concerned with "reappraising the very labels that have been foisted upon them" (Goodley, 2004a:119) and could prove to facilitate strategies to support parents with learning difficulties in the future.

Organisations run by disabled people, (although rejecting the medical model of disability and its associated labels), have expressed their 'support' for the 'label' learning difficulties (Goodley,2004b). This is in preference to labels linked with historical discrimination and medical model approaches to disability, such as learning disabilities' or 'handicapped' (People First, undated: Phillips,2004). The label 'learning disabilities' was first introduced in the "White Paper *Caring for People* (Department of Health,1989) and is casually used by professionals" and in Government Publications" (Hollomotz,2011:17)

Social Barriers and Parents with Learning Difficulties

Attitudes

Disability and parenting is an area where stereotypes abound and negative attitudes prevail. As already discussed, it is often "anchored in medical model thinking and in sets of negative assumptions about the capacity for disabled people to parent" (Olsen and Clarke,2003;27) it is an arena where reductive attitudes are highlighted. Barnes and Mercer (2005) assert that "assessment and diagnosis" often link with barriers that relate to "societal attitudes, power relations and particular constructions of privileged knowledge" (Barnes and Mercer, 2005:50). Research studies involving disabled women; have highlighted negative social attitudes towards people who become parents (Gillespie-Sells et al,1998; Wates and Jade,1999; Booth and Booth,1994; Olsen and Clarke,2003). Becoming pregnant is (generally) seen as a time of celebration for many non-disabled mothers, but conversely, disabled mothers report "disapproval" (Swain et al,2003;67) horror, shock and disgust when they reveal their pregnancy to family and friends (Gillespie-Sells et al,1998).

And here, by implementing the social model of disability, barriers and inequalities relating to disabled parents become more apparent. Social care systems balancing "the right of parents to bring up their children against the need to protect children from harm (Booth and Booth,1994;129), and

interventions by non-disabled professionals, often discriminate again disabled

parents. Some authors have stated that the failure of the child protection

system to engage with disabled parents is "tantamount to abuse"

(Tarleton,2006) And while some women acknowledge challenges faced by

their own individual impairment, it has been argued that;

> "it is often the lack of understanding and access to
>
> services to support pregnant mothers (and their
>
> partners too) that the issues raised here become
>
> intrinsically related as much to "equal opportunities"
>
> (Olsen and Clarke,2003;27),

as they do to both 'disability' and 'barriers'.

Professionals set the benchmarks here, giving them ultimate power over the

very outcomes and life changes that will affect the opportunity for disabled

people to parent their own children. This confirms the "supremacy of the

medical [….] professionals as 'owners' of disability" (Hurst,2005:69) and for

disabled parents, the situation is further compounded by the 'unspecified

standards' relating to parenting (Booth and Booth,1994). Again here,

professionals, working within medical model guidelines, have the power to

determine the 'normal', yet unspecified boundaries of 'acceptable' parenting behaviour for those within their jurisdiction.

Isolation

Booth and Booth (1994) cite Whitman, who states that people with learning difficulties represent "an invisible and underserved special-needs population" (Booth and Booth,1994:7). This issue links intrinsically with isolation. Isolation is a huge barrier for people with learning difficulties, and further evidence will support this in Chapters 4 and 5. As disabled people, parents with learning difficulties have an impairment that relates to their ability to learn or process information. An often hidden impairment, it means that some parents can fail to access any additional support offered to disabled parents (Choppin,2009), and conversely, they often struggle to engage with services on offer for non-disabled parents too (Leaviss et al, 2011). Hence, they find themselves muddling through, in a kind of no-man's-land, with many parents choosing to hide their disability, rather than potentially be judged as incapable of looking after their own children (Hodge,2008).

As discussed, isolation and stigma are two issues already identified here. People with learning difficulties are also faced with 'stereotypes' relating to their intellectual impairment. 'Child-like' and 'vulnerable' (Hollomotz,2011) are just two character traits readily associated with people with learning

difficulties. Therefore, when it comes to considering the needs of *parents* with learning difficulties, fundamental stereotypes such as these, can result in a number of additional barriers being present.

Primarily, people with learning difficulties who aspire to accepted social 'norms' such as parenting, may find that this "existing politics of difference" (Berg,2005;pp.32-49) towards people with learning difficulties per se, can thwart their efforts towards integration and full social inclusion.   With negative stereotypes prevailing, it is hardly surprising that parents with learning difficulties are assessed in a way that "[renders] them one dimensional", by processes relating to their "grading and labelling" (Ward,1990;13). Ward goes on to say that, assessments of people with learning difficulties have traditionally been about "testing people to find out their deficits not their strengths" (Ward,1990;13). This is further supported by research among disabled mothers (Gillespie-Sells et al,1998;Wates and Jade,1999; Booth and Booth,1994), whose personal stories of discrimination, and experience of reductive attitudes among health professionals, validate the frequency of oppression within this area.

Nind and Seale (2008) in their study around access for people with learning difficulties, highlight the paucity of literature available in this area (SCIE,2005). Literature available to parents is often not accessible to parents with learning

difficulties who often have a lack of formal education (Stone and Kaczor,2003). Again, this issue relates to lack of equal opportunities constituting discrimination, something that CHANGE (2010) states is "contravening the DDA 1995" (CHANGE,2010:31) and subsequently the Equality Act (2010). This highlights how little understood learning difficulties actually is, and moreover, this can only have a negative effect on the level of understanding of learning difficulties by health professionals and support agencies within this field. Leaviss et al (2011) state that, many healthcare professionals who support people, have merely "fair or limited knowledge of the additional health and communication needs of people with a learning disability" (Leaviss et al, 2010:7).

The Poverty Trap.

"There is a well established link between disability and poverty" (Pupulin,2005), and for many of the parent participants who took part in this research project, this too was a reality. Of the six participants, five were reliant on benefits, living in council run homes in inner city towns, and struggling to survive, often relying on handouts from friends and family. And although these social factors do put additional stress and strain on parents, they relate intrinsically with other issues such as lack of accessible information relating to benefits and support, something that often goes unnoticed by the agencies contacting parents through inaccessible communication channels

(Simons,1995).   Social exclusion is another factor that affects parents here.

Many professionals fail to consider that parents may have "grown up in

institutional settings and may therefore have lacked appropriate parental role

models" (Olsen and Clarke,2003:13) thus judging their parenting ability to a

stringent criteria, something rarely applied to non-disabled parents (Booth and

Booth,1994).

Deficits within the education system often affect the long-term opportunities for

parents with learning difficulties to find employment (Davis,2004).

Compounded further by restrictive attitudes about the capacity of disabled

people to hold down employment, people become caught up in the poverty

trap, reliant on benefits and thus answerable to professionals within the field of

learning difficulties and child protection.

Strategies for Change

Research carried out within the field by Olsen and Tyers (2004), lists a

number of recommendations for supporting disabled parents effectively.

Primarily, they state that:

> "professionals should 'think parent' and view disabled
>
> parents in the same way as non-disabled parents: the

vast majority want to parent their children well" (Olsen

and Tyers,2004:unpaged).

Booth and Booth (1994) go on to discuss how 'standards of parental

competence' is something that is non-specified. Wates (1999) states that

"drawing attention to the barriers and prejudices faced by disabled parents

would benefit everyone" (Wates,1999:97).   In his work researching issues

affecting parents with learning difficulties, Tim Booth has highlighted various

strategies to support and engender positive outcomes for parents with

learning difficulties. These strategies are outlined in full in Appendix 2a of this

study, and they encompass outcomes highlighted in the Government White

Paper *Valuing People* (Department of Health, 2001), such as championing

civil rights, independence, choice and inclusion. Booth and Booth (1994) state

that interactions between professionals and parents with learning difficulties

should be more reciprocal, valuing the experience and voice of disabled

parents within all aspects of child protection. This will go some way towards

"balancing the rights of parents [.....] with the need to protect children from

harm" (Booth and Booth,1994:129). Attitudes and prescriptive deprecatory

beliefs associated with learning difficulties are to be avoided by professionals.

Concrete strategies to keep families together, supported by clearly defined

child care tasks, and the active participation of parents in formalising these,

are stratgies advocated here as empowering to the parent participant (Booth and Booth,1994).

This is further supported by research within the field by Leaviss et al (2011). Their strategies take into account the lack of accessible information relating to parents with learning difficulties. They highlight the need for "information booklets" (Leaviss et al, 2011:32) to support a reciprocal relationship between professionals and parents. They point to attitudes of professionals and how their lack of knowledge of learning difficulties can be problematic too (Leaviss et al,2011). They also highlight the need for parenting groups and accessible contacts for advocacy service support for parents. These strategies will influence a political awareness and support empowerment for parents with learning difficulties enabling them to "resist the oppression of others" (Oliver,2009:102).

Conclusion

This chapter has highlighted that many barriers facing parents, are not just issues relating to 'disability', they are also issues linked with human rights, equal opportunities and oppression too. But whilst the rhetoric of legislation champions the rights of people with learning difficulties to become parents and to capitalise on improved access within their communities, it has not readily

embraced issues of accessibility, support and funding, that make this a viable long-term option for the individuals' autonomy.

Some of the common barriers facing parents with learning difficulties have been contextualised within this chapter. And far from relating to the ability for individuals to parent, it would appear from existing studies, that parents are simultaneously judged and compromised by both external systems of 'support' and preconceived notions surrounding 'disability'.   Chapter 3 will now begin to underpin the findings with methodology. The methodology will explain how the research will be carried out, with whom, and how information will be thus analysed.

<p align="center">**************************</p>

Chapter 3

Approaches to Research and Parent Participation

Introduction

This following chapter will explicate and outline the chosen research

paradigms adopted within this project. Research here will be underpinned

by a social model approach, linking barriers facing parents with wider

societal issues, thus making 'disability' a society's collective responsibility

(Oliver,1983). Within this context, the choice of *emancipatory research* will

be further explored. It will highlight why the participation of disabled people

is fundamental to an emancipatory research paradigm.

It will then examine the choice of *qualitative research techniques* (ie.one-to-one interviews / personal histories), in preference to quantitative research methods, which involve surveys and statistical based evidence. The chapter will explore the involvement of parent participants, giving some background to the participants and why *grounded theory* (Bogdan and Taylor,1975: Bryman and Burgess,1994) in particular, is the chosen method used to explore and analyse data.

There will be a section included within this chapter that summarises some of the potential *challenges faced* when *facilitating research involving people with learning difficulties,* and how important it is that research is tailored to the requirements of parent participants themselves.

The Research Paradigm : Qualitative Data Collection

By aiming to include a group of parents with learning difficulties within the research process, the research undertaken here will aim to adhere to an emancipatory research model, "by confronting social oppression at whatever level it occurs" (Oliver,1992:110). However, authors such as Gerry Zarb (1992), make a distinction between 'emancipatory' and 'participatory' research. Zarb concludes that it "makes more sense to talk about doing 'participatory' rather than 'emancipatory' research" because "by simply

increasing participation and involvement will never constitute emancipatory research" (Zarb,1992:28).

Walmsley and Johnson (2003) draw attention to the use of labels within research to identify specific groups. They state that this can "be positive" but it can also be inherently discriminatory" (Walmsley and Johnson,2003:81). And as researcher here, I am aware that there is a responsibility upon me to take this issue into account. By drawing attention to parents' 'difference', there is a danger that the research process itself, could be facilitating the very nature of 'oppression' that it chooses to critique. (Walmsley and Johnson, 2003).

To address this, by aiming here to "facilitat[e] a politics of the possible" (Oliver, 1992:110), this project will aspire to equip participants with research that will be in some way relevant, accessible and inclusive. By engaging with the suggestions of participants throughout the research process and by equipping parents with an accessible copy of the research findings, it will aim to provide information that participants may be able to utilise in an empowering way in the future. Reinforcing this further is the ongoing participation of one of the parents who acted as 'consultant' on matters relating to accessibility of the 'easy read' version of the research findings.

Supporting this approach with 'qualitative' research methods, that "[emphasise] words rather than quantification in the collection and analysis of data" (Bryman, 2008:366), it will prioritise the views and experiences of parent participants, an epistemological position which is described as 'interpretevist'. This means that understanding of the world and parents' subjective place within it will be noted through the eyes of parents themselves (Bryman,2008).

An Emancipatory Approach

An emancipatory research model, one that includes and is informed by participants, is a vital element underpinning this project for a number of reasons. Primarily, it exposes "disabling barriers as part of the wider politicisation and empowerment of disabled people", and secondly, because as Barnes states, "political outcomes are elevated to centre stage when judging disability research" (Barnes,2008:pp.458-473). Furthermore, it is hoped that by establishing an effective dialogue, it will give participants opportunities to steer the path of the research process itself, facilitating "self-empowerment of disabled people" (Barnes,2008:pp.458-473). Subsequently, this will allow me (as researcher) to take my lead from disabled people and thus explore a "reciprocal, two-way dimension of access" (Nind and Seale,2009:274). This chosen approach will align itself,

in part, to the "researcher [moving away] from being 'the expert' interpreter of the world to being the servant of disabled people" (Walmsley,2001:195).

Recruiting Participants

Although 8 parents seemed a very realistic number of participants to engage with within the time-span, it initially proved very difficult to contact a larger number of parents with learning difficulties from which to define a sample. This supports and further validates the 'invisibility' of this participant group (Wates and Jade,1999: Booth and Booth,1994:Crow,2003:CHANGE,2010), although research does state that numbers of parents with learning difficulties are reportedly growing (Guinea, 2001:Pixa-Kettener,2008).

Communicating with parents with learning difficulties, often involves 'gatekeepers'. Gatekeepers (Beazley et al,1997) are those who have fairly unrestricted access to the lives of people with learning difficulties, for example, parents, carers, social services or voluntary sector groups. They often 'screen' interactions between disabled people and wider society. Within this research process, parents were initially contacted by a known 'gatekeeper', who offered to facilitate meetings.

However, there were initial problems with the gatekeeper accessing individual participants and arranging appointment times etc. On three occasions meetings were cancelled or rescheduled. This had a dramatic

effect upon the research timetable scheduled here, setting progress back by between 4-6 weeks. The gatekeeper subsequently moved away from the area and could not maintain commitment to the project, and the onus was then firmly upon me, as researcher, to try and contact parent participants and reconvene on a revised basis.

It proved easier to make one to one appointments to see individuals within their own homes. It was here that methodology was revised to change the communication method employed too. The communication method chosen by the researcher and participants, for example; letter, phone, text, email etc, had to be individually tailored to the preference of the individual. It can be hard for many people to even understand the concept of the research itself without an appropriate method of communication at the initial research stage. Therefore, as Hollomotz (2011) defined in her research, "people with learning difficulties use a more concrete, rather than abstract frame of reference" and research needs to focus on " one point at a time" (Hollomotz,2011:20). Many people with learning difficulties have a lack of formal education and a limited ability to read. Therefore, personal phone numbers need to be obtained. Reliance solely upon letters etc may hinder the participation of people who, due to previous negative experiences may view 'external' involvement and research with a degree of suspicion (Phillips,2004).

On at least two occasions here, interviews with parents did not go ahead, or parents retracted all interview data. Reasons cited by two parents, were that they did not want social services to get involved, and their experiences with social services had been too painful, they did not want to rake over old ground and reawaken past any emotions. This again proved to be a defining factor, as the 'grounded theory' approach, meant that the research itself would be steered, in part, by parents' own input.

'Snowball sampling' enabled 6 participants to be identified and a chain of contacts to be made (Bryman,2008) it overcame the 'invisibility' of the participant group.   Snowball sampling builds upon known contacts, expanding the participant group.   However, to an extent snowball sampling did limit the geographical range of participants, most people lived within close proximity as most parents found it hard to travel outside of their town/city and the participants here tended to be from similar backgrounds and ethnicity.

All of the parent participants were articulate and used speech as their primary communication method. This limited the sample to an extent, because it did not include people with more 'severe' or 'profound' learning difficulties (Hollomotz,2011).   However, people with more severe learning

difficulties could be included in a wider, lengthier study. Widening participation may influence the communication methods required to support 'one-to-one interview techniques' and to establish dialogue with parents who do not use speech as their primary communication method. Timescale would need to be extended; this would reflect the additional time taken to identify and establish communication methods and to interview parent participants.

Interviews and focus groups

Existing research suggested that 'life histories' (Booth and Booth,1995) or 'personal documents' (Bogdan and Taylor,1975), although very time consuming, can offer the insights that paint a more accurate picture of an individual's subjective experience. Therefore, having revised the methodology in line with the initial barriers to parent contact, one-to-one interviews were chosen as a revised starting point for this research project. The number of parent participants was limited to 8 people; the data from only 6 parents was finally included, despite interviews with 8 participants having taken place. It was hoped that this would however begin to highlight some of the more common barriers facing parents, whilst facilitating research that provided a safe space in which people could discuss very personal, often highly emotive issues.

The Parent Participants.

With emphasis upon the experiential data conveyed by parents themselves, the methodology here employs what Guba and Lincoln (1994) define as "trustworthiness and authenticity" as criteria for assessing qualitative research. In line with the view that disabled people are "true knowers", experts within the field (Stone and Priestley,1996:19), research methods aim to address any issues arising from the researcher / researched dichotomy, issues synonymous with power and oppression (Stone and Priestley,1996). By consulting with, and adapting to the input from parent participants, it was hoped that this would go some way towards addressing any power imbalance between researcher and researched (Stone and Priestley,1996). A purposive sample of 8 parents was identified. A purposive sample determines the relevance of participants who will be part of the research process (Bryman,2008). The criteria here was determined by the research questions, therefore the sample would include *parents with learning difficulties*. It was made clear to participants at the initial contact stage that they did not have to be actively parenting their children; this study was exploring any societal barriers facing parents.

Table of participants

Name	Age	Sex	Relationship Status	Ethnicity	Parenting Arrangements
Michelle	20-29	F	Single	White, British	Looking after child with support from her mother.
Christine	40-49	F	Married	White, British	Not living with children.
Joanne	30-39	F	Single	White, British	Looking after two children, third child adopted.
David	30-39	M	Single	White, British	Step-father, not actively parenting his ex-partner's children.
Robert	40-49	M	Married	White, British	Not living with children.
Sandra	20-29	F	Single	White, British	Looking after children, one child adopted.

NB: All participants' names are pseudonyms

Abbreviations: M=Male   F=Female

Data Analysis.

It was discussed with parents at preliminary meetings or conversations via telephone, that empirical data would be obtained through interviews within parents' own homes, or agreed locations. Participants were asked if they were happy to agree to the interviews being recorded and transcribed. I explained that this process would record their words verbatim. If at any time, they felt that they were not happy to proceed with an interview, then they had the right to stop it or take a break. Of the 8 parents approached who agreed to be a part of the project, one of the participants subsequently decided that he chose not proceed and his information was therefore destroyed. This followed a conversation with his partner who felt uncomfortable about the anonymity of the data.   A further participant, although initially very supportive of the research, was wary about her information being identified and used by social workers, compromising her position with her children. This was supportive of existing research within the field (Phillips,2004).

Within the research methodology, analysing data proved to be a hurdle to fulfilling the criteria of 'emancipatory' research. Although the process of 'codifying information' (Bogden and Glaser,1975) in line with the 7 barriers was relatively straightforward, I was concerned that this part of the methodology did not allow parents to take an active part in the research process. This is a challenge that faced existing authors who undertook research with people with learning difficulties (Chappell, Goodley and

Lawthon, 2001). It was here that restricted timescale proved to be a barrier to engaging the views of parents on codifying strategies. To fulfil the aim of emancipatory research, this aspect would need to be factored in to the timetable to allow communication strategies to be established that fully incorporated the parents' feedback (Barnes,2008).

Ethics: challenges of conducting research involving people with learning difficulties.

Existing studies have highlighted some fundamental phenomenon that *may* exist when undertaking research involving people with learning difficulties. Issues such as "empowerment of disabled people" (Zarb, 1992:127), concepts of access (Nind and Seale,2009) and "acquiescence" of people with learning difficulties (Stalker,1998:6) have been highlighted within existing studies. In her study, outlining the challenges facing researchers when involving people with learning difficulties in the research process, Kirsten Stalker (1998) identified a number of issues that will inform my work with the parent participants within this study. For example, these relate to "raising expectations of continuing friendships [….] addressing issues of "accountability" and "acquiescence" (Stalker,1998:5) and other issues relating to a paucity of accessible literature for people with learning difficulties (Nind and Seale,2009).

However, my aim was to be as non-judgmental as possible, aiming to take the role similar to that of an "enlightened witness" (Miller,1997:unpaged). Alice Miller states that many people have benefited from finding someone who "helped them to recognize the injustices they suffered, to give vent to their feelings of rage, pain and indignation at what happened to them" (Miller,1997:unpaged). However, the emotional nature of this research can give rise to feelings of attachment and loss, and I gave the participants the opportunity to discuss any dominant feelings with me in a de-briefing session that took place after the interviews (Hollomotz,2011).

Dr Val Williams from the Norah Fry Research Centre in Bristol works alongside people with learning difficulties. In her work she employs strategies relating to 'self – advocacy' an integral part of the empowerment pathway for people with learning difficulties. Walmsley cites her here as she:

> "describes the Bristol self-advocacy group's work as a move towards reciprocity [.......]the group worked out its own agenda, undertook the interviews and shared in the generation of theory and data" (Walmsley,2001:198)

Another issue raised by Stalker (1998) relates to the issue of acquiescence, she states that:"some people with learning difficulties have a tendency

towards acquiescence,[……] because so many aspects of their lives are controlled by others" (Stalker,1998:6). There are two issues to address here, and the first relates to control and power. To avoid contributing to the ongoing oppression of disabled people, this project, by aiming to conduct emancipatory research using a qualititative framework, concludes that all aspects of methodology must be aimed towards the *inclusion* of people with learning difficulties. And, to avoid the perceived tendency to agree with either researcher, dominant group members or an understood "socially accepted opinion" (Smithson,2000:116) questions to the participants will be open ended, within one-to-one (semi-structured) interviews. This, it is hoped will both "validat[e] and publicis[e] [participants'] views" (Smithson,2009:116).

Conclusion

This chapter has provided an insight into the methodology and participatory strategies employed throughout the project.   Highlighting the need for research that enables participants to access the study was of paramount importance throughout all stages of research in line with an emancipatory design. The chapter outlined how parents' views underpin the research throughout most stages of the process. It has also contextualised how the methodology employed here, relates to challenges identified by previous authors within the field, and how this may impact upon the way in which research is carried out. Finally it has identified ways in which the project will

aim to balance the participation of parents, with the need to address the relevant questions to hand. The following three chapters will discuss the findings from the parent participants own perspectives, collating evidence under the respective research areas of labelling, barriers and strategies for change.

<div align="center">****************************</div>

<div align="center">

Chapter 4

Parents' Feedback : Labelling

</div>

Introduction

This chapter is the first of three to explore the feedback and personal experiences of the parent participants. In line with the three research areas of *labelling, barriers* and *strategies*, this chapter will discuss parents' experiences of attitudes and associated stereotypes relating to 'labelling', specifically the label of 'learning difficulties'. Some of the parents cited here, refer to themselves as 'parents with learning disabilities'; this is often aligned to the everyday terminology used by professionals or care agencies that

support them. It is underpinned by the medical model of disability but will be adopted here in line with parents' own preference and voice. The chapter will evidence issues synonymous with labelling: attitudes, stigma, self-identity and personal autonomy. It will explore how negative attitudes and labelling, can facilitate the ongoing oppression of parents with learning difficulties.

Labelling, Learning Difficulties and Identity.

Self Identity and Stigma.

From the interview data, overall consensus from the parents' feedback, indicated that 'labelling' was indeed associated with 'difference'. This was perceptible in the interview with Jo, who stated that "other people just think that we are different in a kind of way" (Smith,J.2011:line 34). Although learning difficulties are often hidden, the 'label' of learning difficulties set parents apart in an almost abstract kind of way, with the "notion of 'otherness'" (Hollomotz,2011:119) creating barriers and boundaries. Only one of the participants felt that being 'labelled' with learning difficulties was wholly positive.   David, a staunch advocate, said "I think it's really positive" (Jason,D.2011:line 81). However, feedback generally indicated, that if someone is perceived to have learning difficulties, it is synonymous with 'lack' or 'deficit', something defined by your need for social service support or 'professional' intervention. This validates existing research that highlights

how the perceived need for social and health care services, devalues the experience and place of disabled people within society (Ramcharan et al,1997).

Both Jo and Michelle said that it was not a positive label, with Jo actively stating "I don't have a learning difficulty" (Smith,J.2011:line15), whilst feedback from Christine and Robert linked their 'label' to stereotypes of "victim" and 'passivity' (Kinsey,R.2011:line136). This further validates the generic stereotypes of disabled people, particularly women, who are often perceived as "pathetic, passive victims of charity" (Gillespie-Sells et al,1998:104).

Interestingly however, feedback from two of the participants did offer a more positive interpretation of the label 'learning difficulties' and its associated traits.   In the interview with Sandra, she recounted how she was labelled as having learning difficulties whilst at school, as were three of the other parents (Jo, Christine and Michelle). In all cases, this was linked to their academic prowess and speed of learning. Jo, Christine, Sandra, David and Michelle had all been labelled as 'slow'.   However, where others felt that this was negative, Sandra stated that when she was told that she was 'slow', she said:

"If I'm doing it slow, then at least I know that I'm doing

it right. If I'm doing things too fast, then I really feel that

I am going to mess it all up. But I really believe that

everyone should have equal rights, and I don't think

that they should treat people worse because they've

got learning difficulties, I really don't".

(Davies,S:2011:lines 177-182).

Swain et al (2003) discuss the "assumption that disabled people want to be other than they are", rejecting in the process their "identity and self" (Swain et al,2003:71).   Both Sandra and David refuted the belief about rejecting their identity.   Sandra, and particularly David, had established their own learning 'norms' within the process. With David totally rejecting societal norms asserting that "to me there is no speed. We think we'll do it, we want to do it, and we'll do it in our *own* time" (Jason,D.2011:Appendix1d.Lines 250-251). Jo, to a lesser degree, also separated the 'stereotypes' associated with 'labels' from her intellectual impairment, stating that "I suppose I have always struggled to understand things [.....] but I think I'm pretty bright and can pick things up if people tell me 2 or 3 times" (Smith,J.2011:lines18-19).

The reclamation of 'labels' has been an intrinsic part of the move towards politicisation for other marginalised and oppressed social groups. For example, Fitzpatrick (2008) states that the "gay movement helped to transform a stigma into a politicised movement" (Fitzpatrick,2008:unpaged) thus reclaiming 'labels' associated with homosexuality and enabling people to redefine their own 'norms'. The person with the greatest autonomy and sense of a 'disabled identity' was David. However he had no real day to day responsibility for active parenting and as a white, middle class male did not face the social and economic challenges experienced by other parents such as Jo and Sandra, both single parents reliant on benefits. David had immersed himself in the self-advocacy movement, and this, he felt, had awakened his knowledge of the political issues associated with 'disability'. David had a job and aspirations, all of which he felt could be attained. Of the parents who had active involvement with their children, Sandra, who had previous experience of disabled parents' groups and a good support network, seemed to link her own disabled identity with her personal growth in confidence, autonomy, self governance and good, consistent support.

Sandra herself had received much support and encouragement from the people around her in recent years. Although she had negative experiences when dealing with social services in the past, recent interventions had enabled her to have a voice, and to actively participate in the upbringing of

her children. Her self esteem she felt was growing, and she recognised how negative attitudes de-valued people, prioritising instead rights to equality. She separated the *impairment* related to 'learning difficulties' from the stereotypes, reclaiming her individual right to establish her own 'norms' and not those imposed on her by both non-disabled society and professionals alike.

Conversely, Jo, Christine and Robert in particular, all had very negative experiences of dealing with professionals, and this, it appeared, had negated their own view of what it meant to have learning difficulties. The label 'learning difficulties' certainly appeared to be synonymous with disempowerment and control dynamics. Phrases such as "that lot at you" (Kinsey,R.2011: line 1081) and "on your back [......] judging you all the time" (Smith,J.2011:line51) personified professionals as invasive, an almost parasitical force within parents' lives. They appeared to have internalised 'stigma' associated with the label 'learning difficulties', evaluating the control invested to professionals, with their own lack of power to defend their right to be heard. This left them feeling both de-valued and frustrated, and in the case of Robert "wanting to commit suicide" (Kinsey,R.2011 :line104). The negative feelings expressed by Jo, Christine and Robert, compounded their belief that to have learning difficulties meant "having social services on your

back" (Smith,J.2011: lines 42-43). This evidence supports research that states that parents;

>"frequently fall victim to an expectation of parental
>
>inadequacy [….] made real through the decisions and
>
>actions of those with the power to influence their lives"
>
>(Booth and Booth,1998:2).

However, it was not just professionals and authority figures such as teachers or social workers, who 'gave' parent participants their label of 'learning difficulties'. In Michelle's case, it was her mum who told her this when she was a small girl. Michelle said, "it's ok for me. My mum said I'll never get a job but I am happy at home and I have good friends" (Robinson,M:2011.lines 25-26). This links to stereotypes about people with learning difficulties and demonstrates how ubiquitous negative attitudes actually are. This further validates Alison Sheldon's assertion, that "to eliminate all kinds of oppression, we need to transform society" (Sheldon,2004:73).   Michelle's mum saw her daughter as someone with a deficit, intrinsically 'de-valued' by society and limited by her impairment, here the "perception of stigma reduces the expectation of others" (arasite.org,undated:unpaged). David too, although someone who does not see himself as 'vulnerable', a trait commonly associated with people with learning difficulties (Hollomotz,2011),

did state that "my parents think I am [vulnerable]" (Jason,D.2011:line193). In many ways, this reflects the views of wider society, and highlights the way in which negative attitudes are one of the most pervasive and oppressive of all the barriers facing parents with learning difficulties.

Labelling and 'abuse'

To all of the parents, when analysing their comments, it appeared that the label learning difficulties was in some way linked with external perceptions of 'abuse'. Their experiences relating to 'abuse' varied, but seemed to be linked mainly to professionals' attitudes about their individual capacity to parent children, and the subsequent risk that their 'learning difficulties' would pose. To parents such as Christine and Robert, particularly Robert, it was a reflection of the professionals' own lack of understanding of the barriers facing parents with 'learning difficulties'. Robert stated that "social workers really do need to walk around in our shoes, instead of everything being [structured] to suit them" (Kinsey,R.2011:lines 494-495). He went on to point out that he challenged social workers who visited the couple, asking "have you got kids yourself? and if they [said] 'no' [saying to them] well how can you come here and talk to me about bringing up kids?" (Kinsey,R.2011:472-473). In her interview, Jo stated,

> "I think it must be really bad if you are seen to have
>
> real learning difficulties, or if you are a severely
>
> disabled person. God knows how people cope. […..]
>
> they are always judging you" (Smith,J.2011:lines 49-
>
> 52).

Jo had attended courses addressing abuse, after bringing a man back to her house. And fear of 'abuse' appeared to underpin many professionals' attitudes, linking abuse to unspecified standards of parenting and vulnerability within domestic relationships. This was further validated by David, and particularly Christine and Sandra. All stated that they had past experiences of abuse. In Sandra's case this was first hand with her ex-partner. He was however, offered support and therapies, instigated by social services. However, his reluctance to engage with the "whims of social services" (Davies,S.2011: line 390) meant that the family was no longer together.

'Potential' for 'abuse', appeared to parents to be determined by indicators such as the level of 'cleanliness' of a person's house (Jo, Christine, Robert and Sandra all referred to this). This evidence supports existing research, which states that parents are subject to "standards of tidiness and cleanliness that were foreign to their neighbours, families and friends" (Booth and Booth,1994:51). And more importantly, research also states that these

factors "were unnecessary in terms of the health and wellbeing of their children" (Booth and Booth,1994:51). Further indicators of abuse were linked to signs of 'neglect', e.g. stained clothes and everyday injuries sustained by children (Robert and Christine mentioned this). And in Jo's case, her choice of partner was also seen as a potential threat to her children.

And indeed, whilst all of these factors can relate to abuse in some cases, parent participants felt that the 'fear' of abuse afforded to them, related to both unspecified standards and heightened negative preconceptions about their ability to parent their children. Christine stated that minor situations were taken 'out of context', with professionals often judging a statement as a real stand alone threat, such as 'I'll kill you' ; without taking into account the behaviour of her son that motivated such a statement, or the build up of emotion that warranted the outburst.

Throughout the interviews, labels such as learning difficulties were perceived as fundamental barriers to "just [getting] on with it" (Smith,J.2011:Line,222), something afforded to those who were fortunate enough to be away from the scrutiny of social and health care systems. Parents reacted to labels in differing ways; Robert actively separated himself from the label and its negative connotations, and having learned more about social services than

they understood of him, he felt empowered and finally able to reclaim his life. Jo and Sandra, both single mums with no partner, felt that they accepted their label to varying degrees, but both knew that the onus lay with them to conform to social services' expectations to get the support they required. Michelle was the most accepting of the label. Whether this was because her mum 'gave' her the label, and she saw it as part of her dependency upon her mum was unclear, but she was comfortable in the bosom of a supportive family environment where her sisters too also had learning diffculties. David was the least resistant to the label itself. This was a reflection of his politicisation about rights, equality and discrimination. But David did feel that other people saw the label, and in his case his physical characteristics associated with Down Syndrome, and pre-judged him. And he also felt that professionals in particular, "use[d] disability as an excuse" to "treat people differently" (Jason,D.2011: Lines 257-258).

Conclusion

The findings here strongly suggest that the negative attitudes and stereotypes surrounding labels, do indeed impact upon parents' lives. Those contacts external to parents lives, specifically professionals, support agencies and non-disabled society in particular, were able (through their influence and power) to reinforce and perpetuate oppression linked with labelling or 'othering'. Family and friends were considered a vital support

network to parents, providing a sense of inclusion and acceptance intrinsic to counteracting negative messages. Parents with learning difficulties, given no opportunity to challenge or define their own 'norms', are often left oppressed, frustrated and on occasion 'suicidal'.

However, stories of the hope of a more empowered future were offered by at least two parents. David and Sandra were both finding their own way to establish a 'disabled identity', linking their experiences more to an accredited impairment (learning styles) rather than a 'disability'. This indicated that the social model of disability, does indeed have relevance to the self-empowerment of parents and their vision of independence and equality.

****

Chapter 5

Parents' Feedback : Social Barriers

Introduction

Of the seven social barriers identified (SCIE,2005) in Chapter 1, some barriers link directly to issues such as poverty, low socio-economic status, unemployment and social isolation. Many of these constraints often affect parents with learning difficulties (Booth and Booth,1994: Dowson,1997;Tarleton,2006). And here, within the research findings, it appears that these issues have great resonance with parent participants too,

resulting in oppression and discrimination that has the potential to drive parents to the point of physical and mental breakdown.

Poverty, social isolation and lack of explicit standards

Poverty

Often compromised by their social status, parents with learning difficulties are merely surviving, living within areas of inner city towns that face economic decline and struggle. All but one of the parent participants here, were living within the confines of the benefits system, struggling to manage the vast increasing daily costs of living. This was a particularly challenging aspect of life for those parents who were living alone.

Both Jo and Sandra were bringing up families without the support of a partner. And both women were feeling the pinch, particularly Jo, who often has to "ask friends if I can borrow £5". She goes on to say that "I had to borrow money to buy some pants for my kids recently" (Smith,J.2011:Line 32). Jo seemed highly attuned to the economic crisis facing the country. She had a grasp of cuts in services and how these could impact upon other parents with learning difficulties too, "all these cuts by the Government. How are people like us going to cope if they close Sure Starts down?" (Smith,J.2011:line136). Jo recognised that parents, particularly those living

alone with children, were reliant upon services and support to keep them afloat.

Jo also had a real insight into the stigma associated with her social position; this was hard to hear, particularly when Jo talked about the professionals who:

> "think that people aren't capable of bringing up their kids. They [….] don't know how hard it is when you don't have any money and there's no-one there to support you" (Smith,J 2011:lines:24-25).

It was Jo who decided to give up her third child for adoption and there was a direct link here with poverty "I couldn't afford to look after three [children], not on the benefits that I get" (Smith,J.2011: Lines 70-71). Christine and Robert too were faced with the benefits trap and reliant upon Social care services for support. Christine stated that:

> "when we initially approached [Social Services] it was because we were on benefits and we were told that they would help us. So we went to ask them about a

washer […...] and that's when it all kicked off"

(Kinsey.,C.2011:lines 552-554).

From a positive outset, it would appear that both Christine and Robert's personal view of professionals and support services as a helpful and supportive intervention, deteriorated over time.

Therefore, from the information collated within the parents' transcripts, poverty does indeed appear to be a presiding factor underpinning the daily lives of many parents with learning difficulties. It further compounds any negativity relating to parents with learning difficulties, restricting opportunity for self-governance and it reinforces parents' status as oppressed. Jo defined this further when she talked about the climate of 'potential abuse' defining her involvement with social services professionals. She states that:

"they would be poking around the house, looking at the

carpet and saying it was dirty. It wasn't dirty it was old,

it was all I could afford and they said I wasn't

hoovering enough" (Smith,J.2011:Lines 58-61).

However, Susan Mc Gaw (2000) in her study of parents with learning disabilities states that:

"Poverty and disadvantage cannot entirely account for

the difficulties disproportionately experienced by

parents with learning disabilities. Remedial

intervention must therefore address individual,

environmental and wider social problems such as lack

of social support" (Mc Gaw,2000:3).

Lack of explicit standards

This leads on to another important issue facing parents with learning

difficulties, the 'absence of explicit standards'. This is an area where a real

sense of discrimination exists within social care systems. It systematically

affects the chances for disabled people to equally participate with socially

accepted 'norms' (such as parenting) without incurring 'penalties'

associated with being labelled as a parent with learning difficulties.

One of the most prevalent issues relating to a lack of explicit 'parenting

standards' is how the application of 'randomised' parenting standards

becomes almost synonymous with potential abuse and neglect, when

applied to parents with learning difficulties. For example, how often is the

cleanliness of a bathroom used as an indicator of parenting capacity for

those outside of social services jurisdiction? In this one area alone, there

was evidence from Christine, Robert, Jo and Sandra, that their everyday standard of 'cleanliness' within the home was an indicator of potential 'abuse' or 'neglect', something rarely applied to non-disabled parents within their everyday lives.

Christine supported this with a story about a social worker who came to her house looking for apparent signs of abuse. She recalls that the odds were stacked against both her and Robert from the outset, something which became obvious when the social worker asked to see their bathroom. Christine showed her the bathroom and she asked "do you use your bathroom?" and when Christine said "yes", the social worker said, "only its *too* clean" (Kinsey,C.2011: lines178-180). The social worker assumed that the bathroom was not used because it was too clean, and yet, if the bathroom had been dirty, this would have again been somehow linked with potential neglect or abuse.   Taken as a stand alone indicator this clearly demonstrates as Dowson (1997) asserts that for parents with a learning difficulty, "the struggle for power must take place on territory securely under the control of social care professionals and their service agencies" (Dowson,1997:104). And it is here, through discriminatory systems, stacked against parents and recognising "presumption of incompetence" (SCIE,2005:unpaged) that Booth and Booth (1994) state "much remains to

be learned [.....] not least how to achieve a balance between the welfare of children and the rights of parents"(Booth and Booth,1994:144).

One of the more positive aspects that linked with the 'lack of explicit standards' around parenting, came via Sandra's story. From an initially negative past experience of social care services and parenting, Sandra's recent journey was a completely different story. From Sandra's own perspective, having a supportive social worker had helped her to write her own personal parenting guidelines and to further establish routines relating to parenting tasks. Linking with Sandra's own learning style, the continuity of easy read routines and network of support services, helped to define her own place as a disabled mother, establishing a sense of control and enabling her to access prompts if the routine was forgotten. However, despite the positive outcomes as a result of support interventions, throughout the interview there was a sense of ongoing lack of autonomy within Sandra's own life. Even when she acknowledged her success at establishing routines she said, "it's different now, I'm in a place where I know what [social care services] do expect" (Jones,S.2011:Lines161-162). Here, it became apparent that Sandra was constantly mindful of the weight of expectation on her shoulders, and that social services had the power to remove her children if she wasn't able to "up [her] game" (Jones,S.2011: Line128) in line with given tasks and routines.

Power, control and fear are factors determining the ongoing oppression of disabled people (Finkelstein,1981), and although Sandra worked well within guidelines established by social care professionals, and even determined the pathway to devise some of her own routines, she was still 'beholden' to them, and recognised that "sometimes I have been looked down on by professionals" (Jones,S.2011: Line188). For Sandra, occasional recognition of her status as 'disabled parent', gave rise to ongoing feelings of fear. This drove her to constantly prove herself 'capable' as a parent, enabling her to offset any external criticisms relating to her ability to parent her children. This drove her to hide illness, seen here as a sign of weakness. She states:

> "I wasn't well the other month; I felt awful and could
> hardly get out of bed. But I didn't phone them and tried
> to carry on. When they found out what I had done,
> they asked me why I didn't ring for help. I said it's like
> admitting you can't cope, that you've failed, and I was
> worried that the children would be taken away"
> (Jones,S.2011:Lines 404- 408)

The fear of having their children removed from their care is an intrinsic part

of the relationship between disabled parents and non-disabled professionals.

Within the power dynamic here, disability is viewed within a deficit model,

relating to weakness, incapability and inadequacy. And this is often a view

that is internalised by parents themselves. This is despite the fact, (as

Sandra has ultimately proved to herself and others) that when good, stable,

reliable support *is* available; parents often cope admirably and succeed in

ways that surprise both themselves and their support workers alike.

Social isolation

This chapter has so far discussed barriers relating to poverty and lack of

appropriate support, issues that further compound the situation for disabled

parents. Another issue relates to environment and prevailing social attitudes

surrounding disabled people and parents with learning difficulties alike.

Most parents involved in this study, were living under the umbrella of social

care support and accessing benefits systems. All but two of the parents

were living in Council owned housing, located on estates within inner city

towns.

One of the issues facing many people with learning difficulties is social

isolation and specifically, harassment. Despite the move towards integrating

people within communities, research states that "90% of people with a

learning disability experienced harassment and bullying – with 32% saying it was taking place on a daily or weekly basis" (Parton,2011:unpaged). Therefore, the reality of social integration is startlingly different for many parents with learning difficulties. Reports from parents highlight the situation facing disabled people within their local communities. Jo stated that she had had problems with her neighbours, who had, on occasion, reported her to the police for beating her children (Smith,J.2011) lies that were (she felt) founded on dislike of people seen as 'different'. She felt that her neighbours were "real nosey parkers" (Smith,J.2011:line 238). And ultimately, Jo wanted to escape the area in which she lived. Both Christine and Robert too felt hounded within their local area and had moved there originally because one of their children had "been attacked by a neighbour" (Kinsey,C.2011:Lines5-6). However, with the experience of hindsight, Robert stated that he was glad that they were "still here" and that people they know, say to them, we're "glad you stuck your ground you know" (Kinsey,R.,2011,Lines:1051-1052).

And social isolation within communities is a factor that does impact upon the chances of parents being seen as competent and capable. Sandra talked about "feeling really lonely [……] really enclosed" (Jones,S.,2011:Line144) and how "just having people to talk to. It's a real help to me" (Jones,S.2011:Line153). Having support can help alleviate some of the

pressures and strains of parenting, and in the case of Christine and Robert, lack of support networks meant that when Robert was hospitalised, Christine found the situation "a nightmare" as she had "nobody really" (Kinsey,C.2011:line460-461).

And social isolation further reinforces and perpetuates negative attitudes that are associated with disabled people, people who are seen as 'other' and 'different', social misfits and outcasts. But the situation of isolation needs to be grounded within the realities and hardships of life facing many parents with learning difficulties, the lack of choice and control, lack of money and support, and negative stereotypes and overriding lack of understanding of social barriers (Valuing People Now,2009). All these things combine to make things so much harder for parents, and it means that to succeed, they are constantly having to reach higher to meet the unspecified outcomes of others.

Unemployment and low socio-economic status

This chapter has outlined how some of the issues introduced in Chapters 1 and 2 of this study, relate to the findings from the parent participants. But there is so much more to say. Unemployment and low socio-economic status affected all but one of the parents. This is in line with research that suggests that "less than one in five people with learning difficulties are in paid

employment" (Hollomotz,2011:82). Jo and Sandra in particular both aspired

to escape grinding poverty by attaining work and a proper job. For David,

the only participant who had a paid job, a sense of personal autonomy and

self identity were linked to his status as employed, this validates research

which states that "employment provides individuals with valued social roles"

(Hollomotz,2011:83). David's background in self-advocacy had raised both

his self esteem and expectations and he saw self-advocacy as a path to self

expression and having a voice. David had supportive parents from a

comfortable background and although he felt that they saw him as

"vulnerable", (Jason,D.,2011:line193) they also supported his right to

independence and autonomy.

No one barrier appears to exist in isolation and for this reason a

collaborative, supportive approach to addressing the issues facing parents is

needed.

In the interview with Jo, she constantly refers to social workers as being "on

my back" (Smith,J.,2011:Lines 43 and 51) an almost parasitical analogy. The

lack of trust that Christine felt towards the numerous social workers that

impacted upon her life, conveys the emotive aspect of their dealings with

professionals who have the power to remove children. One important issue

that was again made apparent here was the inequitable relationship that

exists between the 'expert professional' and the 'disabled parent'. The in-depth interviews with Christine and Robert revealed aspects of the communication breakdown within the power dynamic here, that relates to general social inequalities for disabled people.

Christine highlighted the issue of communication barriers, when she described how a particular social worker, one of at least 20 who had supported their case across the years, who "used to come in, stand in the hallway, talk to you for two minutes and then go. She never came in and sat with us" (Kinsey,C,2011:1b:Lines:8-9). The overriding sense of confusion, loss and frustration was palpable throughout the interview with Christine and Robert, both feeling that the lack of continuity of support from social services was a vital factor in how the system came to penalise them and ultimately fail them as parents.

Accounts from Jo, Christine and Robert, all highlight and expose flaws within the social care system that compromised their autonomy as parents with learning difficulties. All parents alluded to the common fact that there was very little continuity of support from social workers. By this, the group suggested that they had a procession of different social workers, who relied heavily on the accounts of previous colleagues to access the facts relating to the parents' individual circumstances. This is supported by research that

states that there is a huge paucity of social workers within the field of social care (topnews.co.uk:2010) with the specific needs of parents with learning difficulties as being insufficiently supported. This links to issues of communication breakdown, where social workers are not adequately schooled to communicate effectively with people with learning difficulties.

Conclusion

No one barrier appears to exist in isolation and for this reason a collaborative, supportive approach to addressing the issues facing parents is needed.   Booth and Booth outlined 9 points that need to be considered by professionals when supporting parents (See Appendix 2a), but the list is far more expansive. Fundamentally there is a need for society to recognise parents' rights to be treated equally and support them to establish ways of voicing their opinions within a reciprocal, equal footing with professionals and wider society alike. To do this, strategies for change were suggested by parents and these will be discussed within the following chapter.

<p style="text-align:center">**************************************</p>

Chapter 6

Parents Define the Pathways for Change

Introduction

This chapter will take the findings from the discussions with parent

participants and link them to evidence of 'good practice' within the field.

Points raised by Booth and Booth (1994) [See Appendix 2a] and the seven

barriers raised in Chapter 1 of this study (SCIE,2005), broadly outline the

parameters for change. Government guidelines such as *Valuing People*

(Now) (Department of Health,2001 and 2009),*The Equality Act* (2010) and

Good Practice Guidance on Working with Parents with Learning Disabilities

(2007) all highlight strategies for supporting parents and families effectively.

Legislation and existing studies within the field relate to issues of improved

access to multi agency support services, improved communication,

advocacy and information tailored to suit the needs of the parents

themselves (Norah Fry,2009: Leaviss et al,2011:Booth and Booth,1994).

However, it is recognised that,

> "many children and family social workers do not feel
>
> adequately equipped to work effectively with [parents]"
>
> and simultaneously, " many adult learning disability
>
> services struggle to effectively support parents with
>
> learning disabilities" (Department of Health et al,2007).

Here, as mentioned in previous chapters, the existing system to support

parents with learning difficulties has the potential to fail.   Many parents are

facing a complex combination of social and economic barriers that

influence their decision to hide their accredited impairment. This is to avoid

the further risk of stigmatisation and negative pre-judgment related to

labelling and disability. Therefore, support often reaches parents when

they are already at crisis point. And when it does reach them, often the

need to protect their children is prioritised within a system focusing on the 'deficits' rather than the long term strategies to support parents' strengths (Phillips,2004: Booth and Booth,1994).

However, within this research project, parents own opinions and views will determine where *they* see change being most effective, and it is these suggestions that will inspire recommendations for future strategic improvement.

Self Advocacy

Previous chapters have alluded to the importance of self-advocacy and advocates, in the fight for equality for people with learning difficulties (Department of Health et al,2007; Valuing People,2001;Walmsley and Downer,1997). Booth and Booth (1994, see Appendix 2a) highlight advocacy within Support Points 2, 3 and 10. And within the primary research collated here, parent participants raised this issue too. Parents such as Sandra had been part of support groups and mother and toddler groups, she said "just having people to talk to. It's a real help to me". (Jones,S.2011:Line157).

Christine and Robert had benefited from the support of an independent advocate who had been "a real Godsend" (Kinsey,C.2011:Line 631). David,

himself an advocate for others, had championed self-advocacy groups throughout his own career, he felt that drama was a strategy that could bring "people out of their shell" (Jason,D.2011:Line220). He conveyed his experiences of showing "professionals how information is not accessible" (Jason,D.2011:Line 87) within the healthcare system, this he felt, had been a real positive experience. Conversely, Christine and Robert met with huge resistance and were accused of "insulting" (Kinsey,C.2011:Line728) social workers when they enacted a group perspective of a case conference meeting. However, strategies for self-advocacy, such as support groups and peer support were raised by parents throughout the interviews as pathways towards positive change.

Sandra took her dad along to case conference meetings to act as her advocate, because "sometimes you really feel like you can't speak up" (Jones,S.2011:223). And it was access to an advocate at case conferences, that inspired Robert and Christine to ask Social Workers to "change the system so we can be a part of it and at least understand" (Kinsey,R.2011:170). The findings suggested that if parents had accessed a channel for self-expression, or self-advocacy, they felt validated, supported and included (Phillips,2004). Where this intervention had been denied them, parents felt disempowered, frustrated and isolated within their community, struggling with issues that were escalating outside of their control.

Continuity of Support.

This is an issue that is raised in conjunction with Support Point 4 (Appendix 2a) by Booth and Booth (1994). They state that "[c]onsistent, non-intrusive and non-threatening" (Booth and Booth,1994:pp.21-22) support is vital to parents, something championed here by the parent participants too. Sandra faced problems, when, having established care plans and routines with professionals, "they started sending other people" to support her. (Jones,S.2011:194). She goes on to state that "different people kept changing things and thinking that another way was better" (Jones,S.2011:Lines194-195). This became very confusing for Sandra, and at a subsequent case conference, her dad spoke out on her behalf, asking that established routines be respected and not altered, this is further supported by Booth and Booth (1994) in Support Point 6 (Appendix 2a). Here, advocacy overcame the barrier to communication, highlighting the need for someone to act as an advocate for parents in times of crisis.

Sandra's story bears testament to the success of continuity of support. And lack of consistency was a huge barrier facing Christine and Robert. They had experienced reams of social workers throughout their protracted case, with over "250 people" (Kinsey,R.2011: Line1022) estimated to have been

involved with the couple throughout their case history. The lack of continuity impacted upon the couple with support workers reliant on "opinions written down on paper" (Kinsey,R.2011:Line 573) and acting upon incorrect information that had been recorded in files (Kinsey,C.2011). The importance of clear, informed and consistent information is crucial; a deficit here could compromise parents and prove oppressive and discriminatory, resulting in negative pre-judgments and ill informed decision making.

Communication : accessibility for all

Communication was a huge issue, not only for parents but for people with learning difficulties (and disabled people) per se. As already discussed, case conferences, chaired and organised by non-disabled professionals, punctuate the ongoing interactions between parents and external agencies. Christine and Robert experienced extreme discrimination within these meetings, and they voiced frustration about having only ten minutes prior to meetings to examine inaccessible papers written by a multitude of professionals. Their experiences date back five years or more. However, mothers currently engaging with the system such as Sandra and Jo, also expressed their feelings of exclusion when professionals appear to be " just getting on with it and you're scared to say something, or you can't keep up with it all" (Jones,S.2011: Lines223-225). Again, it is here that advocates

are deemed vital to re-dressing the balance, providing support and validation for parents within these challenging meetings.

Parents talked about the need for "paperwork and all of the red tape [….] to be [taken] down a few steps" (Kinsey,R.2011:Line 612). David clarified this further, stating that information should be "communicated in a way that parents understand" (Jason,D.2011:Line122). He said that information needs to be "clear, large print, no difficult words. He said to ask parents if they understand if not, put photos or pictures in by the words as a prompt" (Jason,D.2011:Lines123-125). David went on to state that "professionals need to improvise, find a way of communicating that parents understand" (Jason,D.2011:Lines 144-145). Photo-symbols were cited as preferred methods of communication for many people with learning difficulties (Jason,D.2011)

Sandra, Jo and Michelle all discussed sex education provided within schools.   Research suggests that this is an area, although greatly improved, one that still excludes people with learning difficulties (Hollomotz,2011) and further research indicates that there "continues to be a lack of suitable sex education for people with 'severe' learning difficulties" (Hollomotz,2011:53). However, the younger parents, Jo, Michelle and Sandra, all said that they had received information while at school, although Jo stated that "it didn't go

far enough" stating that things are "better than before", she suggested that practical advice about being pregnant and the implications of parenting were needed (Smith,J.2011:143-145). And this was further re-iterated by Sandra who said that "I think there should be more information given to kids at school, you know, about getting pregnant and having kids, there's not enough of that" (Jones,S.2011:Lines310-312). It seemed that very generic information is given to young people with learning difficulties, and as stated by Hollomotz (2011), information for people with learning difficulties needs to be "broader and more concrete than for non-disabled individuals" (Hollomotz,2011:165).

As examined in chapters 4 and 5, negative attitudes towards parents with learning difficulties are a huge barrier to equality. This links to support points 1, 2, 5 and particularly Point 8 (Booth and Booth,1994: Appendix 2a). If a reciprocal relationship is established, within a mutually committed collaborative network of support, parents appear to benefit, and ultimately, so do their children (Booth and Booth,1994).   Parents' views about the attitudes of external professionals varied dramatically.

Even Sandra, who had integrated with systems designed to keep her family together, got visibly upset when she recounted how she felt that she "had been looked down on by professionals", stating that she felt that they thought

"this person's going to fail" (Jones,S.2011:Lines189-190). The power dynamic relating to the labelling of parents with learning difficulties is palpable, and it is both oppressive and discriminatory for professionals not to take this issue into serious account.

Conclusion

Booth and Booth (1994) state that "support should be provided to parents and children as people first" (Booth and Booth,1994: See Appendix 2a of this study). And this is fundamental to *all* strategies employed to support parents and children in the future. David validated this when he said "parents can speak for themselves and they should play a big part in how things are made easier for them" (Jason,D.2011:Lines173-174). Self advocacy groups and advocates are an intrinsic tool to enable parents to have a voice in life changing, often crisis situations. Easy read information is vital, as is the support and information shared with young people, potential parents of the future. Collaborative, concrete routines, modelled and shared between parents could prove vital to the empowerment of parents with learning difficulties in the future.

But all of these strategies need a wealth of trained, empathic staff to initially support and guide parents through the early stages of parenting. Establishing pathways takes time and effort, something difficult for cash

strapped local authorities cutting back services and looking for cheap solutions to problems. This is no answer to these issues and a real investment needs to be made by central and local Government to the needs of disabled parents and their families. The final chapter will provide a summary of this report and highlight the need to develop further research in specific areas.

Chapter 7 :
Conclusion

Introduction

This final Chapter will collate and evaluate the findings from the research project. It will consider the barriers that face parents with learning difficulties in light of the Social Model of Disability. It will assert that wider society, policy makers, professionals and non disabled people alike, must begin to acknowledge the rights and voices of disabled parents, to affect the breaking down of social barriers that can ultimately oppress. By revisiting the three research questions, it will evaluate whether labelling and barriers do indeed affect parents, and it will, from the parents' own input, highlight potential strategies for change. The chapter will further define the strengths of the project, and suggest ways in which less successful areas of the research

methodology could be improved. Finally, it will recommend areas for future research development, and how parents with learning difficulties should play an intrinsic part of any future research within the field.

The Research Questions Revisited

The research questions posed within this study explored three different, but intrinsically related research strands, namely labelling, barriers and strategies for change. The findings collated through the literature review and via parent participants' own feedback, supported to a greater extent, the assertion that labelling and societal barriers, negatively impact upon the lives of parents with learning difficulties. Indeed, it appeared throughout the interviews, that negative attitudes in particular, affected the opportunity for parents to be viewed in an unbiased way. Pertinent issues highlighted within the literature review, introduced the ways in which barriers and labelling of disabled people can compromise parents with learning difficulties, and subsequently influence the attitudes and systems of those that support them.

Negative attitudes from professional staff had driven certain parent participants such as Robert, to the brink of suicide. Even the parents, who had received more constant and individualised support, felt that they were looked down upon and seen as 'different'. This supported the findings from existing research studies within the field, suggesting that labels do indeed

create a barrier between non-disabled professionals and disabled people, establishing power and control dynamics and perpetuating oppressive practices (Dowson 1997 ;Goodley,2004b; Hollomotz,2011).   To re-dress this imbalance of power, a support network and avenues for self expression and self-advocacy were seen as determining factors. These factors governed how parents internalised any feelings of 'stigma' relating to any label imposed upon them.

Those parents who had received positive feedback, or ongoing support from key individuals, felt more comfortable accepting their 'individual impairment' whilst embracing their personal strengths (Hollomotz,2011). Other parents such as David, had separated his 'intellectual impairment' from stereotypical associations of the label 'learning difficulties', a defining marker in the politicisation of 'oppressed' groups (Simons,1995). David and Sandra possessed a sense of "an identity marked by positive potential rather than the negative assumptions of others" (Simons,1995:176) However, those parents who had battled to assert themselves, isolated and without constant advocacy support, felt embittered. They were powerless to resist any label imposed upon them, and their frustration and anger defined their ongoing experiences of persecution and oppression. Their self esteem and identity were intrinsically linked to the messages internalised from those around them. This highlights the issue of power imbalance between non-disabled professional and disabled parents, raising what Dowson (1995) asserts, is

the need to "shift the balance of power" by means that do not merely offer "empowerment" as a gift to bestowed on the oppressed. (Dowson,1995:105).

Stigma, a resulting effect of being labelled as 'different', does indeed (from the evidence) appear to affect parents with learning difficulties. And this assertion was aligned to the issues raised within this project's literature review. Fear of being labelled as 'different', drove some parents to disassociate themselves from anything that marked them out as having a learning difficulty. To reach unspecified standards set by professionals and to avoid stigma, many parents worked incredibly hard to maintain the status quo of professional expectation and thus retain their right to parent their children. Signs of 'weakness', for example everyday illness, were therefore often hidden, despite the offer of support from external agencies. Stigma and fear of the removal of their children, was a factor that drove parents to great lengths to be seen as 'capable' parents.

Parents experienced confusion about the lack of 'standards' relating to parenting. And whilst this is the case for non-disabled parents too (there is no magic handbook to parenting), parents with learning difficulties, once under the jurisdiction of social services, are faced with an almost unique combination of social, attitudinal and economic barriers that undermine their efforts to be seen as 'capable' parents (Booth and Booth,1994). And it is

here that the greatest potential for discrimination and oppression seems to exist. Professionals working within the field of both child protection and learning difficulties are often not equipped to fully understand the barriers facing parents with learning difficulties (Leaviss et al,2011). Systems designed to protect children, can often penalise parents with learning difficulties, establishing in the process unspecified standards of parenting that are not effectively communicated. Inaccessible information excludes parents from the processes intrinsic to child protection, and appears to discriminate against them at vital meetings. Jargon and lack of support for parents, establishes boundaries between the 'expert' professional and the disabled parent. This dis-empowers parents at crucial periods within care proceedings, and perpetuates the ongoing oppression of disabled people per se.

Barriers

Aside from the attitudinal barriers and labels, parents find that their situation is indeed often compounded by external (economic) barriers. Poverty and daily hardship undermine the personal independence and autonomy of parent with learning difficulties. Enforced reliance on social services and benefits thwarts parents' attempts to achieve independence. This establishes power relationships that govern the opportunity for parents to even have a say in whether they keep their children.

Factors such as lack of transport, social isolation and financial hardship, further compromised parents' attempts to travel to group meetings or even establish a network of friends. Unemployment is a huge barrier, again establishing a cycle of reliance on benefits. If a parent (ie.David) had access to work, it gave a sense of a positive disabled identity, a gateway to citizenship and entitlement (Hollomotz,2011). However, this is not, it appears, the case for most of the disabled parents here.

Further research and parent participation.

The overall breadth of this project hindered the depth of research in any one specific area. Therefore an overall view of the implications of any one of the issues here was only merely 'achieved' in the allocated time-span. However, issues that arose from parents input, such as the link between learning difficulties and risk of abuse, are areas that could be explored in greater detail by further research with parents. Looking at strategic plans to adopt a more holistic approach to supporting parents, is another area that warrants further research. This would need to incorporate input from disabled parents, their advocates, and how to establish accessible advocacy networks for parents and professionals who support them. Pathways for expression are

needed to re-dress any unbalance between the strategies of professionals and the rights of parents and their families.

Accessible information needs to be continuously addressed. Whether this is in the form of support plans, individualised routines produced to parents' own specifications, or with the dispensation of jargon at child protection meetings, lack of access to information routinely discriminates against parents. Parents are the people who need to be consulted here. What may work for one parent may not necessarily work for another, therefore support agencies need to work with parents to establish the best method for them. Once established, these plans need to be adhered to, not just by parents, but professionals, constancy here is vital. Parenting groups need to work closely with social workers; defining the needs of parents is vital in supporting them well. Again, this is an area earmarked for further research.

Sexual health education, an area that has seen improvement, but parents suggest that information does not go far enough and needs to be developed. Parents again could support professionals in educating young disabled people about the issues that may face them as future parents. And this information needs to look at parenting holistically, encompassing the social and economic barriers that may face people who become parents. Social workers and health visitors need to be a part of young people's schema,

these people are important in the lives of parents and their input needs to be defined on both sides.

Conclusion

Good practice indicates that joined up, effective support for parents, can bring hope for the future. Sandra's story highlights how support has improved throughout recent years. But this holistic, synchronised approach needs to be replicated for others. Often, parents like Jo, also a single mother but without a support network, can flounder and become disillusioned through no fault of their own. Overriding barriers such as poverty can further isolate and compromise attempts for parents to be seen as 'capable', something highlighted again through Jo's observation that her 'old' carpet was seen as an indictor of 'abuse and neglect'.

However, fundamental to the success of any further strategy, is the realisation that parents are indeed, whether with their children or not, experienced within the field of 'learning difficulties' and 'parenting' in a unique way. Attitudinal barriers reinforce the power dynamic between parents and professionals. Commitment to developing strategies to empower parents will involve money and support from local authorities and Government agencies. Again, research to develop effective links between

parents with learning difficulties and local authorities needs to be further

implemented. Without funding, or with further cuts to funding within the area

of disability, oppression and discrimination will further compromise the

potential to effect equality and rights for parents with learning difficulties.

****

**To safeguard participant anonymity interview data has been deleted - :
Appendices 1a, 1b, 1c, 1d.**

Appendix 2a

Strategies were outlined by Booth and Booth (1994), defining a future, more
integrative, collaborative pathway, for both parents and professionals in the
future. These will link with strategies suggested by parent participants in this
research. They will link with feedback from parent participants outlined
specifically in Chapter 6.

"*Support Point 1*: Respect for and support of the emotional bond between
parent(s) and children should be the starting point for any intervention in the
family.

Support Point 2: Support should be provided to parents and children as
people first.

Support Point 3: Parents should be enabled to participate in the making of decisions which have a bearing on their family life or on the welfare of their children.

Support Point 4: Support tends to be effective when it is consistent, non-intrusive and non-threatening.

Support Point 5 : Support is more effective when directed to the survival and maintenance needs of families, followed by child care tasks, than to modifying styles of interaction within the family.

Support Point 6: Service providers must be responsive to any informal support system already in place and ensure they do not interfere with its functioning.

Support Point 7: Problems often arise when a family in difficulty is forced to turn to the very professionals with the main statutory responsibility for child protection.

Support Point 8: The attitude of those who deliver the support is a crucial factor determining its effectiveness.

Support Point 9 : Services need to be organised in such a way that parents are made to feel competent, have a hand in solving their own problems and feel in control of events.

Support Point 10 : A parent-child relationship based on love and affection is more easily supported than replaced" (Booth and Booth, 1994: pp.21-22.)

References

www.arasite.org/goffstig.html. [Online] [Accessed:28.07.2011]

ATKINSON,D.,JACKSON,M.,and WALMSLEY,J.,(1997) *Forgotten Lives: Exploring the History of Learning Disability.* Worcestershire:BILD

BARNES,C.,(1996) 'Theories of Disability and the Origins of the Oppression of Disabled People in Western Society'. In. L Barton,(ed.) *Disability and Society: Emerging Issues and Insights.* Essex:Longman.pp.43-60.

BARNES,C.,(2008) Penultimate draft of an article 'An Ethical Agenda in Disability Research: rhetoric or reality?'. In. D.M. Mertens and P.E Ginsberg (eds.) *The Handbook of Social Research Ethics*. London:Sage.pp.458-473. [Accessed] [Online:28.09.2011] Available from: www.leeds.ac.uk/disability-studies/archiveuk

BARNES,C,.and MERCER,G.,(2004) *Disability Policy and Practice : Applying the Social Model.* Leeds: The Disability Press.

BARNES,C,.and MERCER,G.,(2005) *The Social Model of Disability:Europe and the Majority World.* Leeds:The Disability Press

BARTON,L.,(1989) *Disability and Dependency*. East Sussex :Falmer Press

BEAZLEY,S.,MOORE,M.,and BENZIE,D.,(1997) 'Involving Disabled People in Research : A study of inclusion in environmental activities'. In,C.Barnes and G,Mercer.(eds.),*Doing Disability Research.*Leeds: The Disability Press.pp.142-157.

BERG,S.,(2005) 'Personal Assistance Reforms in Sweden:breaking the assumption of dependency?'. In.C.Barnes and G.Mercer (eds.) *The Social Model of Disability:Europe and the Majority World.* Leeds: The Disability Press.pp.32-49.

BOGDEN,R.,and Taylor, S.J., *Introduction to Qualitative Research Methods : A Phenomenological Approach to the Social Sciences.* London and Sydney: John Wiley and Sons

BOOTH,T., (1990) *Better Lives: Changing Services for People with Learning Difficulties.* Sheffield: Joint Unit for Social Services Research in collaboration with Community Care.

BOOTH,T. and BOOTH,W.(1994) *Parenting Under Pressure: mothers and fathers with learning difficulties.* Buckingham: Open University Press

BOOTH,T., and BOOTH,W., (1998) *Growing up with Parents who have Learning Difficulties.* London:Routledge.

BRYMAN,A.,(2008) *Social Research Methods : Third Edition.* Oxford: Oxford University Press.

BRYMAN,A., and BURGESS.R.G., (1994) *Analysing Qualitative Data.* London:Routledge.

CAMPBELL,J., and OLIVER,M.,(1996) *Disability Politics : Understanding our past, changing our future.* London: Routledge

CHANGE,(2010) 'National best practice in independent

advocacy for parents with learning disabilities: a short scoping exercise' [Online] [Accessed:16.01.2011] Available from: www.changepeople.co.uk

CHAPPELL,A.J., GOODLEY,D.,and LAWTHORN,R.(2001) 'Making Connections: the relevance of the social model of disability for people with learning difficulties'. *British Journal of Learning Disabilities:* 29(2),pp.45-50

CHOPPIN,E,.(2009) 'Families Torn Apart'. In *Disability Now*. [Online] [Accessed: 12.06.2011] Available from: www.disabilitynow.org.uk/living/features

COOKE,E,. and RICHARDS,C., (2008) *Positive Parenting: Supporting parents with learning disabilities. Audio Series 12*. Totnes: Research in Practice.

CROW,L.,(2003) 'Invisible and centre stage : a disabled woman's perspective on maternity services'. Paper presented 15th January 2003 to the Department of Health Open Forum Event of the Children's National Service Framework (Maternity Module)

DAVIS,J.M.,(2004) 'Disability and Childhood: Deconstructing the Stereotypes'.In J.Swain et al (eds.),*Disabling Barriers – Enabling Environments, Second Edition*. London: Sage Publications

Department of Health (2001) 'Valuing people: a new strategy for learning disability for the 21st century - a White Paper' [Online] [Accessed:

16.07.2011] Available from:

www.dh.gov.uk/en/publicationsandstatistics

Department of Health (DOH) and Department of Education and Skills (DES) (2007) 'Good practice guidance on working with parents with a learning disability'. [Online] [Accessed: 14.08.2011] Available from: www.dh.gov.uk/en Publicationsandstatistics/publications.

DOWSON,S.,(1997) Empowerment Within Services : A Comfortable Delusion. In P.Ramcharan et al.(eds.),*Empowerment in Everyday Life : Learning Disability.* London and Philadelphia: Jessica Kingsley. pp.101-120.

Equalities.gov.uk (2010) Equality Act 2010.[Online] [Accessed:23.04.2011] Available from: www.homeoffice.gov.uk/equalities/equality-act/

FINKELSTEIN,V.,(1998) 'Re-thinking care in a society providing equal opportunities for all'. Discussion paper presented to the Open University (3 March 1998).[Online] [Accessed 03.05.2011] Available from: www.leeds.ac.uk/disability-studies/archiveuk

FINKELSTEIN,V.,(1981) 'Disability and the Helper/Helped Relationship: A historical view'. In Brechin,A., Liddiard,P.,and Swain,J.,(eds.) *Handicap in a Social World.* (place) : Hodder and Stoughton. [Online] [Accessed 24 June 2011] Available from: www.leeds.ac.uk/disability-studies/archiveuk

FITZPATRICK,M., (2008) 'Stigma' *British Journal of General Practice* [Online] [Accessed: 28.08.2011] Available from: www.ncbi.nlm.nih.gov/pmc/articles/PMC2277138/

GILLESPIE-SELLS,K., HILL,M,. and ROBBINS, B. (1998) *She Dances to Different Drums*. London: King's Fund Publishing.

GILSHAM,N.,(2010) 'A Strategy to Improve the Lives of Parents with Learning Disabilities and Learning Difficulties – the Good Practice Guidance and Beyond. Presentation : 21 September 2010 : Nottingham. Valuing People Now and Department of Health.

GOFFMAN,E.,(1963) *Stigma.* Harmondsworth : Penguin

GOODLEY,D.,(2004a) Who is Disabled? Exploring the Scope of the Social Model of Disability.In J. Swain et al (eds), *Disabling Barriers – Enabling Environments (2nd Edition)*. London: SAGE Publications.pp.118-125.

GOODLEY,D.,(2004b) 'De-Constructing 'Learning Difficulties' in Educational Contexts:the life of Gerry O'Toole'. In C.Barnes and G.Mercer (eds),*Disability Policy and Practice: Applying the Social Model*. Leeds: The Disability Press.pp.175-191.

GUBA,E.G.,and LINCOLN,Y.S.,(1994), 'Competing Paradigms in Qualitative Research', in N.K.Denzin and Y.S. Lincoln (eds.),*Handbook of Qualitative Research*. Thousand Oaks:Sage.

GUINEA,S.,(2001) 'Parents with a learning disability and their views on support received: A Preliminary Study'.*Journal of Learning Disabilities*. Vol.5 (1) pp.43-56.

HODGES,S.,(2008) 'What is learning disability?' In.E.Cooke and C.Richards (eds.) *Positive Parenting:Supporting Parents with learning disabilities.Audio series 12.* Totnes: Research in practice.

HOLLOMOTZ, A., *Learning Difficulties and Sexual Vulnerability: A Social Approach.* London and Philadelphia:Jessica Kingsley.

HURST,R.,(2005) 'Disabled Peoples' International:Europe and the social model of disability'. In. C.Barnes and G.Mercer (eds.) *The Social Model of Disability: Europe and the Majority World.* Leeds: The Disability Press.pp.65-80.

KINGS FUND CENTRE.,(1980*) An Ordinary Life : Comprehensive locally-based residential services for mentally handicapped people.* London : Kings Fund Centre

LEAVISS,J.,EWINS,W.,KITSON,D., and WATLING,E.,(2010) 'Inclusive Support For Parents with a Learning Disability' (A project funded by the Department of Health). Mencap, ACT and NCT.

McGAW,S., (2000) 'What Works for Parents with Learning Disabilities' (Summary) [Online] [Accessed:20.12.2010] Available from: http:// www.barnardos.org.uk

MEEKOSHA, H,.(2006) 'What the Hell are You? An Intercategorical Analysis of Race, Ethnicity,Gender and Disability in the Australian Body Politic'. *Scandinavian Journal of Disability Research*, 8(2)161 — 176

MILLER,A,. 'The Essential Role of an Enlightened Witness in Society'.
[Online] [Accessed: 15.07.2011]
Available from: www.alice-miller.com/index_en.php?page=2

NIND,M., and SEALE,J.,(2009) ' Concepts of Access for People
with Learning Difficulties:towards a shared understanding' *Disability
& Society*: 24(3),pp.273-287

NORAH FRY, (2009) *Supporting Parents with learning disabilities
and learning difficulties : Stories of Positive Practice*. Bristol :
Working Together Parents Network.

OLIVER, M.,(1983) *Social Work with Disabled People,* Tavistock:
Macmillan

OLIVER,M.,(1992) 'Changing the Social Relations of Disability Research
Production'*. Disability,Handicap & Society*: 7(2),pp.101-115

OLIVER,M.,(2009) *Understanding Disability: From Theory to
Practice (Second Edition).* Basingstoke:Macmillan

OLSEN,R.,and CLARKE,H.,(2003) *Parenting and Disability: Disabled
parents' experiences of raising children.* Bristol:The Policy Press

OLSEN,R.,and TYERS,H.,(2004) 'Supporting Disabled Adults as Parents'.
Joseph Rowntree Foundation.[Online] [Accessed: 14.02.2011]
Available from : www.jrf.org.uk/publications/supporting-disabled-adults-
parents

PARTON (2011) 'Mencap to launch campaign about Disability Hate Crime' [Online] [Accessed:06.09.2011] Available: www.ldtonline.co.uk/2011/04/mencap-to-launch-campaign-against-disability-hate-crime

PEOPLE FIRST.,(undated) 'What do we mean by People with Learning Difficulties'. [Online] [Accessed: 03.07.2011] Available: http://www.peoplefirstltd.com/index.php

PHILLIPS,D.,(2004) 'The Dynamics of Partnerships and Professionals in the Lives of People with Learning Difficulties'. In C.Barnes and G.Mercer (eds.), *Disability Policy and Practice: Applying the Social Model.* Leeds: The Disability Press.pp.160-175.

PIXA-KETTNER,U,. (1998) 'Parents with Intellectual Disability in Germany: Results of a Nation-wide Study. *Journal of Applied Research in Intellectual Disabilities.*Vol.11(4)pp.355-364.

PRIESTLEY,M.,(1997) 'Who's Research?: A personal audit Mark Priestley'. In. C.Barnes and G.Mercer (eds.) *Doing Disability Research.* Leeds: The Disability Press.pp.88-107.

PUPULIN,E.,(2005) 'Disability and Rehabilitation: reflections on working for the World Health Organisation'. In C. Barnes and G. Mercer (eds.), *The Social Model of Disability : Europe and the Majority World.* Leeds: The Disability Press. pp.193-209.

RAMCHARAN,P.,ROBERTS,G.,GRANT,G.,and BORLAND,J. (1997) *Empowerment in Everyday Life (Learning Disability).*

London: Jessica Kingsley.

REEVE,D., (2004) 'Counselling and Disabled People: Help or Hindrance?'. In. J.Swain,S,French,C.Barnes and C.Thomas (eds.) *Disabling Barriers-Enabling Environments (Second Edition).*London:Sage.pp.233-239.

SCIE (2005) 'SCIE research briefing 13: Helping parents with a physical or sensory impairment in their role as parents'. [Online] [Accessed: 03.07.2011] Available from: www.scie.org.uk/publications/briefings/briefing14.index.asp

SHELDON,A,.(2004) Women and Disability. In J.Swain et al (eds), *Disabling Barriers – Enabling Environments.(2nd Edition).*London: SAGE Publications.pp.69-74.

SIMONS,K.,(1995) 'Empowerment and Advocacy'. In N.Malin (ed.), *Services for People with Learning Disabilities.* London: Routledge,pp.170-188.

SMITHSON,J,.(2000) 'Using and Analysing Focus Groups: Limitations and Possibilities'. *International Journal of Social Research Methodology.* 3(2)pp.103-119.

STALKER,K,.(1998) 'Some Ethical and Methodological Issues in Research with People with Learning Difficulties'. *Disability & Society,*13(1),pp.5-19.

STONE,S.,and KACZOR,L.,(2003) 'Strategies for Success Research Report'. [Online] [Accessed:06.09.2011].Available from www.nald/ca/library/research

STONE, E. and PRIESTLEY, M. (1996) 'Parasites, pawns and partners: disability research and the role of non-disabled researchers'. *British Journal of Sociology*, 47 (4). pp. 699-716.

SWAIN,J.,FRENCH,S.,and CAMERON,C.,(2003) *Controversial Issues in a Disabling Society*. Buckingham :Open University Press.

TARLETON, B (2006) 'Providing the right support? Evaluating the work of the north east parents support project and the Walsall Parents advocacy services' *Internal report for Mencap*. Bristol: Norah Fry Research Centre.

THOMAS,C., (1999) *Female Forms: Experiencing and Understanding Disability.* Buckingham and Philadelphia : Open University Press.

TOP NEWS (2010) 'Social Worker Crunch Leads to Poor Child Protection'.[Online] [Accessed: 20.09.2011] Available from: www.topnews.co.uk/212721-social-worker-crunch-

VALUING PEOPLE (2001) 'Valuing People: a new strategy for learning disability for the 21st century - a White Paper'. [Online] [Accessed: 12.03.2011] Available from : www.dh.gov.uk/prod_consum_dh/

VALUING PEOPLE NOW (2009) Department of Health. Valuing People Now: a new three-year strategy for people with learning disabilities. [Online] [Accessed:15.07.2011] Available from: www.dh.gov.uk/prod_consum_dh/groups

WALMSLEY,J,.(2001) 'Normalisation,Emancipatory Research and Inclusive Research'. *Learning Disability.* 16(2),pp.187-205

WALMSLEY,J,. and DOWNER,J,.(1997) 'Shouting the Loudest: Self-Advocacy,Power and Diversity'.In,P.Ramcharan et al (1997) *Empowerment in Everyday Life: Learning Disability.* London and Philadelphia: Jessica Kingsley.pp.35-47.
WALMSLEY,J., and JOHNSON,K.,(2003) *Inclusive Research with People with Learning Disabilities: Past, Present and Future.* London: Jessica Kingsley

WATES,M., (1999) ' Not Exactly Eye to Eye'. In M.Wates and R.Jade (eds.) *Bigger than the Sky : Disabled Women on Parenting.* London: The Women's Press.pp. 170-171.

ZARB,G.,(1992) 'On the Road to Damascus: First Steps Towards Changing the Relations of Disability Research':*Disability & Society.* 7(2),pp.125-138

****

My friends, who have supported me throughout the past two years and always believed in me. And to the parents, all of you. Thank you. This is for you, you made this happen.

****