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Widening participation in the church

An ethnographic case study of two Evangelical churches in relation to inclusion of believers with intellectual impairments

MacKenney-Jeffs, Frances

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Author: Frances MacKenney-Jeffs

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WIDENING PARTICIPATION IN THE CHURCH:

An ethnographic case study of two Evangelical churches in relation to inclusion of believers with intellectual impairments

by

Frances Mackenney-Jeffs

Thesis submitted for the degree of
Doctor of Philosophy, King's College, London

2013

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For my late family:

Mother, Father and Brother,
Julian.

Abstract

This thesis explores the relationship between the Church and disabled believers and thus locates itself within the debate surrounding the Disability Movement and the institutional Christian Church. In particular, it examines the validity of claims that the Church constitutes a further form of oppression for persons with disabilities: at the theoretical level by constructing disability negatively, and at the practical level by being exclusive of disabled people. *Part One* aims to locate Christian theology and praxis in the context of the emergent and broadly secular debate on disability and emancipatory practice with the Disability Movement. It explores the secular discourse of disability in society in general and in the Judaeo-Christian faith across time. *Part Two* aims to explore Christian praxis and applied theology in relation to the issues raised by the Disability Movement, focusing especially on the issue of widening participation for persons with disabilities, and in particular those with intellectual impairments, within the Evangelical Church. It presents the results of a pioneering empirical case study, conducted at two Evangelical sites over a one-year period, that combines the sociological method of participant observation and interviewing with an ethnographic case study approach. *Part Three* aims to develop Christian theological perspectives by offering an explicit theological rationale for reflexive practice with regard to disability, in the light of insights gleaned from the previous two sections. It is designed both to enhance theory and practice within the Church and to enrich the secular debate on disability. Both disablist and feminist ecclesiologies are engaged with, and the work of Evangelical, Catholic and Orthodox theologians is drawn upon. The major findings of the thesis are threefold: First, contrary to charges made by some secularists, among others within the Disability Movement, the practice of the Christian communities observed during the empirical research reveals patterns of good practice, with significantly high levels of social inclusion. Second, the ability of helpers and leaders within these communities to articulate their understanding of disability was limited and fragmented: they frequently oscillated between theological and secular perspectives and struggled to conceptualise their practice in a theologically coherent and holistic way. Third, the theological resources available to the Church, especially in relation to issues of suffering, personhood and emancipation have the potential to further the reflexive practice of the Church and to make a substantial contribution to the discourse and praxis of the secular Disability Movement.

Part One

Disability in social and theological context

1. INTRODUCTION

1.1 Context

Disability in the 21st century is a topic which has come of age. There is a view that it is the last civil rights movement (Driedger 1989) coming as it does after a degree of liberation for women, blacks and, gay and lesbian people. Predictably, perhaps, now that society has turned its attention to disability as a form of social oppression the church is taking stock of the fact and considering its own position with regard to disability. This work seeks to uncover the extent to which disability is negatively constructed in the Christian church and the degree to which the church is exclusive, and/or oppressive, of disabled people in its practices. Furthermore, it seeks to consolidate some of the progress that has come as a result of disability legislation both in the US and in Britain and the high profile that legal requirements have accorded the matter in the conviction that there is something of a *kairos* moment here for people with disabilities in the church.

The topic of this thesis is widening participation and the church. Widening participation relates both to diversity and inclusion and is essentially about raising expectations of people not usually expected to take an active role in the institution (be it Higher Education or the Church). Inclusion is seen as a universal human right, the aim of which is to embrace all people irrespective of race, gender, and/or disability. It is about equal access and equal opportunities and removing discrimination. (Devon County Council accessed November 2010) Widening participation is applied here to persons with disabilities and especially those with learning disabilities. The focus of the thesis is the response of the Christian church to people with learning disabilities. This is understood in the wider context of disability which is a sub set of minority inclusion in society, along with gay and lesbian people, feminists and some racially marginalised people. This is then located in the wider context of emancipatory discourse which importantly also draws on insights from feminism, due to the life experience of this writer and the emancipatory nature of

feminisms' remit. Working with emancipatory goals is consonant with feminist aims¹ and Cook & Fonow (1984) specifically see a participatory paradigm as feminist. Some would argue, that feminisms are primarily, if not solely, concerned with improvement of the lives of women and the experience of women (Nielsen 1990:19; Ruether 1983:18). Although this limited view is not the view in this thesis, it must be said that disabled people include women too, a point that feminism has been accused of neglecting (Morris 1991: Elshout 1994: Fontaine 1995). Christian feminist theologian Serene Jones (2000:6) asserts that feminism's

concern is not only for the liberation of women but for ALL who are broken, physically and in spirit by the oppressors of our world? Feminists emphasise the inclusive scope for the future for which they struggle by saying 'we are struggling for the liberation of women and ALL people.'

While the wider society is of interest there is a specific focus here on the Christian church with particular reference to its Evangelical wing. The Evangelical wing was selected as the present writer has most experience of this sector and duly anticipated that it might have difficulty with offering full inclusion to persons with intellectual disabilities because of its bias towards the rational, and a concern with 'good order.'

There are four main areas covered by disability: physical impairments, sensory impairments, learning disabilities and mental health needs. Learning disabilities is the politically correct replacement for mental retardation, which is a term that is still in current use in the US but not in Britain. Learning disability is synonymous with the term intellectual impairment. (see 2001:501 - chapter 4, p91). Previously learning disability was subsumed under mental health needs but the two categories are seen as totally distinct now. However, because of this historical tendency, in the literature review the two may be conflated. This thesis focuses on the first three areas: physical impairment, sensory impairments and learning disabilities, giving priority to factors which are visible and permanent, as it is likely that as a consequence, a person will have been persistently marginalised within mainstream culture. Of the three, particular focus is placed on intellectual impairment. The empirical work was conducted with this constituency as it was thought that if those with learning disabilities were fully included then all others would likely be included too; for

¹ Serene Jones (2000:9) says that feminist theory is driven by prophetic and emancipatory impulses.

intellectual disability had been a late addition to the field. The attempt to unify all people with impairments had not been unproblematic. From the 1960's organisations were formed which crossed impairment boundaries, the BCODP (British Council of Organisations of Disabled People) being one formed in the 1980's. Despite the need for solidarity, disabled people themselves, often having internalised a lot of society's attitudes regarding disability, wished to distance themselves from others with dissimilar impairments from their own which may be perceived as worse (French 1993:22). Thus a wheelchair user with spinal cord injury may not really consider themselves impaired compared with someone who is intellectually disabled (Oliver 1993). Thus intellectual disability became a marginalised group within disability itself. (Leach 1991; Aspis 1991; Walmsley 1993).

1.2 Aims

The aims of this thesis are fourfold. Firstly the objective is to locate Christian theology and praxis in the context of the emergent debate which at the current time is largely secular. The secular Disability Movement² offers a sharp critique of Judaeo-

² I am using the term Disability Movement in the rather loose way in which it is used in the literature. A quote from Michelle Mason (1996:110) in *Disability Politics* illustrates the point.

Like many disabled people I have belonged to the Disability Movement since childhood. The day I threw away the holy water from Lourdes and said to Jesus, 'I think they are missing the point' was the day I joined the movement. I was 9 years old. I did not know if there were any other members then, or if it was just me and Him.

Clearly, she is not referring to a formal organisation with paid up members but more a point on the social map where solidarity is found among disabled people with a shared perception of the moral meaning of disability. However, it does seem that there is a recognised meaning for the term within the movement. It denotes a social movement with a focus on civil rights, consciousness raising and in its second phase, the quest for a collective identity. Not dissimilar then, to the Women's Movement or the Gay Rights Movement and in the same way merely to be a woman or to be gay does not imply sympathy with the unashamed political objectives of the movement.

According to Mike Oliver, the Disability Movement can be defined by its three distinctive concepts: the social model of disability, independent living and civil rights.

David Pleiffer (1985) says regarding the origins of the Disability Movement:
'It can be argued that eugenics caused the rise of the disability movement in reaction to it.'

There is an historical event that gave rise to the current use of the term 'Disability Movement.' In 1981 Rehabilitation International held a conference in Winnipeg, Canada. RI is made up of primarily non-disabled professionals working in the area of disability. At this conference only 200 of the 3000 delegates were disabled persons and they asked for a representation of 50% on the board. This was refused and as a result the disabled delegates stormed out and met to form their own organisation which they called The Disabled People's International. (DPI) The focus of this organisation was disabled people running their own organisation and the slogan 'nothing about us without us' was

Christian thinking claiming that it is responsible for the negative construction of disability in society and is therefore oppressive. It could be said that the Disability Movement, at the present time, presents the church in a dismissive, ideological way which perceives the church as narrow-minded, and legalistic as if all Christians were fundamentalists. Nevertheless some Christians with impairments have found more understanding within the Disability Movement than within the Christian Church. (Eiseland 1998).

This rich debate is a liberal humanist one, yet it must be noted that the Gospel itself offers plentiful resources for the full flourishing of all people, and a mandate for all persons to be welcomed and embraced as those made in the image of the Creator God. This is not to say that the church does not fall short of what she is called to be and the critique of the Disability Movement may be more relevant to some sectors than to others. There is a tension in this thesis between what is found in the fieldwork and its contrast to the wholly negative expectations and indeed largely unfounded assumptions, of the Disability Movement and also, between what is found in the church and the even greater inclusivity that Christian theology would indicate.

From this exploration arose a second aim which was to conduct a piece of empirical research in order to explore the hypothesis put forward by many in the Disability Movement including (Barnes 1996; Rose 1997) who tend to see Judaeo-Christian belief through the narrow lens of certain isolated texts, largely from the Old Testament scriptures and may over-generalise from some specific things said by Jesus to individuals ignoring things he said to other individuals which clearly show that Jesus did not endorse a popular belief in a link between disability and personal sin. While this assumption is not evidence-based, but rather stated as a self-evident truth claim, Jewish psychologist, Ellen Wertlieb has done some comprehensive work on Talmudic sources to test this view and found them to be far from correct. For this thesis a contrastive case study was conducted at two Evangelical sites over a one year period. The findings did not at all confirm the expectations from the literature

formulated and widely used. According to McCloughry & Morris (2002:14) it was from this point that the phrase 'the disability movement' became regular currency as it denoted a shift from powerlessness to disabled people feeling empowered and in control of their own lives.

review and the findings were complex and nuanced as were the findings of Ellen Wertlieb. This work was considered important to conduct firstly because the writer had had experience of the Christian church as being oppressive to women and therefore took the claims of the Disability Movement seriously and also because disability is an important topic in this era and it was deemed important for the church to properly reflect the inclusivity that is at the core of the Gospel.

A third aim then emerged which was to explore the implications of the literature review and the case study findings for the development of Christian theology. It was seen that Christian theology could learn from disability by recovering its theology of suffering, personhood and emancipation. With reference to suffering as suffering is seen to be normative in the Christian life and not indicative of the presence of some covert sin; with reference to personhood for a Trinitarian theology clearly demonstrates an understanding of all persons being created in the divine image and therefore having immeasurable worth, regardless of their value to a market economy, and finally with reference to emancipation for the Gospel proclaims freedom to all through Christ. The case study revealed evidence of some rich theological resources which could be mined more effectively to enhance the theological praxis, for the praxis where good was so almost by a process of osmosis, the leaders and helpers having internalised a lot of good Christian theology which they were less able to articulate than to demonstrate in their working relationships with people with intellectual impairments.

A final aim relates to the future as it is to reflect on the implications of this case study for future theory and practice in the church and also to enable the church to enrich the secular debate on disability. The Disability Movement is seen to be lacking on account of its *a priori* rejection of wisdom and insights of theological origin. This thesis is not merely a piece of academic work but is driven by a strong desire to see change in the Christian church for disabled people including those with intellectual impairments and indeed to see change in the wider context of widening participation for all who have traditionally been side-lined. As Flynn (2003:19) sharply comments. 'It is not enough to have people in our congregations like dogs on a lead; present but not active.'

1.3 Methods

Subjectivities

In approaching the literature essentially I started with things that had an immediate existential relevance to me, having been on the receiving end of gendered discrimination in the church for many years. I draw on some literature on widening participation, for when I read *Combating Social Exclusion in University Higher Education* by Julia Preece (1999) I saw some stark parallels between Higher Education and the Church, both having an institutional culture which tends to favour certain people and marginalise others. It was clear to me that a similar piece of work needed to be done on the Church. I took the direction of intellectual impairment as I became aware of two suitable churches for my research, both of which were working with people with learning disabilities. My early years as a Christian were spent in the ultra-Conservative Restoration Movement³ which I suspect took its theology on gender from the Brethren church from which it had come. Being single at that time I was further disadvantaged as women were only truly valued through marriage. They did not teach an Augustinian view of women but what they taught was consonant with that.⁴ From this very negative and prolonged experience I developed a passion for inclusivity not least because while the church may be excluding, the Gospel of Jesus is clearly not. I listened to the secular disability movement for their criticisms of the church resonated with my own experience, yet my understanding of the Gospel was at odds with my life experience, and I seriously wanted the church to be true to her calling to be the Body of Christ on earth drawing rather than repelling broken people and doing further damage. I also use some feminist sources as during my 'wilderness' decades in the 'conservative' Church I found the emancipatory writings of some feminists and especially some Christian feminists to be a source of strength and hope. My conversation partners were drawn from the secular world, because I think it important to listen to people with marginal status as they best understand the issue of exclusion and also those from within the church who were from a range of theological stables thus making the Christian side of the work

³ Also known as the Shepherding movement.

⁴ In *Misogyny and the Western Philosophical Tradition*, Beverly Clack summarises Augustines's view of the Imago Dei: 'man is completely in the image of God whereas woman is only in the image of the divine when in partnership with her husband (Clack 1999:63). This view is corroborated by Sarah Coakley (1990:350) and Grace Jantzen (1990:341).

ecumenical yet thoroughly orthodox. These Christian writers, such as Stanley Hauerwas, Mary Grey, Serene Jones, Jean Vanier, Letty Russell, and John Swinton have one thing in common: namely, a healthy disregard for the *status quo* on account of its tendency to be elitist.

Theological method

Although I am a committed Christian and a regular member of an Evangelical Anglican church with a charismatic background, this should not imply that I am uncritical of the Church and particularly in its practices when it comes to issues of social inclusion. Although I value the Evangelical church for introducing me to Jesus and the charismatic movement for teaching me about the gifts of the Holy Spirit, there is much that can be learnt from other Christian sources. Although I am writing as a Christian feminist, my beliefs and faith commitments are thoroughly orthodox: I hold to classical incarnational Christianity and am working ecumenically here with Catholic, Orthodox, Presbyterian, Pentecostal and Evangelical theologians. At times I quote approvingly from lesbian sources, as those on the margins have the most insight into social exclusion and a lot can be learnt from them without advocating their moral or political views.

Empirical methods

The third method relates to the empirical work in *Part Two*. The methodology here was framed by the concept of critical disability research. This sort of research aims to be participatory or going further, emancipatory: involving disabled people in the research process at every stage. While some limitations were put on this for pragmatic rather than ideological reasons, the values of a critical disability research method were upheld throughout. Within this context there was discussion regarding the relative merits of a qualitative or quantitative research methodology. Since the research was interpretive in approach qualitative research methods were preferred. The primary method was a case study approach using ethnographic tools: participant observation and semi-structured interviews and one focus group. The research attended to matters of informed consent, confidentiality, anonymity, and reciprocity and this could be said to be of particular importance given that the research was

conducted in the context of intellectual impairment.⁵ The fieldwork settings in which these methods were used were two local Evangelical church groups who provided a specific ministry to people with intellectual impairments. The fieldwork was conducted over a one year period so as to sample the routine rather than the particular.

1.4 Outline

This thesis is comprised of three sections: *Part One* sets the social and theological context, *Part Two* is the empirical work and explores the case studies at two Evangelical churches. *Part Three* formulates a constructive theology of disability. There are eleven chapters in all, each one concluding with a short summary to aid the reader through the lengthy text.

Part One contains three chapters, including the introduction and sets the social and theological context. Chapter 2 charts disability in Britain in historical and contemporary perspective, looking at recent trends, and then the formation of a number of distinct models of disability. Chapter 3 then focuses on the Christian church in particular and an historical overview of the church's chequered relationship with persons with impairments. A number of specialised ministries for people with intellectual impairments are identified including a recent 'fresh expressions of church' for people with learning disabilities and the development of some disablist ecclesiological and theological perspectives.

Part Two is the largest section as the empirical work forms the core of the thesis. It consists of three chapters all of which are related to the empirical work. Chapter 4 sets out the methodology and methods used, exploring the qualitative research methodology, a case study approach and a critical discussion of disability research. Next the study design is set out and the settings, sample and access outlined. After the methods are explained ethical considerations are explored and the location of the researcher is made explicit. Finally the data analysis is presented. Chapter 5 introduces the research findings, identifying six key themes that emerged from the data which are the models of disability in evidence, the sense of personhood,

⁵ The research subject was actually the church rather than people with intellectual impairments,

theological perspectives, the modes of engagement with the members, whether the leaders saw the members as same or different and within this in either positive or negative ways and finally inclusion. Chapter 6 offers a discussion of results, first expressed through a conceptual diagram, followed by a comparison of sites and a further critical discussion of cultural issues that arose from the field work.

Part Three offers a formulation of a constructive theology of disability and consists of five chapters including the conclusion. Chapter 7 provides a comprehensive discussion of the issue of suffering, exploring the nature of evil and whether suffering can be said to have any redemptive qualities. Chapter 8 offers an equally thorough exploration of the subject of personhood drawing on psychological, sociological and theo-anthropological perspectives, among others. Chapter 9 sets out some tenets of an emancipatory model of church drawn first, from an exploration of black, feminist, and Latin American liberation theologies. Chapter 10 then moves into a formulation of an emancipatory model of church that can foster full inclusion for believers with intellectual disabilities, identifying the need to challenge the *status quo* and to reconceptualise the church as a place of reflection and hospitality where grace is an essential commodity and where reciprocity is the norm. Chapter 11, looks at the implications of this research for the institutional church and addresses a challenge both to the institutional church and to the Disability Movement. It examines both the implications for further research and limitations of the research. Finally, it concludes with some practical recommendations.

1.5 Findings

My first aim was to locate Christian theology and praxis in the context of the secular debate. While praxis was better than anticipated, for a deep love and regard for disabled people was evident at both sites, its theoretical underpinnings were poorly articulated. There was some evidence that there had been some reading on disability and the church, as it evolved four decades earlier starting with the work of David and Madeleine Potter (1993/1998). Yet awareness of new models of disability which had superseded the medical model, notably the social model, and the minority culture model, was patchy and this led to a lack of fit between the praxis and the theory in most cases. One church had started out by doing a course with their helpers

specifically designed to surface negative attitudes towards disabled people and to weed out any unhelpful responses, or the helpers themselves if unable to move forward. All helpers and leaders at both sites flatly rejected any notion that disability was evidence of some hidden sin. No Old Testament ‘clobber texts’ were alluded to and many mentioned the fact that Jesus in John 9 clearly rejects the folkloric link between disability and sin. Although both sites were Evangelical there was some evidence of leaders drawing on the work of Catholic writers such as Henri Nouwen and Jean Vanier, yet no-one named any of the key people in the secular Disability Movement or indeed key Christian writers like Nancy Eiseland. The need for a holistic understanding of the church in relation to people with disabilities, including those with intellectual impairments, was uncovered.

The second aim was to conduct some empirical research to test the claims of the Disability Movement that Judaeo-Christian theology is essentially oppressive of disabled people. Contrary to expectation, the field work revealed a surprising level of inclusivity in churches towards people with intellectual impairments. This can be accounted for by the fact that the key players were mature Christian people who, over decades, had internalised and lived out the values of the Gospel which has been noted are thoroughly inclusive and mindful of all on the margins of society. Furthermore these people displayed an impressive level of practical wisdom in their dealings with intellectually impaired persons. One leader explained that the work with people with intellectual impairment had begun during a mission to the town shortly after the introduction of ‘Care in the Community’ where counsellors were concerned that a lot of people who seemed impressionable were coming forward and they sought advice how to be careful not to unwittingly exploit them in any way. However, in some cases there was a need to consciously move beyond a tendency to regard people with intellectual impairments as children, and this tendency could be said to be oppressive. Nevertheless there were also examples of people being highly aware of this historic tendency and displaying a profound resistance to it. Being the first piece of empirical work of its nature this is a new piece of knowledge.

The third aim was to consider the implications of the research for the development of Christian theology, it was evident that there were rich theological resources which were informing practice albeit at a subconscious level and that there was room for

development along theological lines of inquiry, especially with reference to issues of suffering, personhood and emancipation. In this way it was identified that the Church, far from being the root of the problem for disabled people, was in a position to develop its reflexive practice and become a front runner in the discourse on disability, going beyond the secular Disability Movement, with regard to emancipatory goals. The Disability Movement could be said to have hampered itself by a wrong reading of Judaeo-Christian theology. As Wertlieb rightly points out some of the key people in Jewish history were themselves disabled: Issac was blind, Leah was partially sighted, Moses had a speech impediment, and further Jacob became physically disabled as a result of his ardent pursuit of God. Furthermore much recent work is being done from the perspective of liberation theology (Hannah Lewis 2001; Nancy Eiseland 1999; Jane Wallman 2001 to name but a few), a movement that the Disability Movement seems wholly unaware of, despite the fact that critics often regard the two movements as Marxist in flavour.

2. THE HISTORY OF DISABILITY AND CURRENT MODELS

‘The history of disability is critical to understanding the contemporary situation.’(Scott 1976:47)

On the basis that we also need to look at where we have come from in order to see where we are going (Waite 1995:1), we will now consider the historical situation for disabled people.

2.1 History of disability

Disabled people may be viewed as the largest minority group and the most marginalised people group in the world (Dicksen 2004). It is estimated that in Britain there are approximately 8.2 million people with an impairment and 500 million worldwide and the issue is pressing as these figures are set to rise in the coming decades (Barnes, Oliver & Barton 2002:2)

After some general observations about attitudes to disability, I will look at the history of disability from early civilisations: commenting on the differing perspectives of the classical and Judaeo-Christian worldviews, then charting the history through the medieval era up to the modern era and into the present day.

Recent attitudes

Since the 1970's there has been a significant move away from the representation of disabled people by charitable organisations who spoke for disabled people towards self-determination and self-advocacy. The current social movement of people with disabilities which took off in the 1970's seeks to challenge oppression in terms of attitudinal, organisational and environmental barriers which throughout history have forced disabled people onto the sidelines of society. The aims of the Movement are to produce cultural and structural shifts to enable people with impairments to fully take their places on the social landscape invested with all the same rights and opportunities as their non-disabled peers (Dowse 2001:123).

The International Disabled People's Movement politicised disability (Davis 1993; Driedger 1989; Oliver 1990a) and since that time a number of academics, some of whom are themselves disabled, have reconceptualised disability as a complex form of social oppression (Oliver 1986). Analysis has moved from a focus on individuals and their impairments to a disabling society which erects physical barriers in addition to oppressive social attitudes and values (Finkelstein 1980; Oliver 1983; Oliver & Barnes 1991). The institutional oppression of disablism is not dissimilar to racism or sexism or heterosexism (Barnes 1991; Vernon 1998) although, of course, it may also intersect with any or all of these. However, this academic group may have further marginalised people with intellectual impairments, creating something of a hierarchy of disability with intellectual competence at the top. Interestingly though, some prominent intellectual Christian thinkers who write on disability, including, Stanley Hauerwas, Frances Young, John Swinton, Jean Vanier, Henri Nouwen and Hans Reinders have championed the cause of people with intellectual impairments especially arguing for their centrality in the Christian Church.

It has been argued that The International Disabled People's Movement is the last human rights campaign⁶ (Driedger 1989), the aims of which have been summed up in an adaptation of a well-known phrase 'to boldly go where everyone else has gone before.' (Abberley 1996:159) and this goal is, perhaps, epitomised in the Movement's demand for independent living. The movement in this country consists of issue-specific lobby groups, direct action coalitions and a network of grassroots organisations, all run by disabled people themselves under the leadership of the British Council of Disabled People (BCODP). The British Council of Disabled People is the British arm of The International Disabled People's Movement. As Britain's national umbrella organisation for groups controlled by disabled people, it has 130 member groups in England, Scotland and Wales. (BCODP home page accessed January 2011)

In line with rejecting a passive and tragic view of disability, some new developments have included: acts of civil disobedience carried out by people with impairments, and

⁶ Mike Oliver, in a 'comradely way' takes issue with this claim as he insists 'in capitalist societies, there can be no last civil rights movement, for the struggle is constant and rights constitute part of the terrain in which conflicting and contradictory forces constantly battle.' (1990b:94)

the advent of the Disability Arts Movement which has been instrumental in creating a more positive image of people with impairments. The Disability Arts Movement is seen as one of the most progressive developments for disabled people, to date, as according to Hevey (1993:229) it is the first sign of a post-tragedy disability culture and is addressing the cultural vacuum created by this paradigm shift.

Since it is impossible to pinpoint the exact historical factors influencing attitudes to disability, [not least because the voices of disabled people in history are largely silent (Garland 1995)] a number of suggestions have been advanced. One important view is that our perception and attitude to impairment and disability is heavily influenced by a deep-seated psychological fear of the unknown, the 'abnormal' and the anomalous (Douglas 1966).

Two other factors have been thought to be salient, the economy and culture (Barnes 1996; Abberley 1996). With regard to the economy, capitalism and in particular, the Industrial Revolution have been thought to be key elements in the segregation of disabled people. However, Barnes (1996:51) says 'there is evidence of a consistent bias against people with impairments in western society prior to the emergence of capitalism.'

Early Civilisations

Blind cleric, Jane Wallman (2001) cites some interesting points from early civilisations. She refers to cave paintings thought to date back to as long as 30,000 years ago, depicting the community's strongest and fittest warriors. What is of interest is that juxtaposed with these symbols of strength are human beings transfigured, part human and part beast; some with additional heads, wings or malformed feet (Wallman 2001:47) Furthermore, ancient Babylonian tablets depict humans engaged in ritual practice who appear to have congenital defects. However, this is counter intuitive as in Babylonian society the birth of a defective child was generally regarded as an evil omen for the family. Wallman (2001: 49) claims that 'fostomancy and teratoscopy (examination of foetal remains and defects in a born child as forms of divination) were used to discover the deeper relevance of the birth

of the deformed child for the society at large and the family itself. As is typical in pre-scientific thought, the sex act is seen to be the source of the problem; in this view the adequacy or excess of the supply of semen at conception is thought to result in variations of form. Other related views include the notion that a shock received by the mother during pregnancy was the reason for deformity. Wallman (2001:52) concludes concerning Greco-Roman culture

The value system of the democracy we have inherited was founded on concepts of order and degree; balance, symmetry, images of perfection and beauty. Disablement, by its nature, is the antithesis of much that was held precious in Greek and Roman culture, for it encapsulates dependency, uncertainty and weakness.

The Classical Worldview

Regarding culture, the foundations of western 'civilisation' were laid by the ancient Greeks (Barnes 1996) which would account for this bias in western society. The Achievement of the Greeks in terms of philosophy, arts and architecture has had a profound effect on western culture. The lack of access for people with mobility-related impairments that we have been aware of until recently, had its origins in the influence of Greek architecture on building design in Europe and America (Davenport 1995) Another insidious factor which Barnes warns is often overlooked (1996:52) is the fact that the Greek economy which was based on slavery, was hierarchical and violent in nature. Although the Greeks are credited with asserting citizenship rights and the dignity of the individual, these were never intended to be universally extended either to women or indeed to any non-Athenians.

Furthermore, in this society physical and intellectual fitness was highly prized so there was understandably no room for anyone with a bodily imperfection or flaw. Garland (1995:viii) in his study of deformity and disability in the Greco-Roman world comments

...in the major arts the Greeks, and, to a lesser degree, the Romans present to the outsider's gaze an image of physiological perfection which is so consistent and unwavering that it virtually denies the possibility of the accidental and true-to-life deficiencies of authentic human anatomy.

Yet, previously he notes that 10% of the population were affected by disability from an early age (1995:vii).

The concept of stigma comes from the Greek custom of marking or burning a person to indicate they were a slave. Hevey (1993:117) says that ‘the aesthetic construction of a part or parts of the body as the site of all that is socially unacceptable, a flaw, began life within classical Greek theatre (Boal 1989) and has continued today. The Greek obsession with bodily perfection led to some excessive measures which were infanticide for children born with impairments or indirect infanticide through exposure to the elements as practised in Sparta where it was actually a legal requirement. (Tooley 1983; Garland 1995). The Greek gods and goddesses were the models which all were encouraged to emulate and notably there was only one, Hephaestes, (the son of Hera and Zeus) who was flawed. Zeus effectively practises infanticide by banishing him from heaven.⁷ Later when the Romans conquered Greece they adopted its cultural legacy (including infanticide) and so as the Roman Empire expanded, the worldview spread.⁸ For an exploration of disability in cross-cultural context see appendix 4 as space does not permit its inclusion in the main text.

Judaean-Christian perspectives

The Judaean-Christian worldview rests on belief in an infinite and personal God who has spoken directly through the Old Testament prophets and revealed himself fully through the person and teachings of Jesus Christ. The knowledge of God held by the Jews and Christians rests on revelation rather than on speculation. They have always lived by values which are absolute, which brought the early Christians into bloody conflict with Rome as they refused to worship Caesar as God, insisting that Jesus Christ alone is to be worshipped.

⁷ The rest of his fate has implications for some of society’s assumptions about disabled people and sexuality.

⁸ According to Barnes infanticide was actually a norm in Britain right up until the Victorian era when it was finally eradicated as a result of a rise in Christian morality (Barnes 1991:16). The New Testament improved concerns for the welfare of children.

Some Biblical texts are open to very negative interpretations and many writers caution against mere surface reading of those texts. The Bible is a plural text (Norman-McNaney 1998) as are many other sacred texts and theologian Amos Yong (2007:42) cautions

...a redemptive theology of disability for our time has to go beyond a mere surface reading of scriptural texts on disability (because the plain interpretation of those texts has over centuries been oppressive to people with disabilities) and set them within a wider, biblical and theological – even pneumatological horizon.

The wider horizon is so vital to good pastoral interpretation in all contexts. In addition, as Jewish psychologist Ellen Wertlieb shows, a deeper understanding, can sometimes throw up some very unexpected interpretations.

Wertlieb takes seriously the claim, assumption even, that Judaeo-Christian thinking has given rise to a negative construction of disability. It is popular to make such claims,⁹ yet, Wertlieb states that these claims with regard to disability have never been systematically researched and she sets out to conduct an in-depth analysis of Talmudic sources and finds the evidence to be very far from conclusive of those claims.

Wertlieb (1988:193) starts the debate with a startling and incontestable fact,

This stress on being 'unblemished' is an enigma in light of the fact that many of our Jewish heroes were, in fact, disabled. Issac, for example, was blind during most of his adult life; Leah was visually impaired (Henkin 1983) and Moses had a speech impediment (Gruber 1986)¹⁰

A further difficulty arises regarding our assumption that anything to do with priesthood is connected with privilege and therefore desirable.¹¹ Wertlieb (1988:193) shows us the Hebrew understanding of the priestly office.

According to the Talmud 'they who sacrifice are regarded the same as those which are sacrificed (Zevahim 16b). Since this statement suggests that the priests are regarded as objects, it can be argued that they are not, in fact, being treated on a higher level than individuals who have disabilities.

⁹ Eiseland notes that criticisms 'fail to acknowledge a growing movement of people with disabilities who have begun to articulate a liberatory theology of disability.' (2002)

¹⁰ This list does not include Jacob who startlingly *becomes* disabled as a direct result of his encounter with God.

The prohibition in Leviticus 21:16-17 'No man of your offspring throughout the ages who has a defect shall be qualified to offer the food of his God.' must be read through this understanding.

However, Wertlieb looks at the Talmud and how the Rabbis were inclined to interpret the Torah and rule on that basis and the practices uncovered offer some refreshing surprises. Wertlieb (1988:206) unpacks the practice and regulations regarding blind people serving as judges. She surmises that the practice of Rabbi Shesheth to accept such evidence was most likely motivated by his own experience of blindness and his consequent struggle for equality. The presence of blind Talmudic Rabbis at these debates is also seen as having a positive impact. (Wertlieb 1988:206)

While discussing matters relating to people with visual impairment, notably Rabbi Shesheth, Wertlieb tells a story which underscores the right for blind people to be self-determining - even against divine agents it would appear. Rabbi Shesheth, who was blind, refused to yield to some ministering angels. He felt pressured to do as the angels wished. In his distress, the Rabbi turned to the Schechinah¹² who instructed the angels to leave the Rabbi alone. (Talmud, Megillah 29a) (Wertlieb 1988:205)

Having largely absolved Hebrew texts from the accusation of disablism, Wertlieb concedes that while in the Talmudic discussions disabled persons are not regarded as inherently bad, nevertheless bad people are sometimes portrayed as disabled (as continues to be the case in the secular media today (Tom Shakespeare 1997 and others)).

If it is concluded that the Hebrew texts are not discriminatory of disabled persons *per se*, what then could be the reason for this emphasis on physical perfection? Wertlieb, characteristically has two important things to say on this based partly, on an in-depth analysis of the Hebrew language. Numbers 25:12 is controversial for translators as it can read 'covenant of peace' but equally can be translated 'covenant of perfection'. Wertlieb points out that it is likely that the two terms have been conflated for the root

¹² A visible sign of God's presence.

for Shalom (peace) and schelmut (wholeness) is the same namely, SH-L-M; there being no vowel sounds in written Hebrew. She argues therefore that the unblemished priest symbolises the power which enables us to overcome our differences and impairments - a power that we all have and have need of. Essentially it is about the freedom we have to establish new personal identities (Omer-Man 1984). From her psychological background she links this to Maslow's hierarchy of needs.

...the unblemished priest can be viewed as representing an inward striving that we have to be 'whole' human beings. This physical symbol of 'wholeness' may signify what Maslow (1968) describes as the human need to become self-actualised and develop one's potential so as to live a rewarding and fulfilling life.

I now look at the figure of the historical Jesus and the Gospel accounts which have sometimes been problematic for the Disability Movement.

Historical Jesus and disability

In this first section I will consider the historical figure of Jesus Christ and his praxis regarding inclusion. This will be explored in the context of first century Judaism and the Jewish tradition.

The Jewish world was a theological patchwork, although there were some consistent themes, notably, the nature of holiness. The prophetic writings of the Old Testament especially of Isaiah depict a view of YHWH as inclusive and universalistic, reaching out with salvation to the ends of the earth, (Isaiah 49:6). Nevertheless, some other parts of the Old Testament, for example, the books of Ezra and Nehemiah focus on the exclusivity of God's covenant with Israel. At the time of Jesus, Judaism was struggling with the issue of how to reconcile exclusivism and inclusivism.

Furthermore, the world into which Jesus was born was dominated by four main groups: Pharisees, Priests/Sadducees, Zealots and Essenes. The Zealots mounted an armed resistance to Rome while Jesus made clear, when Peter cut off the ear of the soldier during his arrest, that violence had no place in his kingdom (John 18:10). The Essenes sought to withdraw from society waiting an apocalyptic end that would deal with their enemies. The Pharisees and Priests/Sadducees shunned contact with the

masses for reasons of ritual purity, believing the ‘ends of the earth’ to be a place of chaos, in sharp contrast to the Temple. The Pharisees and Sadducees/Priests all sought ritual purity, the former through obedience to the Torah in the synagogues and the latter through cultic obedience in the Temple. Although Jesus confirmed the permanence of the whole Torah (Mt 5:17-19) he was more interested in adhering to the deeper meanings than a mere conformity to a surface understanding of the requirements of the law. (e.g. Jesus remarks on adultery Mt 5:28).

(Wright 1996:36) describes the society of the Pharisees as ‘angrily insisting on its own purity towards outsiders’. Theirs was a strict adherence to surface matters which led to a form of nationalistic xenophobia. Interestingly, the word ‘sinner’ was itself a term used primarily by the Pharisees and refers to those who ‘did not accept in practice the Pharisaic programme of holiness for Israel and could not be trusted with tithing and cleanliness (Borg 1995:84). Jesus enraged the Pharisees because he was proclaiming this extravagant welcome to himself as pivotal to the coming Kingdom (Wright 1996:38), in marked contrast to the elitist expectations of the Pharisees. Both the Torah which was the law of the priests and the Dead Sea Scrolls of the Qumran Community revealed the practice of excluding people with bodily imperfections (Lev 21:18)¹³ (1QM 7:4-6). Qumran aimed to create a restored community by excluding people with disabilities (Wright 1996:46).

The inclusivity found in Isaiah appears to have been forgotten by these main groups but significantly, not by Jesus. The inclusivism of Jesus was very much concerned with returning people to the circle of fellowship within the community. When he healed the man with leprosy (Mark 1:44) Jesus sent him back to the temple to offer a sacrifice thus drawing him back into the practices that the Torah indicated and from which he had been excluded while leprous. This appears to be the main thrust of many of the healings that Jesus performed. He demonstrated *philozenia* (love of outsiders) demonstrating a radical openness to others: speaking with women as seen in (John 4) the Samaritan woman and (Mark 7:26) reaching out to the Syro-Phoenician woman; engaging with gentiles as in (Mark 5:1-20) the Gadarene demoniac, enjoying table fellowship with sinners and befriending tax collectors

¹³ See Ellen Wertlieb in this chapter for a discussion of the complexity of interpretation of some Jewish texts.

(Mark 2:13-17). Jesus differed in his values from all the main Jewish groups: he upheld non-violent resistance only, engagement with the world, rather than withdrawal, he practised acceptance of outsiders and freedom from oppression to insiders (Wright 1996:39) and a concern for absolute personal integrity rather than a superficial appearance of holiness. Since Jesus' own holiness was not based on surface matters he happily mixed with outcasts thus making himself ceremonially unclean. His holiness was so intrinsic that he did not fear contamination, rather when Jesus touched someone unclean (e.g. lepers) they received his wholeness.

Luke's Gospel with its beatitudes and woes (Luke 6:20-26) reveals a 'preferential option for the poor', but Jesus seems to involve himself with some notably rich people, thus ruling out the most obvious interpretation of 'the poor'. After a full exploration of the possible meanings, Green states 'in the Third Gospel, 'good news to the poor' is pre-eminently a gracious word of inclusion to the dispossessed, the excluded.' Economic matters are seen to be less significant than issues of status and honour. (Green 1994:69).

From this it can be seen that most of the Jewish groups were exclusive while Jesus practised a radical inclusivity. Jesus is reported to have healed a good number of people. Borg (1995:55) notes 'the stories of his healings shatter the purity boundaries of his social world' We are ready now to turn to the important related issue of Jesus healings and the issues they bring out in relation to the contemporary disability agenda: namely, why was it necessary for people to be healed rather than simply being accepted as they were?

Post-colonial disability theologian, Sharon Betcher (2007:79) objects 'there's something about that healing touch of Jesus and its ability to disappear us that persons with disabilities have come to suspect, especially in terms of using us for its own narrative conclusions'. This critical reading of Jesus' healing miracles is not supported by the theological understanding of the significance of miracles found in the Gospels. In Mark 2:9 we find the story of Jesus healing a man with palsy. He says 'your sins are forgiven' and then 'take up your bed and walk'. At first blush this

story appears to forge the popular link between sin and disability which is understandably objectionable. However, Tim Keller (2010:28) suggests that Jesus is highlighting that we all need to be freed from the power of sin even if we are otherwise fine. Seeing sin as the real problem is a universalising response which does not put people with impairments in a different league to the rest of humanity.

Furthermore, in the healing narrative of the blind man in John 9 Jesus *expressly refutes* the forkloric link between sin and disability when his disciples ask him to comment on whose sin has brought about the man's infirmity. However, the rest of his answer 'so that the work of God might be displayed in his life' raises new objections: the usual ableist interpretation of this is that Jesus is using the man's blindness as an opportunity to display his power. Nevertheless, some believers with impairments, notably Grant (1998:84) regard Jesus statement 'that the son of God might be glorified' as indicating not so much the healing of the man but his transformation into a disciple. 'We can see him as an ordinary human being moved to witness to Jesus Christ in the service of God' (1998:86).

In Mark 7:25-30 Jesus reaches out to the Syro-Phoneocian woman healing her daughter. The fact that he appears to call her 'a dog' (a common insult used by the Pharisees towards the gentiles) does not imply disrespect, for the word Jesus uses is a diminutive form meaning 'puppy'. Jesus is speaking in parables and the woman gets the point that in families, the pets eat too, but not before the children have eaten (Keller 2011:87). Jesus is demonstrating the inclusive view of Isaiah for salvation to be first to the Jews and then to the gentiles: a point made in the version found in Matthew's Gospel (15:24) Jesus may want to observe an order here but no-one is to be denied their requests. As a woman and a gentile she is a double outsider, yet Jesus shows her kindness and compassion. Some have commented on the healing of the profoundly deaf man in Mark 7:31-37 as making most sense if Jesus is using a form of sign language: putting his fingers in his ears and touching his tongue. Also taking him aside from the crowd shows sensitivity to the likelihood that the man is used to being made a spectacle and Jesus is refusing to re-abuse him in this way.

Many current objections to the healing narratives involve an anachronistic reading, reading back into the texts of the first century a modern concern with the cult of

normalcy which is intrinsically linked to capitalist societies and thus involves an overlay from the 19th and 20th centuries onto the texts. It is important to note that for the early Christians miracles were indications of the advent of the messianic age and a sign of the restoration of right relation of an individual with a community, with God and not least with themselves thus making inclusion possible. Jesus is interested in restoring people to the circle of fellowship where they can flourish.

Historically, Jesus shows a remarkable concern for inclusivism that is reflected in the ideals, though by no means always the practices, of the Christian church. The Kingdom of God is an inclusive community: God's love and grace breaks all boundaries: national, cultural, gender, disability etc as Paul strikingly writes ' In Christ there is neither Jew nor Gentile, neither slave nor free, nor is there male and female, for you are all one in Christ Jesus. (Gal 3:28).

We see from discussion so far, that Judaeo-Christian thinking is not disablist *per se* yet when we come to the Medieval era we will find a different situation on account of an unholy alliance between classical thought and a Judaeo-Christian worldview.

The Mediaeval era

Finkelstein (1980;1981) while wanting to trace the origins of attitudes to disabled people rather than charting an exact history, gives one of the most compelling explanations of how disabled people came to be segregated from everyday life. He claims that before the industrial revolution, disabled people were easily accommodated in the pastoral life of a feudal society. This meant they were integrated within their communities having a number of legitimate social and indeed economic roles which included 'the village idiot' or 'beggar', (Oliver 1993:51) roles which subsequently disappeared. They were part of an undifferentiated mass of poor (Borsay 2002:103) but not excluded from their non-disabled peers. However, mechanisation changed the way of life completely. Equipment was designed for use by a 'standard' operator so that people with impairments found themselves increasingly excluded from the workforce and the social milieu. Also the pace of work was less amenable for disabled people. Ryan & Thomas (1980:101) note

The speed of factory work, the enforced discipline, the time-keeping and production norms – all these were a highly unfavourable change from the slower, more self-determined and flexible methods of work into which many handicapped people [sic] had been integrated.

Borsay (2002) argues against the assumption that life in pre-industrial societies was more accommodating for disabled people and takes issue with Oliver, Finkelstein and Gleeson for suggesting it to be the case (2002:102). Borsay (2002:104) quotes a Quaker cloth merchant in 1714 promoting the work ethic and concludes 'Given such espousal of the work ethic, the pre-industrial labour market may not have been very hospitable to impaired participants.'

As has been seen, in the ancient world the classical and the Jewish worldviews were very different, the Greeks being preoccupied with pleasing the capricious gods, who had no concern for humanity, using them as mere pawns in their games; while the Jews were in a covenantal relationship of love with the creator God who had made them in his own image and called them as a special people. This was not in order for them to lord it over other nations but to be a conduit of love and mercy to the whole world. The fact that this has not always been the reality and is still not so, most notably in modern day Bethlehem, does not take away from the divine intention. We turn now to the medieval synthesis.

In the medieval era, two prominent theologians sought to create a synthesis between Christianity and the Classical worldview: Aquinas merging Christian thought with the Work of Aristotle and Augustine¹⁴ melding Christianity with Plato. It could be argued that much of the liberatory thrust of Christianity was lost in the Medieval synthesis. Medieval Christianity strayed from what had been handed down by the Apostles and taught by the Church Fathers. As we have seen Greco-Roman culture held a very negative view of those disabled from birth. Aristotle introduced the spurious idea of inferior and superior human beings. Critics of Christianity tend to have a medieval model in mind when they lay all the ills of the modern world at its door. However, we must bear in mind that Western culture, which critics often conflate with Christianity, is built on the classical model and primitive Christianity

¹⁴ The dating of the medieval era is controversial but some cite Augustine as the first philosopher of the period (Britannica internet guide selection).

shared the Oriental influences of the Jewish culture, and thus is more Eastern than Western.

Our goal here is to recover the purity of that original Judaeo-Christian vision rather than to jettison it and embrace a secular model which will not be able to deliver as it cannot address the core issue of the human heart and its need of radical reform. Trinitarian Christianity presents a God who embraces humanity in its rich diversity and is able to radically transform persons so that they too can embrace each other in their manifold differences.

Up to and including the Victorian era

With regard to English history, the exclusion of disabled people from familiar settings co-incident with the introduction of segregated institutions and asylums which was to deal with the 'extra'¹⁵ population (Drake 1999; Barnes 1991). Drake (1999) notes that in an inventory of pre-1900 legislation containment, which was a Victorian rationale for dealing with disability, is shown to be the primary goal. A further negative consequence of industrialisation was the separation between work and home which caused the boundaries of family obligations towards disabled people to be redrawn. Sadly, in this situation the emergence of asylums and workhouses met a legitimate need among poor families who now more than ever before were in danger of being overwhelmed by the burden of care (Oliver 1990a; Ignatieff 1983).¹⁶ Oliver also notes that a further consequence of this social separation was that 'disability became a thing of shame' and that the process of stigmatisation was a catch all affecting the 'deserving' and the 'undeserving' alike. (1990:34)

A statute in 1388 mandated local officials to differentiate between the deserving and the undeserving poor. Nevertheless, although people with impairments were among the deserving poor they were not really separated from the rest of the community of poor. (Barnes 1991).

¹⁵ caused by immigration as a result of wars and poverty.

¹⁶ It is probably from this point where men worked outside the home and women were confined to it that the assumption that women would care for disabled family members arose and this is a feminist issue which we will come to later and which is divisive within the disability movement.

In the 16th century the church became poorer and weaker on account of a series of unsuccessful political confrontations with the monarchy. Also an increase in the vagrant population in England due to poor harvests and the plague and immigration from Ireland and Wales led to an increasing demand for charity (Stone 1985). The Tudor monarchs were obliged to make some economic provision for those dependent on charity and the 1601 Poor Law Act was the first step in recognising a need for the public authorities to intervene in the lives of disabled people (Barnes 1991).

The 18th and 19th centuries were marked by an intensified oppression of disabled people and Barnes (1991) quite logically, attributes this to the prevailing ideologies of the era which emphasised the rights of individuals over the group or state, in relation to culture, politics and property rights (Macfarland 1978). The publication of Darwin's *Origin of Species* in 1859 was sometimes used to provide a 'scientific' authentication. On Darwinism, Barnes (1991:19) contends that 'it had an understandable appeal to a society dominated by a relatively small elite of property-owning, self-interested, 'rational' individuals who welcomed any opportunity to justify their newly-acquired wealth, status and power.'

This 'scientific' view was swiftly applied to human societies and 'social Darwinism' provided the justification not to assist the disadvantaged as their sufferings were seen as the inevitable outcome of progress.

The 1868 Poor Law Amendment Act allowed for any deaf and dumb child or blind child to be sent to any school suited to their needs. In 1885 The Royal Commission on the Blind, Deaf & Dumb was set up and four years later it reported that this provision had not been acted upon and that there was an evident lack of compulsion due to education being regarded as a charitable concession rather than a duty. As a consequence of this report in the early 1890's Education of Blind and Deaf-Mute Children Acts were passed in Scotland, England and Wales. Schooling was then later extended to include disabled children with less visible impairments e.g. epileptics.

In an enlightened move The Royal Commission stated that if poor families were unable to provide for the cost of education for their disabled children then the responsibility should fall to the school board of the parish to pay out of the school

fund for the necessary elementary schooling. Drake (1999) notes that this position indicated a shift in Victorian policy as no longer was containment seen as the only appropriate response to disability but now philanthropy and compensation were coming in to play. Some of the Philanthropic institutions had names such as: 'Guild of the Brave Poor Things,' 'The Crutch and Kindness League,' and 'The League of Hearts and Hands'. Those who were drawn into such establishments were the luckier ones as others continued to become victims of the Poor Law being forced into the workhouse, or those who were homeless could be imprisoned under the vagrancy laws (Drake 1999:47).

One further move in the Victorian era that Drake (1999) claims was related to disability was legislation introduced to deal with the disabling consequences of accidents with machinery. In 1897 and 1900 there were Workmen's Compensation Acts which held employers legally responsible to compensate their employees for industrial accidents. Other measures sought to regulate the use of dangerous machinery such as the Chaff-cutting Machines Act of 1897. Under Victoria's rule aid was offered to disabled people in very limited ways and injury at work was one of the prime contexts for help. However, one could argue that these acts were aimed at protecting the interests of able-bodied people who may incur disability rather than offering support to disabled people *per se*. However, one area of support for disabled people, as we have seen, was the provision of elementary schooling but even this was a mixed blessing as it was through education policies that disabled children first came to be segregated from their non-disabled peers. In 1890 the Education of Blind and Deaf-mute children Act (Scotland) made provision for separate schools to be built. The Education Act of 1921 obliged parents to make use of these specialised schools.

Furthermore, people with cognitive impairments fared particularly badly as between 1837-1901 there were in excess of 20 measures addressing insanity.¹⁷ The Lunacy Legislation of 1845 empowered doctors to dictate where people with mental health needs could live and to move them around against their will. Barnes (1991) traces the dominance of the medical profession in all aspects of disability back to this point. In

¹⁷ Today learning disabilities would be regarded as distinct from mental health needs but when the term was mental handicap it was incorporated into insanity.

1886 the term 'idiot' was formally introduced for such people in the establishing of the Idiots Act. In 1896 the National Association for the Care and Control of the Feeble-minded was set up as a pressure group for the life-time segregation of people with mental impairments. The invention of Intelligence Quotient tests by the French psychologists Binet and Simon and their widespread use worsened the situation as leading psychologists, notably Cyril Burt, made strong assertions to the effect that IQ was innate and therefore fixed and that 'the majority of defectives were ineducable' (Barnes 1991:19). Children with mental impairments were excluded from schooling under the 1944 Education Act and it was not until 1970 that an Act was introduced to give the right to an education to children with special educational needs.

The Modern Era

The advent of the two world wars also produced a shift in thinking about disability. After the First World War 1.5 million British soldiers had been weakened either through being wounded or the effects of gas, more than 40,000 of them returning from the French battlefields as amputees (Taylor 2001). The collective national guilt felt towards those who had become disabled in fighting for their country led to new measures characterised by compensation. However, in the plethora of provision for injured ex-soldiers, disabled civilians found their needs displaced especially in the search for work, accommodation and health care (Drake 1999) by the new priority given to what I will call 'the formerly able-bodied.' A clear example of the discrimination that existed was in the provision of artificial limbs. If the limb had been lost through war or an industrial accident then a better quality item was permitted. Aluminium limbs were routinely reserved for servicemen as they were more costly than the equivalent wooden peg. Again it is difficult not to notice that the priority seems to be towards those who were previously able-bodied rather than to those who had been impaired from birth. In addition, Drake notes that'divisive public attitudes took hold, to the effect that the war wounded were 'unnaturally abnormal' while disabled civilians were 'naturally abnormal'(Drake 1999:50).

During and after the Second World War more acts were passed to further compensate those affected by war. These included the War Charities Act 1940 and the Disabled

persons (employment) Act of 1944.¹⁸ Oliver (1993:53) also upholds the view that this legislation was affected by the level of guilt felt about disabled soldiers and their right to work and he also notes that the bringing in of these legislative measures was influenced by a level of shortage in the workforce.

In the inter-war years a new area of segregation opened up in the advent of orthopaedic hospitals (Watson 1930; Drake 1999; Borsay 2002).¹⁹ Childhood physical impairments declined because of reduced incidence of rickets and tuberculosis (Borsay 2002). A further shift was seen in the focus on rehabilitation. The Disabled Persons (Employment) Act of 1944 introduced a number of innovative measures and was supported by all political parties. It introduced vocational courses and rehabilitation programmes. A register of disabled people was set up in an attempt to encourage employers to employ disabled people. Companies with in excess of 20 employees were intended to employ disabled people to the level of 3% of their staff. However, as with other measures it seemed to lack teeth when it came to enforcing the regulations. Drake (1999) quotes Hansard (1994) which records that as many as 80% of firms failed to meet their obligations and that exemption permits were issued in huge numbers. Furthermore, prosecutions were rarely brought which may indicate how tokenist the measures were. Added to this Hansard notes that 'government departments were among the worst offenders.'(1994: col.564) which again would not indicate very serious intentions on the part of the government. Some very low paid menial tasks, such as lift operator or car park attendant were to be reserved for disabled people. In 1944 the government would have been mindful of the new batch of war-wounded returning from the conflict so perhaps the Act was intended to quell some of the discontent felt by those who had possibly experienced the devastation of two major global conflicts. Not surprisingly, under the 1995 Disability Discrimination Act, the quota, which had manifestly been a sham, was abolished.

¹⁸ The 1944 Act was the first in which disabled people were treated as a unified group (Barnes 1991)

¹⁹ However Watson (1930:vii) writes glowingly and naively of these developments saying ' the wonderful advances of orthopedic surgery have very naturally encouraged in this country of their highest achievement a sense of culmination and the end of a journey.' Elsewhere, (Borsay 2002:113) adults writing of their childhood experiences in orthopedic hospitals write of 'torture' and a feeling of unending torment!

In the early twentieth century there was a gradual increase of political suffrage until by 1929, all British citizens over the age of 21 were entitled to vote provided that they were 'of sound mind'. Walmsley comments (1993:260)

Effectively, in the early twentieth century, many people with learning disabilities were denied both political and civil rights, at the same time, according to Marshall, as those rights were being secured for the populace as a whole.

Walmsley continues: 'While Leach (1991) argues that disabled people are low on the Equal Opportunities shopping list, people with learning disabilities do not figure at all.' (1993:260)

The next response to disability was through welfare-orientated services which in the Victorian era had been provided through philanthropy but began to be provided through the burgeoning social services. This began in 1948 as a result of the National Assistance Act and developed fast in the two decades following. The growth in social services was partly a response to the policy of 'Community Care' (Drake 1999:59).²⁰ One problem with this otherwise positive move was that the private sector was put in charge of service provision and people with impairments themselves were still not in control of the purse strings.

Towards the present day

The Seebohm Report 1968 is generally regarded as a watershed in the development of community-based services for disabled people and its recommendations were built into the 1970 Local Authority act and the 1970 Chronically Sick and Disabled Persons Act. (Barnes 1991). The latter took some initial steps to improve access to the non-disabled world. Local authorities were empowered to offer help in the home through meals on wheels, and structural alterations and also with help for transport and holiday arrangements. They also had to become informed about the number of disabled people in their area and publicize all the services available to them. A further measure was the introduction of the orange badge scheme that facilitated free parking for disabled people. During this decade campaigners fought hard for a

²⁰ a phrase first found in the Report of the Royal Commission on Mental Deficiency 1954-7 (Barnes 1991)

disability income which was seen as the only route to people with disabilities having the same range of choices as their non-disabled peers. Campbell & Oliver (1996:63) see the failure of the campaign as the result of the lobbying being done by non-disabled people without the overwhelming support of disabled people 'on the ground'.

It is surprising to learn that as far back as 1970 there was a legal requirement for public places to be accessible for disabled people and for accessible toilets to be provided. However, the act had an ominous clause which was also present in the 1995 DDA in that it is based on what is 'reasonable' (a term that is nowhere defined). For all the recent commotion for public service providers to comply with the final stage of the Disability Discrimination Act, in October 2004, one could be forgiven for thinking that it had been a brand new initiative.

At the end of the 1970's the outgoing Labour government had set up a Committee on Restrictions Against Disabled People (CORAD). The report published in 1982 found evidence of widespread discrimination, yet the incoming Conservative government was dismissive of its findings. (Drake 1999)

According to Drake (1999:56) in the 1980's social security was 'under a Thatcherite cloud'²¹ and changes were aimed at reducing rather than enhancing provision. As access to social security became more difficult the scramble for jobs intensified. From the end of the 1970's an ideology of welfare pluralism²² took hold which was linked to the notion of Community Care. These two concepts underlined a view that the government alone should not be responsible for providing services but should draw on services offered by other groups, including voluntary organisations. The likely motive behind this policy seems to have been cost-cutting. The move into the community was also a consequence of the end of institutionalisation yet some groups argued for some beds in institutions to remain, especially with the media focus on isolated attacks on innocent people in the community by people with mental health issues. However, people with mental health needs are far more likely to be victims

²¹ Barnes, Mercer & Shakespeare (1999:113) concur with this view.

²² Welfare provided by the public sector, the private sector and through families.

of violence in the community than perpetrators (Bryant & Reynolds 2001:11).²³ Feminists also expressed concern about Community Care as they saw it as a euphemism for unpaid female carers (Beresford & Croft 1984). This understandable suspicion has led to a rift in the disability movement²⁴ as some women have argued for a return to institutionalisation, not necessarily for the sake of disabled people but for the sake of the women who will otherwise have to provide the often onerous care.

At the end of the 1980's the Social Security Advisory Committee produced a report urging the government to adopt a more positive and less punitive position towards disabled people who it confirmed found fewer opportunities for work and a concomitant loss of earning power. From this came a review of disability benefits. In 1991 the DLA (Disability living allowance) and the DWA (Disability working allowance) were introduced. A 'care' and a 'mobility' component were included in the DLA. These were paid directly to people with disabilities and therefore marked a breakthrough as disabled people finally had some control over the services they needed and did not have to operate through an intermediary.

One final illuminating area that should be mentioned is the voting experience of people with disabilities. Barbalet (1988:1) says that citizenship defines who is and who is not, a member of society. Furthermore, Drake (1999) argues that the opposite of citizenship is social exclusion. He says 'In the contemporary Western democratic context, the status of citizen is predicated on the capacity to participate in the exercise of political power through the electoral process.'(Drake 1999:41) Some studies have shown that many disabled people do not even appear on the electoral register (Fry 1987; Ward 1987). Other studies support this fact by revealing that many hospital patients do not appear on the register (Barnes 1991). However, those who are fortunate enough to be on the electoral register have tended to face problems of physical access. Since the implementation of the DDA, hopefully that is no longer the case. However, in 1992 during the General Election as many as 87% of polling booths were inaccessible to wheelchair users (Burns 1997). This figure is all the more startling when set against some figures for the US. There, only 6% of polling

²³ They say 'the reality is that very few (about 4%) of the almost 700 murders in Britain each year are committed by mentally ill people, but this fact is lost in the emotive psycho-killer headlines in the Press.' (Bryant & Reynolds 2001:11)

²⁴ It is divisive as it is argued that disabled people include women too!

booths were found to be inaccessible to disabled people (Scott 1994). In the recent past people with physical impairments were also unable to gain access to the Commons if they wanted to lobby their MP's [(Foley & Pratt 1994) in Drake 1999:90] With regard to MP's there was a long history of exclusion of people with impairments from holding office dating from the reign of Charles II. Around the millennium some changes occurred and there have now been MP's and government ministers with impairments.

The most significant move in the past decade has been the introduction of The Disability Discrimination Act (DDA) 1995 which had a ten year lead in and was implemented in its third stage in October 2004. According to some (Drake 1999:63 McCloughry & Morris 2003:20) the final DDA was considered a great disappointment to many pressure groups and a very poor version of the original civil rights measure that had been envisaged. Oliver also claims that the DDA was opposed by disabled people and Barnes & Oliver (1996) point out the danger of trying to work with the government as it tends to lead to the carrying out of the government's agendas rather than those of the disability movement (Barnes & Oliver 1996:115). This is a rather bizarre point since only the government has the right to enforce its agendas. Three years after its introduction it was revealed that in 850 industrial tribunal cases only 10 had had any success and only four times that had been brought regarding services and goods. However, despite being ineffectual, the Act did facilitate a shift in thinking whereby legislators were able to accept that the lives of disabled people were affected as much by attitudinal and environmental factors as by physiological and cognitive impairments.

The DDA made it unlawful to discriminate against a disabled person in connection with the provision of goods, facilities and services, and with employment. Since December 1996, it has been unlawful to treat disabled people less favourably than other people for a reason related to their disability. Since October 1999 reasonable adjustments have had to be made for disabled people and from October 2004

reasonable adjustments²⁵ have had to be made to physical features of a premises if they constitute a barrier to access. A definition of discrimination is in order here and the EDF states, 'Discrimination occurs when people disregard that disabled people are foremost human beings with abilities and make premature conclusions based on disabled peoples' impairments'(2004:1). Discrimination is seen as a human rights issue. For that reason the Disability Rights Commission has now been formed with powers akin to those of the equal Opportunities Commission and the Commission for Racial Equality. The DDA may have been a disappointment to many but the EDF are campaigning for A Disability Specific Directive at the EU for they say that 'Disabled people look with envy to the legislation in the US (The Americans with Disabilities Act) and want a European with disabilities Act and ask for disability specific comprehensive non-discrimination legislation.' (EDF: policy issues 2003:3).

Having taken an overview of the history of disability we move on to consider some of the various models of disability that have arisen.

2.2 Models of disability

In this section I will look at two of the dominant models: the medical and the social. Under the medical I will look at two models put forward by the World Health Organisation. After this some other models which can be seen as straddling the two major models will be examined. I will attempt to chart each of them on a spectrum between medical and social. These include the alliance model, the overcoming model, the minority culture model and a social-relational approach.

The Medical Model

The medical model has historically been the dominant model. In this model the focus is on the individual and the actual impairment, and the role of society is to 'cure' that person in an attempt to 'normalise' them back into the able-bodied world or remove

²⁵ 'Reasonableness' is never defined and since this is a major bone of contention, the Disability Rights Commission has now published information giving examples of cases which either do or do not fulfil the requirements of 'reasonableness' in order to aid interpretation. (Penton 2001:3)

them from society.²⁶ Historically this has been achieved through the use of institutionalisation whereby control was taken of the person's life. McCloughry & Morris (2002:13) insightfully remark that 'while curing the body they can bruise the soul'. The goal is conformity to the standards of the non-disabled world or, where not possible, then exclusion from that world and to facilitate what Miller and Gwynne (1972) identified as a transition from 'social death to physical death'. Since this medical view has been seen to stigmatise people with disabilities this model is distinctly out of favour with the Disability Movement. Rieser & Mason (1990) state that historically medical interpretations and values have given rise to a view that physical and/or intellectual impairments are the basic cause of disability. In this model the reactions of disabled people to the society and environment that disables them is seen as pathological rather than a healthy response to a multi-layered oppression. This model of disability which positions the individual as dependent and in need of 'care' from others gives rise to a theory of personal tragedy focusing on the individual and the impairment and seeing disability as a tragic loss or waste of life. Historically charities operate out of this model, often depicting disabled people in pitiable and fear inducing ways.²⁷

WHO models

The International Classification of Impairment, Disability and Handicap. (ICIDH)
Another model of disability which some objected was still too close to the medical model was that put forward by the World Health Organisation in Geneva in 1980. This operated in terms of a four part medically based classification, which originated in the work of Harris (1971) who conducted a national survey of disabled people and this work was further developed by Wood (1981). It was called the International Classification of Impairment, Disability and Handicap (ICIDH) The link between the key elements served to attribute disadvantage to nature. Abberley (1996) gives the following example: A complaint, like a spinal injury, causes an impairment, like an

²⁶ The concept of 'normality' is highly contentious as it is seen to be in opposition to diversity. However, the phrase 'normalisation' appears in the disability literature and this refers to the right of disabled people to all the same things in life that constitute a 'normal' life e.g. employment, independent living, sexual relationships, parenthood etc.

²⁷ In the United Kingdom, the multiple sclerosis charity did a television and cinema advertising campaign in the 1980's with horrifying images of a beautiful young man and woman semi-naked, with parts of their bodies being ripped apart like paper. Some people with MS objected as they said the images did not reflect their perception of life with the disease. (Naude 2001)

inability to move one's legs, which disables by leading to the inability to walk, and handicaps by giving the individual problems in travelling, getting and retaining a job. Abberley (1996:61/2) argues that a complaint is ultimately responsible for a handicap. A major criticism of these definitions by disabled people was that they were based on able-bodied perceptions about disabled people and that there is a lack of fit between these assumptions and the personal realities of people with disabilities. Furthermore, the Disabled People's International Movement opposed the ICIDH scheme since its inception for while acknowledging a social dimension to disability it failed to see that it arose from social causes (Oliver 1993:61). Barnes (1991:25) argues that the fact that disabled people were not included in the formulation of this model constitutes a major form of institutional discrimination on the part of professionals. Barnes, Mercer, & Shakespeare (1999:28) prefer the definitions offered by UPIAS (union of the physically impaired against segregation) who were at the forefront of those calling for an alternative to the medical model. UPIAS insists that disability is the result of society's failure to include non-able-bodied people. In its manifesto (1976: 3-4) it largely accommodated the medical view of impairment, regarding it as a lack of some body part but completely subverted the classic view of disability taking a social constructivist view arguing that the restriction of activity is caused by organisational factors where a lack of account is taken of people with physical impairments leading to exclusion from participation in mainstream social activities.

Organisations of disabled people continue to debate 'impairment' and some now argue for its inclusion under 'disability' (Barnes, Mercer & Shakespeare 1999:28). As we shall now see, in response to popular dissatisfaction, the WHO definitions were finally reworked, in Geneva in 2001

The International Classification of Functioning Disability and Health (ICF)

As should be clear, the medical and social models were regarded as irreconcilable, so a further model was sought. Seven years research and global consultation conducted by 65 different nations led to the publication in November 2001 of the International Classification of Functioning Disability and Health (ICF) as the previous WHO definitions were redefined. In some places the ICFDH, or ICF is referred to as the ICIDH -2 (Thomas 2002:42). The significant shift in focus was

from 'mortality' to 'life' (McCloughry & Morris 2003) and the term disability is replaced by disablement. Negative terms were replaced by the wholly positive concepts of activities and participation. This also directed attention to what a person could do rather than what they could not and as such incorporated all persons, for everyone has limitations in what they can do. This model creates a link between impairment and social/environmental limitations. It is a biopsychosocial model, being a synthesis of medical and social perspectives on disability (Thomas 2002:42). Disablements are classified under 4 headings: health condition; impairment; activity limitation and participation restriction.

For clarification the example of spinal injury will be used. For spinal injury the impairment is paralysis, the activity limitation is in use of public transportation and the participation restriction is participation in such things as church activities.(Geneva WHO 1998). In contrast, under the previous framework a spinal injury would be a complaint leading to problems with travel and work. The inability to move would constitute an impairment; the disability would be the inability to walk and the resultant problems with travel and getting and retaining a job would be classified as a handicap.

The social model

In advancing a critique of the personal tragedy model of disability, the disabled people's movement has formulated a Social Model which takes a social constructivist perspective. De Jong (1979) formulated the notion that people with impairments are only disabled in as much as the society around is disabling and presents barriers to a full life. Oliver (1983) himself a wheelchair user and a former Professor of sociology, coined the phrase 'a social model of disability' which has become the dominant paradigm and repositions disabled people as citizens with rights. Writers on disability are unanimous in their agreement that the experience of disability is a very real form of oppression. Barton (1996:8) insists 'being disabled involves experiencing discrimination, vulnerability and abusive assaults upon self-identity and esteem.'

Hahn (1986:128) defines disability thus:

Disability stems from the failure of a structured social environment to adjust to the needs and aspirations of citizens with disabilities *rather than* from the inability of a disabled individual to adapt to the demands of society.

On this basis Oliver argues that the correct place for disability services to be determined would be the Department of the Environment rather than the Department of Health and Welfare (Oliver 1993: 41). Jane Campbell (2002:472), who was previously Chair of the British Council of Disabled People, insists that the social model is the disability movement's main tool for inclusion. In acknowledging that it is much misunderstood she explains pungently that, 'it demands an approach that wrecks the foundations of society's main solutions to our so-called 'problems', rehabilitation, cure, institutionalisation and death.'

The social model, while being welcomed for putting political and social concerns to the fore, has been criticised from within on a number of counts. Primarily here, I want to raise the issue of the failure to acknowledge impairment as a factor which leads to further oppression for disabled people. Abberley (1996:61) objects that it can cast them as victims, not of their impairment but of society, leaving little room for agency or resistance (Watson 1998:150).²⁸ A reluctance to acknowledge impairment as an issue does not help in the development of assistive technologies for when information is sought there is resistance to discussion of impairment as it is not seen as an acceptable focus of attention. For this reason it has been dubbed by (Dewsbury et al 2004) as 'the anti-social model of disability'. A further criticism which could be added to these is that the ruling out of all discussion of impairment and its material reality serves to silence those whose lived experience is that of disability, a feature of which is impairment. Such silencing of people's voices is a serious feminist objection (Morris 1991;1996; French 1993; Crow 1996) and is said to arise from the masculinist perspective of the disability movement 'which has had a tendency to avoid confronting the personal experience of disability' (Morris 1991). Jenny Morris asserts 'we can insist that society disables us by its prejudice and by its failure to meet the needs created by disability, but to deny the personal experience of disability, in the end, is to collude in our oppression.'(1991). It may be helpful to talk

²⁸ Deal (2003:897) Cites Goodley (2001) as identifying a 'second wave' within disability studies which foregrounds impairment and critiques the underlying assumptions of the social model of disability.

in terms of a strong and a weak form of the social model of disability. The model has much to commend itself from a political viewpoint and is clearly more empowering for the Disability Movement. Sally French, a wheelchair user (1993:17) positions herself within this model, while pointing out some of its shortcomings. However, she tells how when she raises the issue of impairment with people who buy into a strong form of the social theory of disability, they tell her that she has internalised the values of the non-disabled world and that she simply does not understand what disability is all about. (French 1993) Not surprisingly, she finds such a response galling and insists ‘that some of the most profound problems experienced by people with certain impairments are difficult, if not impossible, to solve by social manipulation’(1993:17).

There does seem to be a somewhat simplistic tendency within this model, an example of which is found in Oliver’s (1990: 7-8) suggestion for re-writing the questions of a survey conducted in 1986 on disabled adults. His objection to the original question is that it reflects too much the ideology of the medical model putting the main focus on the individual and the impairment. The original question 1 reads ‘Can you tell me what is wrong with you?’ He suggests that a suitable reformulation would be ‘Can you tell me what is wrong with society?’ This gives a very naive impression of the problem yet within the same book we read a rather more nuanced statement: ‘ it [social adjustment] is a complex relationship between impairment, social restriction and meaning’ [(Oliver et al 1988:11-12) in Oliver 1990a:69].

Others who broadly support the concept of a social model of disability object to it being essentialist²⁹ (Shakespeare 1996) and others to its tendency to put all the blame onto society thus making disabled people powerless victims (Lloyd 1996: Morris 1991). Corker, (1999) who is not a great proponent of the social model, objects to its essentialist materialism and the implications this has for her work on Deaf culture and disability. She points out some important dualisms underpinning the social model: the body is split from the mind, socio-economic structure is split from culture, social structure is split from human agency and the social is separated from

²⁹ McCloughry & Morris 2002:10 also insist that the medical model is reductionist.

the individual with his/her experiences. One profound result for Deaf people is that they are marginalised and excluded because their oppression is mediated by language, discourse and communication, which are all issues sidelined in the social model.

Oliver gives some historical background (which we have seen in the previous section) showing how disability became a thing of shame. Lewes Smedes, Professor in the School of Psychology at Fuller Theological Seminary, in his book *Shame and Grace* (1993) explains the dynamic whereby those who are made to feel shame pour out that inner pain in a display of contempt towards those who engender such emotions. The social model of disability may provide that type of cathartic relief for some who have felt overwhelmed by an undeserved sense of shame. Although that may be a valid psychological provision it does not necessarily facilitate dealing with the real life situation.³⁰ However, as we have seen in the history of disability in this country we are left in no doubt as to the reality of that deep sense of shame imposed on people with disabilities and understand the need to be rid of its disabling effects, even if exclusively blaming society may not be an adequate solution.³¹

Furthermore, to put all the blame on society would silence any theological questions for if it is all about the disabling effects of society and nothing to do with impairment *per se* then we have no issues to resolve with our Creator. However, this is not the experience of some believers with disabilities³². McCloughry & Morris (2003:17) also note that this model seems 'to disallow grief and pain.'

Regarding the taboo of discussing impairment, Finkelstein (1981:10) says 'Even disability organisations sceptical about experiments to make disabled people 'normal' do not campaign against the prospect of eliminating impairment.'

³⁰ To some extent, in common with other liberation groups, it could be said that the social model has got 'attitude'.

³¹ Moltmann regards the protest of disabled people against social disadvantaging as an act of love: love of self and of neighbour. (1998:108) so we should not think that this type of protest always comes out of pain and anger.

³² Clive Davies (Deaf lay reader) at a training Day on disability 2004 talks of the initial dilemma his impairment led to in his understanding of God. John Hull (Blind theologian) also presents impairment as problematic in terms of his understanding of himself as a disciple of Jesus. (2004 : 8-9)

In addition, it could be said that the social model privileges people with physical and sensory impairments and some commentators (Dowse 2001; Chappell 1998) have argued that it does not include people with learning disabilities nor does it adequately account for their experiences.³³ Dewsbury et al (2004:101) say that with the exception of Simone Aspis (1999) there has been little contribution to the social model literature by people with learning disabilities.

Critics from mainstream sociology, such as Bury (1996) insist that the refusal to allow a link between disability and impairment 'leads to relativism, and that the reification of structural barriers can serve to create a picture that is as incomplete as a traditional medical perspective.' (In Watson 1998:149)

Carol Thomas in her book *Female Forms: experiencing and understanding disability* brings some very helpful insight into the problem which leads to a stand off between Disability Studies and Medical Sociology. Thomas claims (1999:39) that there is a 'residual equation of 'disability' with 'restriction of activity' in some social modelist writing. She shows how the social model embraces both a materialist view of disability and a social relational one yet sometimes the two are conflated thus producing confusion. She explains how the UPIAS formulation of disability expresses an unequal social relationship between those who are impaired and those who are not. This she sees as a direct parallel to patriarchy which issues from an unequal power relationship in society between men and women with men being in the ascendant position. The concept of disability refers to the relationship of ascendancy of the non-impaired over the impaired. (1999:40) The second definition in use among social modellists is conceptualised by Thomas (1999:41) as a 'property approach'.

It hangs on the notion that disability consists of an individual's restriction of activity, then simply reverses the direction of causality so that social factors are seen as 'causing' these, instead of impairment or chronic illness.

These two distinctly separate concepts are often used as if they were interchangeable.

Thomas (1999:60) advances her own definition of disability which she calls a 'social

³³ As we shall see this is likely to be because of the stress on 'restricted activity' rather than the social oppression that many link disability to.

relational' definition. 'Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing.' Rightly she highlights that disability raises barriers both to doing and to being.

Dewsbury et al (2004:146) offer a further objection to the social model of disability which is relevant to any non-disabled researcher. They are concerned about a different conflation of two similar but distinctly separate ideas. 'arguments concerning the impossibility of experiencing the experience of another are conflated with arguments concerning the difficulty of understanding the experience of another, *for they are entirely different matters*' (my emphasis). A conflation of the two ideas would seem to exclude non-disabled people from disability research and as Dewsbury et al (2004:154) express it, 'this position, that, to put it bluntly, disabled people share a 'culture' that is different and inaccessible to others – is less a finding of research than an *a priori* assumption.' This latter view argues for an ethnographic approach being as valid for studying disability as it is for a foreign culture.

Other models that can be charted on the spectrum of medical to social.

We shall now look at four other models of disability: the alliance model, the overcoming model, the minority culture model and the social-relational 'model', (already touched on in passing).

The Alliance model occupies a middle ground in its attempt to combine the medical and social models. While social modellers tend to see the medical model as incompatible with the social model Jane Brett (2002) argues for an 'alliance' model which aims for a marriage of the best of both models: overcoming the tendency of the medical model to render disabled people as passive objects and the social model's inclination to individualism and capitalist values. Theologian, Amos Yong, (2007:116) argues with others for taking from both models as people with intellectual disabilities do not fit well into the social model. He states

...our religious and theological proposals will certainly draw from the best insights of the social model of disability, but I will also suggest that the latter needs the former to ensure the full inclusion of people with intellectual disabilities in the project of social liberation.

The overcoming model would be located more at the medical end of the spectrum as it focuses on the impairment but in a way which seeks to overcome it and continue life as if it were not a factor to be reckoned with. This model is not favoured by many in the Disability Movement as it is seen as divisive, encouraging people with disabilities not to identify with others worse off. Its aim is to show that disabled people can cope and conform to the demands of the able-bodied world and as such it can lead to a lot of denial. Telethon and the Paralympics, where disabled people with strong upper bodies compete in sporting events, have been strenuously opposed by some disability groups, for they are based on this model³⁴ Primarily it is seen to exist to help the 'temporarily able-bodied' cope with their fear and unease.

In contrast The Minority Culture Model posits that disabled people, like other minority groups are discriminated against through the imposition of the value system of the dominant culture and that they have their own culture of which they are rightly proud. As such this model must be charted at the social model end of the spectrum.

Eiseland (1998:210) identifies a shift from a disability rights model to a disability culture model within the movement during the 1980's and 90's. However, Eiseland (1998:214) is clear that this is contentious stating that ' debates about both the viability and existence of a distinct culture have raged within the movement.' The reason she gives for this is that it is seen as unnecessarily separatist and not palatable to those who advocate integration into the dominant able-bodied culture. Also she explains that organisations which have both disabled and able-bodied people among their constituents, tend to have an integrationist agenda. The failure of religious organisations to even recognise the issue of a distinct disability culture, has caused further division between religious groups and activists. Eiseland (1998:214) notes 'within religious communities, however, debates about the viability and /or existence of a distinct disability culture have been curiously absent.'

A minority culture model is obviously problematic for those who are moving towards an agenda of inclusion. However, it could be argued that there should be no problem if inclusion is envisaged on a different basis from the dominant culture

³⁴ Disabled people who do not have strong upper bodies have dubbed these sportspersons 'supercrips' which is clearly divisive (Abberley 1987)

being uncritically accepted as the norm. Nancy Eiseland (1998:224) has one more word that the church needs to heed in this connection.

the disability movement has at its core contested the moral meaning of disability, declaring people with disabilities to be a minority group with a distinct culture. *Whether or not they agree with this definition, religious leaders ignore the moral implications at their peril* (my emphasis)

In recent times there has been a move towards a social relational model of disability (Thomas 1999; Reindal 2008). Reindal's rationale for the social relational model of disability is that it better conforms to the morality of inclusion because the main issue of the social model, oppression, is not obliterated. He uses a social relational model in response to criticism of 'special needs education' which is objected to on grounds that it draws too much from a medical model of disability. Feminist writer, Carol Thomas advances this model to avoid the conflation of materialist and relational views of the social model of disability, as she sees the relationship between able-bodied and non-disabled people as similar to the patriarchal relationship between men and woman with the former being in the ascendant position of power.

It may be conspicuous by its absence that there is no model of disability universally favoured by theologians. The main models can be seen to emerge from the various historical views of disability and are central to the domain of disability studies.

The medical model can be seen to derive from the classical world view with its passion for physical perfection and a concomitant focus on anything that falls short of that standard. This model is out of vogue with the Disability Movement and is not favoured by this author as it is not compatible with a Judeo-Christian worldview. Critics will argue with this statement on the basis of some isolated texts, mostly from the Old Testament but Jewish psychologist, Ellen Wertlieb, already mentioned shows us how some unfavourable texts have meanings which are far more profound than a surface interpretation would suggest, and Pinnock et al (1994) also teach us that in the western world we have filters from a Classical worldview through which we unwittingly misapprehend much biblical material (see chapter 7). The original vision of Christianity as expressed by Paul in Galatians 3:28 reveals a positive disregard for difference, be it social status, gender or race. While it can be said that

Christianity is gender-blind, for example, it would be ludicrous to suggest that the Christian church is gender-blind.

The social model is not entirely incompatible with Judaeo-Christian theology, as each has an emphasis on the dismantling of unjust and oppressive structures in society, and numerous writers, (Penton 2001; McCloughry & Morris 2003) point out that the Gospel itself incorporates a desire for social justice and inclusion of all people. However, the social model does have limitations as social modellist, Sally French, points out that some of the most profound problems experienced by people with certain impairments cannot be solved by mere social manipulation (1993:17). Furthermore without a radical overhaul of the human heart it is unlikely that manipulating social structures will be sufficient to transform society. For as Volf asserts, and we shall see later, people deliberately misjudge and misperceive others because they desire to exclude (1996:68).

This thesis moves towards a relational view (not a model. *per se*, as this Enlightenment concept must be internally consistent and externally coherent in order to exist, and is impossible to square with the mystery of the Trinity) In the final analysis Christians working through a theology of disability are better placed to opt for a narrative theology³⁵. So a relational view fits well with Trinitarian Christianity and with what Catholic theologian Mary Grey calls ‘connected theology’ on which this thesis is built: stressing the connectedness of creation with particular reference here to all human beings. This framework is exemplified both in the Johannine vine in John chapter 15 and Pauls’ image of the body of Christ in Ephesians chapter 4: with its insistence on all members being equally in need of the other, none being able to dismissively say of any other ‘I have no need of you’ (I Corinthians 12:21). Classical, incarnational, Trinitarian theology valorises all persons regardless of gender, race, social status (Galatians 3:28) "There is neither Jew nor Greek, there is neither bond nor free, there is neither male nor female: for you are all one in Christ Jesus." and we could add able-bodiedness or otherwise. Thus a relational view of humanity would cohere well with the theological framework of this thesis, refusing to see disability as an anthropological marker. As such, it would not be a useful term

³⁵ I am indebted to Roy Mc Cloughry for e-mail correspondence on this issue. January 2011.

for disability studies as it does not foreground disability but diversity among humanity as created in the divine image. A Trinitarian theology posits that all human beings are only complete and fully who they are when in relationship with others and this is equally true of all persons.

2.3 Summary

In this chapter we have examined the history of disability, from early times and considered the contrasting perspectives of the classical and Judaeo-Christian worldviews, and then looked at the history: the first century world in which Jesus lived, the medieval era, up to and including, the Victorian period, and finally, the present day. We have noted how history has given rise to a number of models of disability and these have been examined. No secular model of disability is universally embraced by Christian theologians, although the social model has been popular with some for its ability to foreground issues of oppression. However, Judaeo-Christian thinking does not foreground difference but celebrates the diversity of those made in the divine image, and for that reason we must seek an alternative view. In the next chapter this historical enquiry is extended to focus specifically on the church.

3. DISABILITY AND THE CHURCH IN CONTEMPORARY PERSPECTIVE

We will now consider recent trends in the church and after some consideration of the criticisms of the Disability Movement, further the church will be reflected on drawing on criticisms from within the church too. After looking at some harmful attitudes within the church towards persons with impairments some fresh developments within the church will be examined. These fall into three distinct categories: first, some para-church movements (existing alongside the church), second some specialised 'niche' churches for people with learning disabilities and thirdly an integrationist church which does not take the *status quo* as some controlling 'norm' but includes people with learning disabilities as full members and even as pillars of the church.

3.1 Recent trends

For the Church the introduction of the Disability Discrimination Act (hereafter DDA) put disability firmly on the agenda. It has been estimated that in an average parish there will be between 10-15% of people with some type of impairment, a statistic which is seldom reflected in the constitution of the congregation (Bryant & Reynolds 2001:16). For even though there has been talk of the importance of inclusion in the church for nearly three decades, little has been done. As long ago as 1968 the World Council of Churches affirmed that the unity of the church included both 'the disabled' and the 'able-bodied.' A declaration of the fourth congress of The World Council of Churches which convened in Cologne in 1968 on the theme of 'The unity of the church and the renewal of humankind' states that 'Churches without persons with disabilities are disabled churches,' and Jurgen Moltmann (1998:122) also emphasises this. Later, a special ecumenical European consultation which met in Bad Saarow in Germany in 1978 picked up on this theme, stating

When we confess our belief in the complete oneness of all human beings in the family of God, we are clearly affirming that no one may be excluded or exempted from it however severely disabled. No physical, mental or sensory disability may be made a pretext for denying solidarity. (The Bad Saarow Declaration 1978).

Up to this point Church Action on Disability (CHAD)³⁶ had tended to be a lone voice trying to promote healthier attitudes. Some marvel at the proliferation in interest about disabled people and the church which came with the advent of the DDA yet clearly the initiative was government-led. Arguably, this could be evidence of the Holy Spirit at work in the world at large. However, the church had a long way to go to catch up with this enlightened attitude in the secular world. At Spring Harvest in 2003, an almost trick question was asked concerning a church which had a tight budget, should it be spent on a disabled access ramp or on an evangelistic event? When some people replied that an access ramp was an evangelistic event in its own right, it appeared that they had provided the hoped for response. Many of us would not have made that connection at that point in time. The church, as a service provider (in the general sense of the term) along with other organisations, is required not to discriminate against disabled people in any way, and that includes people with physical, sensory, and learning disabilities and also those with mental health needs. That would include such things as no longer being able to ask someone not to bring a person who shouts out and is a distraction or to refuse communion to a person with cerebral palsy because they dribble (a straw can be offered).

Under the DDA disability is now defined as ‘a physical or mental impairment which has a substantial and long-term adverse effect on his [sic] ability to carry out normal day-to-day activities.’ The DDA is not merely about physical access to the building but as Penton points out (2001:2) ‘Whilst access to a church may be seen as gaining entry to it, the concept of accessibility embraces not only entry, but also enjoyment of the use of all the buildings, services and facilities.’

Discrimination should also cover ‘intellectual access’ and Mencap have issued guidelines on accessible language out of which some prayers are now being rewritten.³⁷ Some phrases in well known hymns need to be considered, for example, ‘what exactly does ‘ineffably sublime’ mean to the average church goer let alone a

³⁶ CHAD was an ecumenical organisation which no longer exists and has been effectively replaced by the similarly ecumenical *Churches for All*.

³⁷ The guidelines state that sentences should be short with only one main idea per sentence, that jargon should be avoided as should abstract concepts including all figurative language. Writing should be in the same style as spoken language and all unnecessary detail should be removed. Finally, and crucially, written texts should be supported by visual images so that the message is clear to readers and non-readers alike.

person with intellectual impairments? A preacher could helpfully be asked to sum up what has been said in around two sentences for those with learning disabilities.

Other areas ripe for change are such bad practices (apparently common) as putting an adult person with Downs in the Sunday school with infants because of the 'mental age.' (Bryant & Reynolds 2001).

The changing attitudes in mainstream society have led to some good thinking in the church too. Two important early publications were *The Church among Deaf People* (1997)³⁸ and *Widening the eye of the needle* (2001) which is a guide to meeting the requirements of the DDA, providing detailed information and design guidance to help meet accessibility requirements especially for historic buildings. It was quickly into its second edition incorporating guidance drawn from the first 6 years experience of the operation of the Act and the publication of the new code of practice relating to part III issued by the Disability Rights Commission. In addition, some charities have been established such as *Through the Roof* which is linked to Joni Eareckson Tada's worldwide organisation committed to changing attitudes in the church and wider society.

However, some documents still seem to be fashioned from an able-bodied perspective which may make attractive assumptions which are not, necessarily, well founded. It is clear which documents have been written after a careful reading of the literature and involvement with disabled people and those which have not. Those that have a handle on the issues demonstrate that they realise disability is about rights and not charity and about independence and not care. An example of a policy document which gives the distinct impression that it has been written enthusiastically before sufficient dialogue, was produced in the Diocese of Rochester by the parish of St James and St Philips, concerning the need to welcome people with disabilities the

³⁸ It is important to note that the Deaf community do not necessarily regard themselves as disabled. More often they wish to be seen as a minority language group like any other, arguing that it is society's failure to speak their language that disables. This view is supported by Groce's (1988) research conducted in Martha's Vineyard where a congenital disorder led to a large number of people in the area becoming deaf. Therefore the community learnt sign language. In such a context Deaf and deafened people did not feel at all disabled.

author states. 'I think we are both loving and caring in our attitude to others, but I'm sure we can help people to feel *even more* welcome' (my emphasis)(Biggs:2).³⁹

In *Open to All* (Bryant & Reynolds 2001:29) written by people with extensive experience of working with disabled people we read on the topic of welcoming:

It can be very uncomfortable to hear what people with physical, learning, or sensory disabilities or with mental health needs have to say about the church's attitudes towards them but we need to listen and to assure those concerned that they have been heard.⁴⁰

This less positive view is confirmed by Canadian Sociologist, Avi Rose (1997:396) who in claiming that religious communities are not making the necessary accommodations for people with disabilities says 'This fact seems to conflict with the general perception of religious institutions as havens for all peoples.' Going one step further *The Interim statement of the World Council of Churches* 2003 itself written by people with disabilities and those closely involved with disabled people, while acknowledging that there have been some improvements in the past two decades states:

...It is important to be aware that, in some parts of the world and in some churches, there has recently been a return towards overprotection and even disregard of disabled persons. In some places, we have been manipulated by evangelical groups. Even worse than being ignored, manipulating disabled people could become the Church's new sin. (2003:13 para72)

With the emphasis on widening participation in Higher Education, it may be surprising to note that people with learning disabilities are included in their remit with regard to learning, teaching and research (Boxall et al 2004) and it would, therefore, seem important for the church to emulate such a high aspiration for inclusion. David Potter (1998:8) believes that the church is not necessarily deliberately unwelcoming to people with learning disabilities but insists it is in the nature of the problem, that such people have difficulty with abstract thinking and

³⁹ Only a nation of dog-lovers could fail to see the problem with the experience of a blind man who said the warmest welcome he ever got in a church was when he walked in with his dog and a woman rushed up saying 'Hello gorgeous, would you like a drink?' Hopefully before he had a chance to say 'oh, yes, lovely, milk and one sugar', Fido could be heard lapping his water! Personally I thought that was an example worse than 'Does he take sugar?' for a flagrant disregard of the person present.

⁴⁰ Rev Andy Bryant, in conversation, (June 2004) told me how he stopped going to church when he was touring with a theatre company comprising people with Downs Syndrome. He said that the actors were having a wonderful time and even had the chance to work with the Royal Shakespeare Company. However, when he turned up at churches with them invariably someone added a prayer to the intercessions for them and these were couched in such negative language 'these young people who suffer so' etc that he decided it was better to stop taking them to church.

some may not be able to read and our services are full of abstract ideas and following texts. Thus, unless the church changes its *modus operandi* people with learning disabilities will not be included. Moreover, The Church Times 30 April, 2004, stated that 'People with learning disabilities have spiritual needs that are not being met by the Churches'. This fact is corroborated by a report published by the Foundations for People with learning disabilities, entitled *Why are we here? Meeting the spiritual needs of people with learning disabilities*. The foundation's Chief Executive, Andrew McCulloch, in the preface, insists 'Faith communities are not always welcoming or inclusive, despite the requirements of the DDA'⁴¹

The report insists that the welcome people with learning disabilities receive is at best superficial and stops at the church door as they are never invited into people's homes. It would seem then that it is not simply spiritual needs that are left unmet but emotional and social needs.⁴² It concludes

The challenge for faith communities then is not simply to integrate people with learning disabilities into their various services of worship. The real challenge is to create forms of community where meaningful friendships can be developed, where people with learning disabilities participate in the whole lives of people within religious communities. (Swinton & Powrie 2002:21)

In 2009 a Church report was produced called *Opening the Doors: ministry with people with learning disabilities and people on the autistic spectrum*. Torch Trust produced fully accessible versions of the report, thus putting into practice some of the recommendations of the report. In the foreword, the Archbishop of York, John Sentamu, writes 'This is not just another set of official guidelines – it is an invitation to the church to walk on holy ground' (2009:4) The report covers key issues such as– appropriate language, theological rationale for full inclusion of people with learning disabilities, issues for people on the autistic spectrum, dealing with parents and carers and life events that the church must handle – death and bereavement, love and marriage, confirmation and admission to communion.

⁴¹ Alan Reich (a Quadriplegic) cautions 'It is easy for people with disabilities to blame society for negative attitudes that are keeping them from realising their potential. We have to be very careful because people with disabilities share the responsibility for how those attitudes are formed and developed.' (Quoted in Deland 1999:68)

⁴² This has particularly serious implications as it is well documented that people with various disabilities, especially, learning disabilities are more susceptible to sexual exploitation. Some of the reasons put forward for this increased vulnerability are unmet social and emotional needs, areas that the Church should surely be able to impact on.

3.2 Reflections on the Disability Movement's criticisms of the church

Despite the fact that there are some serious moves afoot to improve the lot of people with impairments in the Church, the Disability Movement, as has been noted, frequently asserts that some of the negative experience of disabled people and indeed those who have disabled children, has its origins in some strongly held beliefs about disability in the Judaeo-Christian tradition.

North American disability activists Eiseland (1994) and Majik (1994) object to the insistence that Judaeo-Christian thinking is oppressive towards disabled persons. On the British scene, Barnes (1996) and Shakespeare (1997:228) state that Judaeo-Christian thinking and that of the Greeks have been detrimental to people with disabilities and this thesis makes the point that during the Medieval era Christianity was overlaid with Greek thinking to the detriment of the purity of the Gospel. Canadian sociologist, Avi Rose makes a much stronger claim than either Barnes or Shakespeare stating 'the views of Western religious institutions have helped to create the social construct of disability as a political state of oppression and have been instrumental in maintaining its power and pervasive nature.' and the strength of this assertion may reflect some significant differences between the American and British Religious contexts.

However, Graham Monteith, a minister in the Church of Scotland, who has cerebral palsy, comments on the Disability Movement. Having been very involved at one time and using much of their valuable research in his writings, nevertheless states

I basically reject the militancy of much of today's disabled movement and I do not much agree with an over-emphasis on Marxist collectivism which pervades the descriptions of the social model of disability (2005:11).

Similarly, Jennie Weiss Block has reservations commenting that the Disability Movement is the product of the democratic liberalism of the Enlightenment, which values, equality, independence and individual rights, in contrast to the two thousand year old Christian tradition which values community rather than the individual and she asks 'where does the strident language of rights find a home in Christian theology?' (2002:19).

Avi Rose, (1997:396) who is especially critical of Judaeo-Christian attitudes sets out four headings under which disability is viewed:

- i) disability as punishment for sin; ii) as challenge to divine perfection;
- iii) as incompetence and exemption from religious practice; iv) as object of pity and charity.

Rose admits that the latter category may be double-edged. On the positive side, because both the Talmud and the Bible instruct people to care for those with disabilities, religious institutions were historically the first and sometimes sole providers of care for disabled people. In the forefront of care were religious orders who offered schooling, medical support and charitable funding for the benefit of people with impairments. However, the downside is that being viewed as objects of pity inclines to objectification of the person, a response which leads to an undermining of the person's essential humanity. Rose points out another danger, warning '...they become a project, a vehicle for others to fulfil their acts of kindness.' (Rose 1997:399).⁴³

A further drawback to this charitable perspective is that where people become a charitable responsibility, their needs are less likely to be recognised as rights but 'as privileges of a society that can afford to care for them.' (Rose 1997:399) This in turn can lead to fickle provision within religious communities, evidence for which was found both by Hawkins-Sheppard 1984 and Fewell 1986. (cited in Rose 1997:399).

Watson (1930) in his *Study of Civilisation and the Cripple*, asserts that the book of Leviticus (especially chapter 21) with its exclusion from 'offering sacrifices' for people with disabilities gave credibility to a view of disability as a sign of 'the curse of God'. Such verses became 'clobber texts' - 'a useful stick with which to beat the cripple' (Watson 1930:2). Expanding on this point he states

The influence of the Old Testament upon the cripple [sic] was both dominating and murderous. To the Christian church the evil of the world was an open enemy to be endured for a season but not to be a source of pity! Such an obvious 'curse of God' as deformity became a sure sign of spiritual degradation. (Watson 1930:2)

⁴³ Paul Hunt 1966, himself a disabled person, and considered by some to be the founding father of the Disability Movement, actually advances the same argument as a positive outcome for a community as it can militate against selfishness in able-bodied people.

As we have seen this was true within the mediaeval era. Building on scriptural trends, some key theological thinkers, such as Augustine (and possibly Calvin/and or Luther⁴⁴) have apparently made matters worse. Augustine saw impairment as a punishment for the Fall of Adam and other sins. The Medieval view that a disabled child was 'a changeling' i.e. a demonic substitute for a human child as a consequence of sin - more often seen as the fruit of a sexual liaison between the mother and the devil, was set out in the *Malleus Maleficarum* of 1487 [(Haffter 1968) in Barnes 1996:55]

Tension between the Gospel and the institutional Church

The tension between the nature of the Gospel and the culture of the institutional church is taken up by a number of writers. Wilks & Pestell (2003:4) show concern for the integrity of the Gospel when they say 'where Christians set up a system that does not express this total and perfect equality amongst God's people, we fail to express and live the liberating heart of the Gospel.'

Alan Lewis in his prophetic article entitled 'God as Cripple: Disability, personhood and the reign of God' (1983:13) makes this powerful claim

'one of the tests of the credibility and relevance of the gospel is the damage it can inflict upon vicious circles⁴⁵.... The circle of alienation is nowhere more vicious, not the need for its rupture more urgent, than in our handicapping of the handicapped [sic].

Numerous writers (Penton 2001; McCloughry & Morris 2003) point out that the Gospel itself incorporates a desire for social justice and inclusion for all people. And Leslie Newbigin insists on the need for the message of the Gospel to be grounded in the lived experience of a community: 'the only hermeneutic of the gospel, is a congregation of men and women who believe and live by it (1989:227).

⁴⁴ Popular stories circulate which are sometimes ascribed to Luther and sometimes the self-same tales are ascribed to Calvin indicating that these people saw disabled children as demonised.(Potter 1993)

⁴⁵ The lengthy middle section of this lucid quote is included here. 'If the human heart, when distanced from its home, becomes "turned in upon itself" collective egotism is similarly circle-shaped. Like clings to like, and in the drive for self-corroboration we shut out the alien and the different. Into such an introverted cul de sac of rejection and retreat we are led by the entropic processes of stigmatisation: difference provoking insecurity, insecurity defending itself with prejudice, prejudice reinforcing difference. Can by contrast, the liberating dynamic of grace and love break into this circularity and open men and women up for reconciliation with the other, fellowship with the unlike, acceptance of the different, honour for the despised?'

While it could be argued that some people in the Disability Movement may be antithetical to the church, it must not be assumed that criticisms of the church are to be found solely from outside. Carole Fontaine (1995:288) insists that the church is one of the places in which the most potent examples of exclusion can be experienced. She believes this is partly because the presence of disabled believers is an embarrassment to the Church's ideology of healing. She concludes 'it is no wonder that churches respond so slowly and ineptly to the special needs of this community, for they are themselves handicapped by their theological legacy.' (1995:295)

Furthermore, Flynn (2003:16) points out

a weakness in evangelical thinking, that is too often visible in both lay and theological circles, is the unconscious construction of a harmonising gloss on the New Testament scriptures so that the unique perspective of the different authors are missed.

Regarding an ideology of healing, Pentecostal theologian Amos Yong, states starkly 'the complaints about Pentecostal-charismatic healing practices are legion in the disability literature' (2007:242) His forthright conclusion is that what we are confronted with is not so much the need for disabled people to be healed as for non-disabled people to be transformed⁴⁶(2007:243) and, indeed, for all persons to have their conceptual lenses, through which people and their bodies are viewed, reground in order to encompass the experience of disability (Deland 1999:48).

Many people within the church have told painful tales of misunderstandings, sometimes by believers who have the sort of simplistic faith that 'Job's comforters' display. Brett Webb-Mitchell writes from experience within the current Western context 'as a person who had some motor difficulties, John, who wanted to be in the church, had a hard time convincing the congregation that he didn't need to be exorcised' (1994:9). John Swinton is also clear that the church is not necessarily a 'safe space' in which to experience acceptance peace and fellowship with other believers (2001:35).⁴⁷ Featherstone and other parents of children with disabilities talk

⁴⁶ Yong quotes the experience of Mary Semple who believed that her tumours had been an agent of God to save her from an abusive marriage. This underscores the danger of the tunnel vision that only seeks the person's physical well being. (Newell & Semple 2002:108)

⁴⁷ Many church leaders naively assume that the church is a friendly place for all. (acknowledging perhaps that it is not so for gay and lesbian people) However, Mary Grey founded a local branch of

about the anxiety of a God of retribution who may be punishing them through the deformation of their children for some known or even unknown sin (Featherstone 1981). Frank Daly (2000:13) points out that for many parents whose children were born mentally or physically impaired there are many burdens to bear and the feeling of being rejected by God is one of them.

Frank Daly in Kelly & McKinley (2000) also takes up the issue of parental injury from false views. He states that historically parents took up vehement campaigns for their children to receive Holy Communion. Daly (2000:13) notes

They were often met with thinly veiled rebuffs from priests more concerned with canonical exactitude than pastoral care. They were told that this could not be because their children 'did not understand' what Holy Communion was. In one dreadful case, a loving mother who nursed her son for 29 years to his death, was told that, 'it would be like giving it to a dog'.

They explain that such priests and pastors fail to see that for these parents being welcome to receive the Lord at Holy Communion, crucially, meant that the Church and God Himself welcomed their child as a human being and a full person. Soberly, they conclude 'our failure to understand this caused much hurt and sadness, which some families have still not got over (Kelly & McGinley 2000).

Another negative response found within the church could be called 'disability as inappropriate'. Professor of pastoral theology, John Swinton writes of the alienating experience in taking a young man with Downs Syndrome to a local church. They were given a stark ultimatum: either to send the young man (not a child) to the Sunday School or leave! Understandably they chose the latter option. Swinton remarks '...in the name of 'orthodoxy' right worship' and 'fairness to other worshippers', the church felt justified in excluding Stephen from the worshipping community (2001:42).

Brett Webb-Mitchell concludes that 'it is our perceptions of others, learned in the culture we were raised in, that shapes our attitude toward all people, regardless of their ability or disability' (Webb-Mitchell 1994:11).

Womanchurch (which was set up in America) in Berkshire, for a similar reason to create safe ecclesial spaces for women so that they could survive within the hostile, patriarchal, established church, from which women were leaving in their droves.

However, there are also some very constructive moves afoot today.

3.3 Recent Initiatives with doing church

Para church ministries for people with learning disabilities

The first steps to make room for people with disabilities came with the founding of a number of ministries for people with learning disabilities that operate alongside the local church. We shall look at Causeway Prospects, SPRED, Faith and Light and L'Arche.

Causeway Prospects was founded in 1976 by David and Madeleine Potter as 'A cause for Concern'. It is a voluntary Christian organisation which exists to support people with learning disabilities in order to help them enjoy a full life. It has very clearly defined values which include: individuality, empowerment, dignity, independence, inclusion and spirituality with a strong emphasis on the individual's right to autonomy and self-determination in all matters concerning their lives. Its current Mission Director, Tony Phelps-Jones sees it as a mission to people with learning disabilities in order for them to know that Jesus loves them. Groups meet for regular prayer, Bible study and friendship. Holidays and regional celebrations are also available. Causeway Prospects provides training and advice for churches on effective ministry and outreach.

SPRED stands for Special Religious Development and was formed in the 1960's in Chicago as a response to the fact that the church was not teaching faith in ways that worked for people with learning disabilities. They meet either weekly or bi-weekly and share food together and listen to the Word together and take part in activities. It is based on the parish system thus enabling members to be linked to a parish church. According to their webpage 'The goal of SPRED is to assist people in parish churches to integrate persons with a learning disability into parish life and worship through the process of education in faith.'

Faith and Light is part of the Roman Catholic Church. It was founded in the 1970's and grew out of a pilgrimage to Lourdes which was run by Jean Vanier who also

founded the L'Arche communities.⁴⁸ At Easter 1968, in response to the needs of one family, a group of 8000 people from a total of 15 countries took part in a pilgrimage to spend Easter together. These groups, on their return, became the first Faith and Light communities, giving support to families who had members with learning disabilities and who had experienced rejection and isolation in the church. To date there are over 1500 communities in 85 countries, and these include people from a variety of Christian traditions. They meet monthly for worship, activities and simply for friendship. Larger events also take place, including retreats and celebrations as they are members of an ecclesial and international organisation. Unlike L'Arche, Faith and Light are not residential communities.

L'Arche communities are well known as they are a worldwide concern for people of a variety of faith traditions and of none. Originally they were a Roman Catholic concern established by Jean Vanier and a French priest. They have been in existence for over 40 years (there are now 130 around the world) but these are residential communities where non-disabled people live in community with people with learning disabilities. They were set up by Jean Vanier and inspiration has been drawn from the writings of both Jean Vanier and the late Dutch Priest and academic Henri Nouwen. L'Arche has a value system which seeks to honour the uniqueness of each person and the right and need of every person to give and receive love and friendship and to grow spiritually. They are quite distinct from any other work with people with learning disabilities as they are residential and aim for non-disabled people to live and work alongside people with intellectual impairments. Because they are a burgeoning organisation and have been going for some time some research has already been conducted on them. The ethnographic research of American pastor Brett Webb-Mitchell, will now be explored. Webb-Mitchell lived at L'Arche, Lambeth for a nine month period from September 1987- May 1988 in order to conduct some ethnographic research.

⁴⁸ Faith and Light and L'Arche were both founded by Jean Vanier, the former is a support group while the latter is a residential home where non-disabled people choose to live alongside people with intellectual impairments as family.

Webb-Mitchell's findings are not quite so unambiguous as the accounts we read from Jean Vanier and others. He writes that the theme of L'Arche as a ghetto was a new theme to him before embarking on his research (1987:44). He finds that at times L'Arche seems no different from any other institution he had worked in with people with learning disabilities. He points out that there are no plans for anyone to move beyond L'Arche towards independence. One local church leader noted that the L'Arche people do not participate in the life of the local church much as they are too busy with things at L'Arche. Webb-Mitchell recommends that L'Arche follows the rest of England in focussing on a developmental approach. He feels that L'Arche has become stuck in 'being' while the rest of society is focussing on 'becoming'. He also sees that becoming is more conducive to participation. On the topic of participation he observes during a two day celebration that the people with learning disabilities are included but notes 'all the people with mental handicaps [sic] were side-kicks in the skits and the liturgies. (1987:16) There are other more significant areas where they are not able to participate, notably attending their case reviews. The data also raises some questions over how much choice the residents at L'Arche have in their personal lives, even to the point of some of them not really wanting to live there (1987:33). On balance, he concludes that there are 'more characteristics of an institution than a community' (1987:327).

Prophetically, taking the image of Noah's ark (L'Arche is French for Ark), he wonders if the ark has now settled on dry ground and it is time to come out of the ark. In this vein he concludes 'maybe it is time for the people of L'Arche to participate more fully in the life of the church rather than creating an alternative for the church' (1987:329).

Aside from these separate ministries for people with learning disabilities some people are now beginning to establish churches specifically for this constituency.

Niche churches for people with Learning disabilities

Claire Dalpra researched two new expressions of church and wrote about them in the Church Army pamphlet *Encounters on the Edge no 44: 'Hidden treasures'*. This is a

move beyond forming a separate group to then feed in to a regular congregation to forming a separate church designed to be appropriate to that specific culture.

Fresh Expressions of church for people with learning disabilities

Fenland Community Church in March, Cambridgeshire meets behind the Sainsburys Superstore in a scout hall, thrice monthly. Chairs are set in a semi-circle, two or three rows deep which is flexible for wheelchair users. There are bright yellow markings on the floor for ball games so location is better than ambience. The Superstore Car park is useful for dropping off and picking up and also for carers to do some shopping while they wait. The service is described as ‘fun, interactive, fairly noisy and active time of worship (lots of people wandering around) lasting about an hour. On the occasion that Dalpra attended, a woman with learning disabilities opened in prayer with a little help from the pastor. Simple songs from Causeway prospects and modern choruses were led by the worship leader on guitar and the leader used Makaton signing. They aim to use songs with as little imagery as possible and percussion instruments and flags are available for anyone to use. They use the visual too and during the songs the leader’s wife imaginatively wrapped large sheets of soft material around members who were unable to move or see to encourage a sense of inclusion (being joined together by the fabric). At one point a large number of people danced in the middle and others waved ribbons and flags.

A time of confession was conducted with the use of stones which were handed round and used to symbolise things we do wrong which could then be brought to the front and laid at the foot of the cross. Objects were often handed round eg wooden crosses, candles, flowers etc . Visual images were projected on to the screen to reinforce what was being said so that words did not have to stand alone. There was also some story telling with puppets too.

Their church logo is a picture of a bruised reed, communicating something of the difficulty that many of their members have experienced in engaging with society outside the learning disability community (2009:9).

Sheffield Church St Paul's Norton Lees, rent a space for fortnightly evening worship which is called Focus. The church is described as a mix of old and new with stained glass windows and carpeting and well lit areas with flexible seating. The team use alternate Sundays for planning perhaps an indication of the labour intensity of this ministry.

Focus begins with worship and volunteers bringing in the cross and lighting the candles. Use of musical instruments and key phrases like 'we're God's family' are repeated. Interactive drama is a main feature. The leader took the role of narrator and members of the congregation volunteered to act out key parts with simple costume and props and the repetition of lines from the narrator.

Prayer needs were identified pictorially on a flip chart and then prayed for with some assistance from those who had identified the needs. The service concluded with a light supper and there was cake to honour any birthday that had taken place. Once transport arrived the meeting broke up and people were taken home.

Although there are a number of similarities between these two groups there are also sufficient differences to establish that each is finding its unique way within the prevailing culture of disability without merely aping what someone else has pioneered. Claire Dalpra (2009:15) states 'the instinct to grow what seems appropriate to the local context rather than pre-determining a framework ahead of time seems alive and well.'

Despite being very intentional in what they do, the leaders seem settled with the idea of Focus as a provision for people with learning disabilities as an expression of church in isolation from the rest of the church. Dalpra (2009:12) explains,

On moving to Sheffield in 1999, David began to explore the possibilities of spiritual nurture for adults with learning disabilities but concluded that *it was unreasonable to expect an ordinary church to change the fundamentals of how they do church* (my emphasis) in order to accommodate the needs of a few people in their congregations with learning disabilities'

However, they rightly point out how ill-equipped the average church is to run such a ministry and note that many so-called 'learning disabled-friendly' churches still have

sermons which are just monologues and little or no understanding of cognitive human development theory. Even with expertise their own team have difficulty communicating a simple message through action and getting it right every time. Dalpra (2009:13) concludes ‘they are also keen to note that the wider church explores the theological implications of engagement with this mission context to avoid ministry that is fuelled by mere sympathy vote or token gesture.’

After her visits to these two churches Dalpra considers to what extent they fulfil the criteria for a fresh expression of church. She notes that the first aspect which is crucial is an instinct for enculturation rather than mere assimilation. In view of this priority she was interested that the leaders of the Cambridgeshire church called themselves cross-cultural missionaries to a lost tribe. Focus have two members on their leadership team who take an active part in the leading of the church by helping to plan the services. They realise that there is also a need to include an awareness of what carers need in this sort of church that can avoid making it ‘a busman’s holiday’ (2009:24). Carers play a key part as they build connections into residential homes which can otherwise be a closed world. Dalpra concludes, ‘these stories tell of Christians living a delightfully counter-cultural stance’ (Dalpra 2009:29).

Regarding inclusion Dalpra (2009:6) notes

I discovered that the leaders of *Focus* believe that *having a dedicated church for those with learning disabilities helps members feel more normal* (my emphasis) [sic]⁴⁹ than they would if they joined a ‘normal’ church. It is better to have a church that takes the learning disabled seriously with the freedom to address the particular issues in their culture. Choice is a big issue for them in that very often they have had precious little. Focus tries to give it back by offering as much choice as they responsibly can at every meeting.

Danger of attending but not belonging is guarded against through emphasis on regular attendance. Knowing everyone’s names, giving a genuine welcome, eating together and using an inclusive seating arrangement, all help to create a sense of belonging over a merely passive attendance (2009:18).

While it may be laudable for people to establish churches that are learning-disabled-friendly, there are some difficulties with this approach. Firstly the notion that they

⁴⁹ I have put [sic] after normal to note that the writers use the term uncritically here while placing it in brackets when it refers to the church. Clearly the whole concept of normalcy needs to be challenged.

feel more 'normal' on their own and more so, that it is not reasonable to expect the church to change its way of doing church (a point also made by a leader in the case study research of this thesis – see *Part Two*). There is a place for specific groups as a first step and a form of consciousness-raising, however, in the final analysis, together, we are the Body of Christ.

Causeway Prospects advocate the approach of groups existing within a wider church structure. Dalpra questions how much mutuality there is in that. Her concern over mutuality is based on a pattern she has seen in churches working to integrate middle and working class cultures and the fact that the more educated group has a tendency to dominate. She notes that the more verbal and intellectual the church tradition is the more difficult this pattern is to break.

Both churches she visited had developed a sacramental aspect to their services and even written their own liturgy. Communion is chaotic and the notion that a tiny piece of bread is appropriate is not easily comprehensible to many of them.

In writing about the gifts of vulnerable mission Dalpra (2009:27) says

I discovered a complex dynamic in which people started as hosts but over time became guests. Vanier describes this as moving from 'doing for them' to 'be with them' that often develops as a permanent vocation to live within the particular culture, in this case the culture of disability. This resonates with insights from our team that connect the cross-cultural missionary as guest to something akin to willing slavery. This is powerful imagery with the New Testament call to servanthood that voluntarily submits itself to the person or the people they are serving. Those leading these churches talked about member's weaknesses unearthing parallel weaknesses in them.

Everyone spoke of the rewarding nature of this ministry.

Their simplicity and spontaneity of life style is refreshing next to the complexity of many. Furthermore, connecting to the insights of Vanier and Nouwen, there is something about an encounter with a learning disabled person that can more easily lead to an encounter with God (2009:28).

Traditional forms of church are found to be 'peripheral, obscure, confusing and irrelevant.' Her final conclusion is this

We must allow church for the learning disabled space to explore what steps in their journey towards maturity will need to be taken and in what order. In reaching out to others in mission, in gathering enough resources to sustain

what they've started and in searching for ways of expressing a catholicity built on mutual appreciation, we, the so-called 'able' have an important part to play in understanding and offering and connection (Dalpra 2009:30).

So we have churches here that have set up in isolation from the local churches in an attempt to create a suitable culture and environment for the members. We will now look at a church that goes further in creating an integrationist model of church that has a prevailing culture appropriate to people with Learning disabilities. Eugene Peterson (2006:12) comments on the North American scene which

... honours and celebrates the beautiful, the rich, and the accomplished with spotlighted, centre stage prominence and makes sure that the lepers and Lazarus are kept out of sight (and smell!!) backstage. Too much of the church, to its immense shame goes along with the culture.

An integrationist Church

While integrationist churches may seem to be the ideal, we should heed Nancy Eiseland's concern that inclusion is not universally desired as it can be based on conformity to the *status quo*. What follows is an example of an integrationist model which does not force people with learning disabilities to be other than they are and values them for what they bring in their own right. This demonstrates the Body of Christ as an organism where all parts are fully participative. In *Part Two* we shall see two case studies which aim to be inclusive and see the contrast between a tendency to accommodate the *status quo* in the one and a critical overturning of the *status quo* in the other.

Brad Jersak, is in church leadership at Fresh Wind Christian Fellowship (BC,Canada) and regards the pillars of his church as 'disabled people, children, prodigals and the poor' through whom he is trying to learn what the Kingdom is about. This is a radical shift as it goes so much further than just including people on the margins to making them central and including people who are well regarded in society as NOT necessarily being the pillars of the church. His book, *Kissing the Leper: Seeing Jesus in the least of these* is a book which Eugene Peterson in his foreword likens to a record of 'Jesus sightings' (in an adaptation of birdwatcher parlance). The third section of Jersak's book chronicles encounters with God through people with learning disabilities. Jersak believes that it is possible to see Christ in all people not

because they become Christians but because Jesus took on humanity in all its multifacetedness.

To conclude this section, we will look at three of the people Jersak encounters who he records here: Meghan, a girl with autism; Kathy who is blind in one eye, a wheelchair user and in constant pain and Pastor Eddie who has Downs Syndrome.

He meets Meghan at an art-friendly church called ‘Canopy’ in Edmonton, where he is their guest speaker. During the worship this young woman went to the front of the church and did a very exuberant and expressive dance. The congregation may have been nonplussed but Brad says he was captivated. Meghan seems to be completely oblivious to what others think and Brad unselfconsciously moves in the same spirit.

He (2006:98) writes

One thing I have learned about autism is that sometimes you can enter the secret world by mimicking the child (or adult) so that is what I proceeded to do. What a sight as suddenly the guest speaker and the little girl repeated the odd anti-choreography together – now twirling, now marching, now thrashing. Scoff, but as King David once said having danced with absolute abandon ‘I will become even more undignified than this.’ (2 Sam 6:21-22)

At one point after she has connected with him she walks towards him and grabs his head and pulls it towards her and exclaims enthusiastically ‘You’ve been to Scotland’ Then she goes into a torrent of ‘Hi Scot man, Scot, Scot, Scot etc’ Unbeknown to her Brad had just returned from Scotland and was struggling with jetlag. She got his attention but then went off on her solo chant again. Finally she started to do a very dramatic and ‘threatening’ thing pointing at him with her index finger and making throat slitting gestures! The girl’s grandmother jumped up and offered to remove her from the congregation but Brad forbade her as he knew that God was doing something through this child. Then God told Brad that he was singing about what was happening and he realised that he was singing ‘I’m trading my sorrows, I’m trading my shame, I’m laying them down for the joy of the Lord’ As he watched the girl he began to realise that she was cursing the effects of jetlag in his body with the cutting motion and in a matter of minutes he received complete refreshment. He was then able to relay what had happened through Meghan to this church which makes space for the gifts of disabled children.

The second person is Kathy West who is a key member of Brad's church and he describes her as a powerful conduit of God's presence. She has a number of disabilities (as mentioned before). Brad attended a renewal service in the 1990's and Kathy's carer brought her to the front. She joined in where the children were dancing and then she put her hand in Brad's and he asked God to love him through her. On feeling woozy he lay down on the floor. Soon after 12 hefty bolts like electricity shot through his body and Kathy smirked, dropped his hand and continued with the worship. Brad was perplexed until a few days later his cousin phoned him in distress as she was very unwell. In no time she was being healed which was not his usual experience. Brad believed that he had received the power through Kathy which had acted as a capacitor [a temporary storage for power] until he needed it for his cousin.

There are three men at Brad's church called Tom, Phil and Eddie who all have a gift of bringing suitable scriptures to a situation. Tom does not even read yet he spends hours pouring over his Bible and marking verses that seem significant to him. The church has learned to take them all very seriously when they have a scripture to share. On one occasion Brad is about to preach and is feeling troubled that he may have lost the right to speak about the poor as he had just got his first mortgage on a house. He was contemplating asking someone else to speak when Eddie, started pointing to a passage before him in his Bible, indicating that he had a word for Brad. The passage was from Jeremiah 29:4-7 where the people are instructed to settle and make homes for themselves with the knowledge that if things go well for them it will go well for the people too. Brad was able to get up and speak without any fear that he had compromised his principles in buying a home for his family. In all these three cases people with learning disabilities are using their gifts without having to conform to an ableist culture.

3.4 Fresh theological perspectives

While it can be seen that there are some welcome experiments with church for people with learning disabilities going on, there is also some useful theologising taking place which engages critically with why we do church the way we do and seeks to challenge some of this rationale. Arne Fritzson and Samuel Kabue (2004:48), both disability activists in the church, caution

The church is a major influencing factor in our society. It still commands such great respect... that its influence permeates to both individuals and communities. Its appropriate understanding and interpretation of disability is crucial to how individual church members will relate to persons with disabilities, both spiritually and socially.

While there are some fresh expressions of church, as we have seen, there are also some fresh theological concepts that foreground disability and some hermeneutical keys to mine wisdom from some of the disability narratives.

A hermeneutic of suspicion

Block advises that interpretation of the Scriptures should start with a 'hermeneutic of suspicion'⁵⁰ which seeks to uncover any bias in the narratives (in this case ableism) which could contribute to marginalisation of disabled people. Graham Monteith (2005) in his book *Deconstructing miracles: From thoughtless indifference to honouring disabled people* raises a number of issues around interpretation. He emphasises 'Christianity is an inclusive religion and inclusiveness without love is tokenism and is bound to lead to disappointment and patronisation. To exclude is a sinful rejection of a major facet of the gospels'(2005:12).

Monteith and Block (2005:2002) are concerned that biblical interpretation should be wary of a 'quick fix' mentality. In place of this Monteith is encouraged by the recent trend to 'build on the foundation of Christian anthropology which emphasises the giftedness of each (Pauline theology) and 'Imago Dei' (2005:65).

Ecclesiology and a disablist worldview

There is not room in this thesis for an extended exploration of ecclesiology but suffice it to say that in recent years there have been some radical re-examination of ecclesiology for today's world. Some of these writers are themselves impaired or have been powerfully influenced by a loved one with disabilities. They include, Amos Yong, Tom Reynolds, Jennie Weiss Block, John Swinton, Henri Nouwen, Jean Vanier, Frances Young, Stanley Hauerwas and Graham Monteith while others

⁵⁰ First expounded by Paul Ricouer 1970

write from a feminist perspective ever-mindful of power and justice issues in a church that seldom challenges the *status quo*; some of these are Letty Russell, Elizabeth Schüssler-Fiorenza, Serene Jones and Mary Grey. In addition Balkan theologian, Miroslav Volf says he identifies with much of the feminist egalitarian agenda as he seeks a style of church that can heal divisions. While not offering us an ecclesiology, Nancy Eiseland reframes a traditional understanding of God positing a ‘Disabled God’. (which will be returned to after looking at ecclesiologies)

Letty Russell in her book *Church in the Round* (1993) emphasises relationship and connection aiming to affirm all persons, across all manner of dividing lines. This vision of church endeavours to constantly seek connection, to each other and to justice for those who are oppressed. It is not exclusive in that it conceptualises a circle of friendship between world and church by looking for ways in which God is reaching out to those on the margins of both, society and church.

Refreshingly she states that it is ‘a church that defines its faithfulness to Christ by being open to those who are marginal and communicates that since all are created by God we are all welcome in God’s household (1993).

The metaphor of a round table is used to denote a Christian community that practises hospitality. It is non-hierarchical and reflects a Biblical image of church found most often in Luke (1993:18). It eschews all forms of dualism and sees round table talk as being able to talk back to tradition, engaging in a ‘theological spiral’(appendix 1).⁵¹ Miroslav Volf sees his own ecclesiology as being very compatible with the egalitarian ecclesiologies of Russell, Schüssler Fiorenza, and Serene Jones. He argues that the church is constituted by the presence of Christ which is mediated through the entire congregation and not simply through its ordained ministers. He states ‘the whole congregation functions as mater ecclesia to the children engendered

⁵¹ Also known as ‘a liberation social ethics methodology’ (Beverley Harrison) and ‘emancipatory praxis’ (Katie Cannon). This type of theologising is a continuing spiral of engagement and reflection which starts with the commitment to the task of raising up signs of God’s new household with those who are struggling for justice and full humanity. It continues by sharing experiences of commitment and struggle in a concrete context of engagement. Next it leads to a critical analysis of the context of the experiences in a search for the historical and social factors that affect the community of struggle. Footnote 51 cond. Finally there arise questions about biblical and church tradition that helps us to gain fresh insight in the meaning of the Gospel as good news for the oppressed and marginalised. This new understanding of tradition flows from and leads to action, celebration and further reflection in the continuing theological spiral.

by the Holy Spirit and ...the whole congregation is called to engage in ministry' (1998:2).

In common with some feminist thinkers, Volf rejects the notion of a separative Self preferring to see the self as existing in a web of relationships, always being indwelt by others and itself inhabiting others. Furthermore, he argues for a church where inclusion means nothing less than all members fully participating in formative ways. Volf sees the church as an expression of the triune God whose essence is personhood, 'the concrete locus of deindividualisation and personalisation is the church' (1998:83).

From the mainstream, Rowan Williams in *Where God Happens* (2005:111) makes the observation that the church is always renewed from the edges and not from the centre. He gives us a definition of a healthy church as

...,one is which we seek to stay connected with God by seeking to connect others with God, one in which we 'win God' by converting one another, and convert one another by our truthful awareness of our frailty. And a church that is living in such a way is the only church that will have anything *different* to say to the world: how deeply depressing if all the church offered were new and better ways to succeed at the expense of others, reinstating the scapegoat mechanisms that the cross of Christ should have exploded once and for all. (2005:27)

Some key disablest theologians

While theologian Frances Young, writing in *Face to Face* (1990) does not offer us a systematic ecclesiology her experience of disability through the birth of her first son, Arthur, leads her into a number of spiritual insights some of which are about the church. Furthermore from the trauma and sense of abandonment by God that she experienced at Arthur's birth she receives a call to ordained ministry. She believes that belonging to the church depends not on our ability to profess faith but on Christ's acceptance of us. Equally she believes that our own acceptance of one another regardless, is a value to be discovered. She also mounts a challenge to much of our assumed theology. Her experience is that the reality of her severely disabled son brought conflict with a lot of her own previously held beliefs and the platitudes

offered to her by others. She is especially outraged while pregnant with a second baby when told that she needn't worry as God would not allow the same thing to happen a second time; mindful of instances of people who have lost one child after another while hereditary diseases took hold. As Tom Smail (2005:30) points out

The world around us has a toughness that will not let itself be endlessly pushed around and manipulated by our prejudices and preconceptions. It answers back and insists that we take account of it as it really is. It shrugs off what our minds project onto it and instead teaches us to adapt our thinking to its givenness.

Tom Reynolds who has a child with multiple disabilities, also gains the insights of an insider position. In common with a number of disablist theologians (Vanier; Nouwen; Hauerwas; Swinton;) Reynolds believes that disability offers a profound challenge to our value system and confronts us with some of the less palatable facts of being human. In *Vulnerable Communion* (2008) Reynolds points out how society has established a 'cult of normalcy'⁵², which becomes a lens through which all of life is viewed. From that vantage point disability becomes something that needs changing. However, if we challenge the *status quo* then it is not disability but the *status quo* which must shift.

Amos Yong, a theologian who has a child with Down Syndrome, writing in *Theology and Down Syndrome* (2007) also challenges the cult of normalcy. From the position of seeing that the basic framework needs overturning he reconceptualises a number of theological categories: creation, providence, the Fall, what it means to be human, death and resurrection, ecclesiology, eschatology and salvation as a start to reconceptualising the whole. He argues that Christian theological reflection and praxis can be renewed when the traditions and doctrines of the church, which have not been aware of disability issues, are brought into dialogue with disability perspectives. Yong (2007:153) hopes to show that Christian beliefs arise out of our faithful reflection on the challenges of disability as we have experienced them, and yet always return to the hermeneutical spiral.

His objective is to enable the formation of suitable Christian attitudes and responses to the experience of disability in late modernity.

⁵²This is epitomised in the introduction of the bell curve.(Yong 2007:86)

Another significant contribution that Yong makes is in his formulation of a 'pneumatological imagination'. This concept is drawn from the Biblical narrative in Acts 2. Yong (2007:11) argues that

The many tongues of Pentecost signify both the universality of the gospel message and its capacity to be witnessed to by those who derive from the many nations, cultures, ethnicities and languages of the world. The significance of this...is threefold. First, it provides an explicitly theological framework for thinking about the perennial metaphysical and philosophical question concerning the one and its relationship to the many. Second,...it provides a theological rationale for preserving the integrity of difference and otherness, but not at the expense of engagement and understanding. Finally, it alerts and invites us to listen to the plurality of discourses and languages in the hope that even through 'strange tongues' the voice of the Holy Spirit may still speak and communicate.

The pneumatological imagination urges us to discern the voice of the Spirit in unlikely contexts, and with this perspective we are also encouraged to discern God's voice through people with learning disabilities as members of the body of Christ. In his ecclesiology he moves towards a church that is not only relevant to disability but is actually constituted by the experience of disability.

A Disabled God?

Before moving on we will return to a discussion of Eiseland's 'Disabled God'. Although such a concept seems radical and strange, the idea is not new and was, in fact, first propounded by theologian, Alan Lewis in 1983 in an article entitled 'God as cripple: disability, personhood and the Reign of God.' In this he argues that Jesus, the healer,

had become the cripple, despised, rejected, weakened with the afflictions of others, sick with their diseases, and for them disfigured by an ugliness (as of some archetypal Elephant man? from which faces are turned away (Isaiah 53:3)(1983:17).

Eiseland (2004) perhaps goes further in that she sees God as a wheelchair user, like herself, as that is how God has revealed himself to her. While this vision offers solidarity to believers with disabilities it does not go unchallenged even among disablist theologians such as Yong who questions whether as a metaphor it may not actually distort our view of God. Deborah Creamer (2004) is concerned that this

view does nothing to help those who struggle with ambivalent feelings about their disabilities, and Hinkle (2003) doubts the utility of applying this concept to a God who is intellectually disabled. Mary Owen (1993) rejects the concept of a disabled God as the concept of the wounded Christ has caused discord among the Disability Rights Movement. She states that those who are Christians are the Easter people so identify more with their gifts than with their brokenness, Further she rejects the Eucharist as a sharing in the broken body of Christ and sees it more as a celebration of the resurrection. Yong (2007:176) concludes

...while Eiseland's theology of the Disabled God is illuminating in various respects - particularly in highlighting God's embracing the full range of the human condition in the incarnation so as to insist on a truly liberative and inclusive community of faith – it is limited as an only or even dominant model for contemporary disability theology and Christology.

3.5 Summary

In this chapter we have looked at the current situation in the church as far as disability is concerned and have reflected on the criticisms of the Church by the Disability Movement allowing critics from within the church to join the dialogue. A tension between the liberating Gospel and the institutional church has been underlined.

Recent developments in the church have been examined in order to highlight the impact that the current change in thinking in society has had. Three approaches have been noted: from separate groups outside the church to 'niche' churches to an integrationist church where the *status quo* is critically set aside. Next we have examined the emergent disablist theology and ecclesiology together with the need for a hermeneutic of suspicion in dealing with the healing narratives. We are ready now to approach the empirical work where we will find two case studies with some similarities yet also a significant number of differences.

Part Two

A Case Study of Two Evangelical Churches

4. METHODOLOGY AND METHODS

Introduction

This chapter will outline the methodology, describing and justifying the use of a case study approach and ethnographic tools. Then, I⁵³ raise some issues which are germane to the context of a critical disability research methodology. Next, I give an account of the fieldwork settings and issues of sampling and access explaining my analytical frameworks. This is followed by an account of the data collection tools, critically explored in terms of fitness for purpose. Finally there is a section on ethical considerations, the location of the researcher, then an explanation of the data analysis, followed by a summary of the whole chapter.

4.1 Qualitative Research

In making decisions prior to entering the research field, all researchers have to consider what it is they want to explore, and which approach (es) is/are best suited to their project. As I have explained in the introduction, I wanted to explore the situated perspectives of groups of people with disabilities, but principally those with intellectual impairments, in terms of how they experience the church. Thus it seemed to me that a qualitative approach was best suited to my project and an interpretive approach was needed.

Qualitative research refers to a tradition of enquiry which primarily concerns itself with meaning and interpretation. In this paradigm the social world is seen as open to multiple interpretations, where individuals and groups construct their own version of reality (Gilbert 2001:33). In contrast, quantitative research issues from a positivist worldview which regards the social world as having one, external, meaning independent of human perception. I decided to use qualitative methods as they allow the researcher to access and explore the respondents' perspectives in depth (Usher & Edwards 1994) and allow space and scope for probing and explaining sometimes unexpected perspectives. (Berg 1989:6).

⁵³ This middle section is written in a more personal style using the first person singular more than in the theoretical and theological sections as this has become more of an established norm for writing on qualitative methodology while other areas within the academy are contested and to some degree still in flux at the time of writing. (See M. Lea 2011).

Creswell (2007:40) argues that qualitative research is useful in contexts where a complex and detailed understanding of an issue is required. In this thesis I am interested in offering accounts which reflect the complexity of the respondents' experiences and perceptions and provide richness of data and thick description (Geertz 1975).

Some researchers argue that the divide between qualitative and quantitative research is an artificial one (Finch 1986; Stanley1991; Barnes 1992; Clough & Nutbrown 2002;Bryman 2004; Silverman 2005). This artificial approach presents research methodology in the form of a binary and much contemporary research utilizes a 'mixed methods' approach which Yin (2009:63) suggests can enable researchers to address more complex research questions and collect 'a stronger and richer array of evidence than can be accomplished by any single method.' While there are a variety of qualitative approaches, Coffey & Atkinson (1996:3) insist that

What links all the approaches is a central concern with transforming and interpreting qualitative data – in a rigorous and scholarly way – in order to capture the complexities of the social world we seek to understand.

4.2 Case Study

I was interested in the perceptions of adults with learning disabilities who were engaged in church activities. In order to explore my research questions in depth, I decided to undertake case study work in two settings. Here, I briefly explain and explore what is meant by case study work, although this is a contested arena.

Yin (2009:18) describes case study method as an

empirical enquiry that investigates a contemporary phenomenon in depth with its real-life context, especially when the boundaries between phenomenon and context are not clearly evident.

The case is a bounded system, with working parts and is purposive in the social sciences. Certain features are within the boundaries of the case while others are outside. Boundedness and behaviour patterns are useful concepts for specifying the

case (Stake 1988). A case study is both a process of inquiry about the case and the product of that inquiry. Case studies are ideal for probing *how* or *why* questions.

Case researchers seek both what is common and what is particular about the case but according to Stouffer (1941) they frequently portray something of the uncommon, drawing from a range of features: the nature of the case, the historical background of the case, the physical setting, other cases through which the case being studied is recognised, and finally the informants through whom the case can be known. Many researchers gather data on all the above. Each case has important atypical features, relationships, occurrences and situations. Researchers are concerned with what is of significance about the case within its own world and context. Yin (2009) describes the purpose of case studies as being threefold: explanatory, descriptive and exploratory.

Case studies are common in social science research as they are concerned with gathering a lot of information from specific instances rather than surveys or experiments. Multiple case studies are regarded as more robust (Herriot & Firestone 1983) and a 'two-case' study is preferable to a single-case design not simply because of the risk of investing so much in one case but importantly for the analytic benefits which may be substantial (Yin 2009:61). Stake (2000:435 cited in Denzin & Lincoln 2000) notes that as a form of research, the case study is delineated by an interest in individual cases and not necessarily by the methods of inquiry used. Stake (2000) expresses concern that case study research has sometimes been constrained even by qualitative researchers (Denzin 1989; Glaser & Strauss 1967; Herriot & Firestone 1983 and Yin 2009) who give less than full regard to the study of the particular. Stake (2000) notes an irony that while theorists still value generalisability above particularity, many practitioners hold *intrinsic* interest in the case while not necessarily being concerned for the advance of social science. Further, using the title 'case study' tends to suggest that something can be learned from the case, either from its particularity or from its generalisability.

However, while my research will take the form of a ‘two-case’ study (see appendix 2) it will be located within a specific methodological approach: critical disability research.

4.3 Critical Disability Research Methodology

So far I have argued that a qualitative approach is most fit for my purpose and I have also outlined my case study approach. In what follows I want to critically explore some of the challenges, tensions and complexities that arise in undertaking research involving people with disabilities.

First, the production of research involving disabled people is a moot point for some key individuals in the Disability Movement (eg Oliver 1992), because of a concern with objectification. Koepping (1987:28) has argued that the notion of ‘subject’ is imbued with colonial connotations so some researchers prefer to talk of dialogue partners. Further, some researchers in the field of disability note a conflict of interests between fulfilling the criteria⁵⁴ of academic bodies and serving the interests of disabled people.(Moore et al 1998)⁵⁵ As a PhD student I needed to fulfil the criteria of KCL, and so the way in which I sought to also serve the interests of disabled people was to ensure that the church and its attitudes to people with impairments (eg disablist society and oppressive practices) remained the central focus.

Second, Moore et al (1998) insist that disability research must be conducted within a social model of disability as they have found difficulties from trying to work with people still wedded to a medical model of disability. (a full exploration of the models of disability was covered in chapter 2)

⁵⁴ This would include such things as a requirement for the researcher to do the data analysis him/herself.

⁵⁵ *Partnership research* is an exception to this as it is a university project where an academic works in tandem with a person with learning disabilities in order to privilege their insider perspective. The topic under review is likely to be about learning disabilities. For example Iain Carson of the University of Manchester told me in an e-mail: ‘the focus of my research is knowledge production by people with learning disabilities. I’m operating within a participatory paradigm and my research is being conducted entirely in partnership with a person who has learning disabilities. He has been fully involved in the research design, the production of data collection instruments, the collection of data and the analysis of data.’

Third, another issue that is raised in the literature is the need for researchers to have regular contact with people with disabilities. Barnes (1992:122) observes that ‘for researchers, with or without impairments, to gain a comprehensive understanding of the meaning of disability it is essential that they interact with disabled people on a regular basis.’ In fact, a study has been conducted which correlates interaction with disabled people with positive or negative beliefs about the moral meaning of disability⁵⁶. This underlines the importance of researchers adhering to the need to gain an insider view through empathetic and regular involvement in order to break through prejudices held within mainstream culture which are likely to have been internalised by the researcher. Certainly such exposure, while engaged in critical thinking on the subject, had a profound effect on me and enabled my negative concept of intellectual impairment to be modified; indeed, for my positive view of so-called ‘normality’ to be challenged too. Earlier exposure to disabled people, in my under-graduate days, had shored up my societal prejudices but then I was not engaged in any kind of critical reflection and neither were the disabled people I knew. McCollum (1998:182) from field work experience, argues that the more face-to-face contact and the better a person knows people with disabilities, the higher the level of acceptance and inclusion. Schneider & Anderson also support this view and Taylor & Bogdan (1989:33) challenge a popular view urging ‘for many people familiarity breeds acceptance, not contempt.’

Fourth, Moore et al (1998) suggest some ground rules for conducting critical disability research, which I was particularly interested in. My synthesis of the ground rules are:

- ◆ To give voice to the research subjects and take their views seriously
- ◆ To celebrate subjectivity
- ◆ To ensure that the research leads to improvement for disabled people
- ◆ To own up to a commitment to be promoting the rights of disabled people
- ◆ To be open about one’s own motivations so that they do not influence the research
- ◆ Always to allow the subjects to speak for themselves

⁵⁶ Examining people from a Judaeo-Christian context, Weinberg & Sebastain 1980 found that the less real contact they had with disabled people the more likely they were to believe negative things about the moral meaning of disability, whereas those who interacted with disabled people regularly were less likely to give credence to oppressive beliefs.

- ◆ To try to ensure that participants are co-researchers and allowed to set the agenda where possible
- ◆ To allow the disabled subjects to be involved in the analysis of the data.

A further reason for making use of this critical disability research approach is that it is consonant with the values of ethnographic research.

The ground rules which I cannot accommodate are the last two: to allow disabled people to be involved in the data analysis or to ensure that they are co-researchers. I take the data analysis to be a research task that I must do for three reasons: firstly because it is a university regulation, secondly, because I did not feel confident to do this before attending specific classes which teach this and finally because the context in which I meet these people is a recreational one and they would, quite understandably, not be likely to want to do any work for me. That applies to disabled and non-disabled people alike.

Fifth, I turn now to the crucial issue of language which has had much attention in recent times. Language is an important issue as it both reflects and constructs the social world around us. As the NATFHE⁵⁷ Guide to Equality Language states

language is not neutral, neither is it a simple transparent medium for conveying messages. Language can help to form, perpetuate and reinforce prejudice and discrimination. Because discrimination continues, so negative feelings and attitudes may come to be associated with a word or phrase. (Williams:1 (not dated))

One slogan of the Disability Movement⁵⁸ has been ‘nothing about us without us’ (McCloughry & Morris 2002:14) and this is a factor in selecting which linguistic terms to use. Hunt 1966; Harrison 1995 and others object to phrases like ‘the blind,’ ‘the deaf’ etc as these expressions imply a group outside the rest of society. However, I do use the term Deaf Community as this denotes a people whose first language is sign language whether they are hearing or not (eg the children of Deaf parents). Generally ‘people/persons with disabilities’ is preferred as it foregrounds that we are talking about a person and the disability is secondary. However, Oliver

⁵⁷ The National Association of Teachers in Further and Higher Education.

⁵⁸ As stated elsewhere I use the term Disability Movement as it is used in the literature which tends to present the DM as speaking with one voice.

(1996) objects to anything that suggests disability is an addition rather than an integral part of a person thus preferring 'disabled person'. Others, i.e. those, like Mercer and Barnes (2004) who hold to a strong social model of disability, would object to this term as society is thought to be the only disabling factor in creating disabled persons. Thus 'impaired' is preferred over 'disabled'. In my study, I will use some terms interchangeably so as to minimise offence. The need to respect the *feelings* of people with disabilities is uppermost in this endeavour and may be at odds with a deeper understanding of linguistics.⁵⁹

In recent years the phrase 'learning difficulty' has been replaced by 'learning disability' as this allows for differentiation between, for example, dyslexia and dyspraxia which can be called 'learning difficulties' while 'learning disability' is the current term for what used to be termed 'mental handicap'. However, although 'learning disability' is widely used in the UK and is the accepted term in government documents it should be noted that self-advocacy groups have expressed a preference for 'people with learning difficulties' (Coles 2001:501). However, a positive reason for using the term 'learning disability' is pointed out by Coles (Coles 2001:189) who says

the widespread adoption of the terms 'learning' or 'intellectual' disability in the 1990's made a clear statement that it belongs to disability. Linguistic changes both reflect and encourage a tendency to see learning disability as a fit subject for disability studies.'

The terminology then has encouraged the inclusion of people with intellectual impairment in the overall Disability Movement and since the main thrust of my work is inclusion, I will take this path notwithstanding the stated wishes of some self-advocacy groups.

⁵⁹ Deborah Cameron encountered a similar dilemma regarding feminism and linguistics. As a feminist she understood the feminist desire to address language issues, yet as a linguist she regarded some feminist ideas as linguistically unsound. To address this issue she wrote 'Feminism and Linguistic Theory'. It could be argued that there is a case for a book on 'Disability and Linguistic Theory', as cognitive linguists see embodiment as central to linguistics. For example conceptual metaphors using 'up' tend to have a positive aspect because of the 'normal' upright position of the body (and the reverse for 'down'). (See Johnson 1987)

4.4 Study design

In this section I will discuss the design of the study, which was a multi-case study exploring the same issues at two separate sites, and the way in which the data was collected. The samples, and settings are also explained, with details of location and access and ethos and format of the research sites.(see also appendix 2a-d).

This study is comprised of two case studies, each case studying one unit of analysis and the two being used for comparative purposes.

My research questions were:

- ◆ To what extent does Judaeo-Christian faith and therefore the Christian church, represent a form of oppression for disabled people, as claimed by the Disability Movement?
- ◆ In what ways, does the church include people with disabilities, especially those with learning disabilities, and are they encouraged to participate in the ministry of the church?
- ◆ To what degree are people with impairments included in the mainstream life of the Church fellowship?
- ◆ Are they respected as adults and encouraged to be self-determining? Also, are they supported in such adult areas as employment, independent living, bereavement, marriage and parenthood?
- ◆ What elements in the culture of a given congregation are conducive to the full inclusion of people with various disabilities?

The study was concerned to explore the culture of two specific church settings Although there is almost a consensus in the literature that the institutional church is oppressive of disabled people (Eiseland 1994; Majik 1994 & Rose 1997) this claim, or, assumption even, has never been fully explored before. The two cases were concerned with what went on in church settings, including social events arranged by those church groups, e.g. discos and holidays, and was not concerned with life beyond that context. The cases used multiple methods of data collection: participant observation, semi-structured interviews, a focus group and some content analysis of seating arrangements at one of the settings.

Nine interviews were conducted each taking between 45 minutes to an hour. All interviews were conducted with the people who shaped and led the work, thus the number is small. The participant observation spanned a twelve month period, with 24, one hour observations at church of the Good Shepherd (hereafter GCS) and 4 two-hour observations at Riverside Church. Also 24 one and half hour participant observations at Kingsway (the specific group at GCS) and 12 two and a half hour sessions at Reach Out (the designated group at Riverside Church). There was also a 2 hour house-group that I attended at Riverside church but no data was taken from this setting as it seemed unethical to do so as it was a private context where participants could reasonably expect their privacy to be respected. I also did some analysis of where members of the Kingsway group sat in the church service in an attempt to start to consider issues of inclusion.

The data aimed to give voice to multiple viewpoints, however, it was not triangulated, as there was insufficient data collected through just one focus group to make this possible. In order to familiarise myself with the settings, I conducted regular participant observation over a 12-month period. I gathered all the data over the 12-month period. I started with the participant observation and then conducted my interviews and the focus group with the hope of probing deeper some of the issues I had noted during my observation. The following table sets out the details of the data collected over a twelve-month period from September 2004.

Table 4.1 Summary of data collected for the study

data	details
interviews	2 leaders, 1 helper, 1 carer @ Kingsway 45-60 mins each 2 leaders. 2 helpers and 1 carer/parent @Reach Out

Participant observation	@CGS 24x 1 hour informal church service
	@Kingsway 24x 1.5 hours
	@Riverside 4 x 2 hours (signed service)
	@Reach Out 12x 2.5 hours
	House group @ riverside 1x 2hours
Content analysis	Seating plan made during CGS 11.00 service denoting where people with learning disabilities sit in relation to the rest of the congregation

4.5 Settings, sample and access

Denzin and Lincoln (1998) suggest qualitative researchers often use purposive rather than random methods of sampling. I visited Church of the Good Shepherd and was given information about a second site; both these churches were within easy distance of my home. Hammersley & Atkinson 1995:39 claim that ‘ethnographers’ often do studies in settings geographically close to where they are based. I will now detail the situation with regard to location and access and ethos and format at both sites.

Location and access

The first site which I shall call the Church of the Good Shepherd (CGS) was a lively Anglican church of an Evangelical persuasion, with a membership of around 300. The building was originally a traditional church with an altar at the East end. However, when the church decided to move to a less formal worship style, it was decided that a new layout was needed. The adjacent side of the church was decorated in a modern, artistic and non-ecclesiastical style to form a new focal point with a platform. The seating in the main church area was arranged in a series of rows such as one finds in an amphitheatre. This was intended to create a more participative feel rather than the passive and receptive style of the priest at the high altar and the people sitting silently in rows up the length of the building. The congregation was mixed in terms of age, race and gender and class which reflected the local context well. Sometimes no more than 100 were present at 11.00 but there could be as many

as 200 by ten minutes past. The vicar made a general plea for punctuality confessing that he had been late for years when he had a young family, identifying with the difficulty of getting there on time. Attendance of the Kingsway group varied for as Greg pointed out it could be a bit 'weather permitting' as none of them could drive and might be deterred from walking in inclement weather conditions. There was a lot of participation from the congregation and week after week different members of the laity preached the sermon. This included both men and women and was racially diverse. The vicar had a very self-deprecating manner aimed at putting people at their ease and interruptions by children were more than tolerated for children were welcomed as children and not simply as 'little adults'. In common with other Evangelical churches there were a number of events mid-week and unusually, CGS had a house-group for people with learning disabilities which served six local churches and I shall call this designated group Kingsway. CGS also had 3 main services on a Sunday: one at 9.30 and informal worship service at 11.00 and an evening service at 6.30.

In order to facilitate access, I attended the informal worship service at 11.00 twice monthly for one calendar year as most of the Kingsway group went to that service and it also enabled me to be there in the changeover between congregations and to observe the interaction between the congregation and the Kingsway members. The congregation, at 11.00 numbered around 150-200 adults plus children. At the 11.00 service I noted a lot of visual input with regular use of the data projector, coloured banners used for dancing during the worship and some use of drama and story telling. I also noted that people (in general) were encouraged to speak for themselves. Often the current vicar (Stuart) would say a few words and then different people would come up to the front and give details of a notice that concerned them. On one occasion the notices were done on the data projector with children from the church being filmed reading them for the congregation. The length of the service was generally about one hour in total with the sermon being confined to a maximum of twenty minutes.

On the occasion that I first visited the morning service at CGS, a warm welcome was extended to me by Greg, who ran the Kingsway group and indeed by the rest of the pastoral team and it was swiftly agreed that I should attend the informal family

service at 11.00 two Sundays a month. I also attended the bi-monthly Kingsway meeting on a Tuesday evening. Access was initially granted by the leadership team as the outgoing vicar (Rodney) was soon to leave and his replacement was already a member of the leadership team so no further permission was required when Rodney left. Access had been gained easily but I was nevertheless mindful of that fact that once permission had been granted it could just as easily be withdrawn (Jorgensen 1989:47).

I will now describe the ethos and format of the Kingsway group and the main church at CGS.

Ethos and format

The Kingsway group met in the church hall which was divided into discrete areas, one where there were round tables and chairs, like a café for people to sit at in small groups, while the other area was more like a sitting room with comfortable chairs. The first half hour (7.30-8.00) was for coffee and socialising. This first 30 minutes for social interaction was important as most people arrived by car having been given a lift from their home. At 8.00 the meeting was continued in the room with a more homely feel. There was singing, Bible teaching and prayer until 9.00 when the meeting ended promptly for lifts home. On an average evening there would be around fifteen members with a higher ratio of men to women and around six helpers with the reverse ratio of more women than men. Helpers were generally caring people but not necessarily trained for this particular purpose. Some members came from institutional homes while others lived independently in the community. They ranged in age from about 17-75. There was a sizeable group of young people and a number in their middle years and a few at the older end. Some were very communicative verbally, while others communicated less in words or not at all. Many were highly communicative in tactile ways. There was a fairly even mix of male and female and all were white Caucasians.

I will now provide a brief vignette of ten (5 male and 5 female) of the most regular members at Kingsway.

Kingsway Table 4.2

pseudonym	Age group	Brief personal profile
Joni	45-55	Lived independently, did cyclothons and other sporting events. Engaged to be married.
Irene	55-65	Lived in institutional home. Spoke very seldom and needed help finding page numbers in song book
Polly	55-65	Lived in institutional home No speech - very communicative - tactile and friendly
Paula	25-35	Lived independently and worked locally
Jilly	15-25	Lived at home with parents and at college
Dan	45-55	Lived independently with carer coming in to help and worked. Enjoyed setting up tables for the meeting and playing guitar.
Chris	15-25	Lived independently with carer coming in to help At horticultural college and liked praying out loud in meetings and putting out tables.
Sidney	35-45	Man who lived in institutional home enjoyed praying aloud and leading the group
Charlie	55-65	Man who lived in institutional home but parents nearby. Prayed a closing benediction like a 'professional'.
Anthony	15-25	Man at college and living at home with parents.

The group were mixed in terms of learning difficulties, some having Downs, some with autism, some having speech, some able to read and many communicating in tactile ways.

I attended all the group meetings on a regular basis (twice a month) for one calendar year, in order to sample the routine rather than picking out what might be extraordinary (Hammersley & Atkinson 1995; Silverman 2006). The ethos of the group in common with the church as a whole was highly participative. Members arrived and set up the 'living room' area for the meeting. Books were distributed by

the members and they were keen to call out numbers for favourite hymns or choruses. Members also made prayer requests addressing issues in their daily lives or the lives of those close to them. One man with Downs syndrome usually opened the meeting and another older man, also with Downs syndrome, gave a closing benediction. Greg lead in the sense of being a facilitator and encouraging participation yet taking control if things got out of hand or if anyone's boundaries were breached or in danger of being so.

I now describe the second site looking at the same features: location and access, ethos and format both of the special group and also the main church.

Location and access

The second site which I shall call Riverside Church was a large Evangelical church. The building was modern (1970's) and there were steps to the front of the building but a slope to one side to enable wheelchair access. However, the building was not accessible for wheelchair users without assistance.⁶⁰ The seating in the main auditorium was set out as in an amphitheatre with tiered rows and there was a designated area on the ground floor for wheelchair users. There were also 2 balconies overlooking the auditorium. There was a central platform with a raised pulpit which was not always used. On the platform there was a music group, using modern instruments such as, guitars, keyboard and drums. Songs were projected onto the wall and coloured banners were available for members of the congregation (often children) to use during the worship time.

There were two main services on a Sunday: one at 10.00 and one at 6.30, both of which were well attended reaching full capacity at around 500 adults and children. There was some general 'disability' awareness as they provided signing in their Sunday morning service each week (However many Deaf people do not regard themselves as disabled but as minority language users).

⁶⁰ It should be noted that moves are afoot to have the building redesigned for greater accessibility for wheelchair users.

The ministry that Riverside Church held for people with learning disabilities I shall call *Reach Out*. The leaders of this group, James and Felicity, were the main gatekeepers. Access had been granted, first by the pastor of the church and then by James & Felicity after a visit to their home where we talked at length as they reassured themselves that their 'clients' (a term that they used) would be safe with me. Although access had been given it is a continual process and can always be withdrawn at any point and I was keen to avoid such an outcome. Consequently, I tried to accommodate the wishes of the gatekeepers as much as possible.

Ethos and format

Reach Out was a much larger and more diverse group than Kingsway. An average session would draw 40 people and a large number of carers and helpers⁶¹, so that there could be as many as 70 people in the hall where they met. Many group members came from institutional homes while some lived independently in the community. A good number had multiple impairments and there were always several wheelchair users present. The hall was attached to the church and there was easy wheelchair access along the ground floor so that everyone could access the toilets, the kitchen and the more comfortable rooms near the entrance which were sometimes used for activities. The ages were mixed but there were quite a lot at the older end even up to 82. There were also some much younger people. As at Kingsway they were all white Caucasians.

The meetings started at 3.00 when all were welcomed and given name badges to wear. There was a strong sense that members were glad to see each other. When most people had arrived, the meetings started with general singing and instruments, such as tambourines, maracas, bells etc and a time of prayer, Bible teaching and singing lasted until 4.00. The teaching was often accompanied by drama or video clips. At 4.00 there would usually be some specific activities to consolidate the teaching and the members usually had a choice of four activities. Colouring in was always one of them and was a firm favourite with some members. Often drama was included and at least one craft activity and these lasted until around 4.30 when tea

⁶¹ Many of the helpers had training in 'special needs', often in education. Also a lot of the carers were professional carers.

was served. One of the group, supported by Felicity, made the tea in the kitchen.. Members sat round tables in groups of six and plates were brought to them loaded with a mix of sandwiches and cakes. The atmosphere was much the same as at any tea party.

I will now provide a brief vignette of 10 of the most regular members (5 female and 5 male).

Reach Out Table 4.3

pseudonyms	Age group	Brief personal profile
Tanya	15-25	Lived independently and worked locally Played drums
Ginnie	15-25	Lived in institutional home, enjoyed reading aloud.
Sharon	35-45	Older woman, lived in institutional home.
Suzie	35-45	Lived at home with parents Usually on the welcome desk writing name badges for visitors.
Betty	65+	Lived independently and also went to Kingsway group. Loved worshipping God
Cliff	25-35	Lived in institutional home enjoyed dancing.
Si	25-35	Lived with parents and mother came too as a carer. Liked to join in.
Johnny	45-55	Came in late most weeks. Lived independently.
Jack	15-25	Young man lived in institutional home. Spent much time colouring in.
Bobbie	35-45	Lived in institutional home but sometimes came with his dad. Moved about a lot. Liked to use the maracas.

The group was mixed with some having Downs or autism, a number of wheelchair users, and many with multiple impairments.

I will now describe the ethos of the morning service at Riverside. The sermons were typically around 40 minutes long or more. The lead pastor and the elders do most of the preaching (all white, males) but there is one woman who does not seem to be an elder who preaches periodically. On one occasion the pastor's sermon only lasted 35 minutes and the shortest sermon I heard was when the woman preached (30 minutes). The woman who leads the signing tells me that the services are too long for Deaf people and the sermons are often too complex to sign to her group.⁶² The total length of the service is between 1 hour and three quarters and 2 hours which is not untypical of Evangelical churches. Aside from the worship and the preaching there are times of personal testimony and people are encouraged to pray aloud from the congregation and even bring 'prophetic words'. The service is led from the platform but there is a sense of participation from the congregation. Prayer ministry is available after the services.

The congregation was mixed in terms of age and gender but there were very few of the members of *Reach Out* in evidence which may simply be because not many of them come from the church. I will now outline the methods used for my research. For a fuller account of the two settings see 3.

4.6 Methods

Since the problem under investigation influences the methods selected (Bryman 2000; Clough & Nutbrown 2002; Silverman 2005) I opted primarily for ethnographic tools: participant observation, semi-structured interviews and focus groups as these enabled me to uncover that which cannot be known by, for example, conducting surveys.

⁶² The Signer explains that many Deaf people who were forced to learn to lip read have a reading age of only around 8 so in common with many people with learning disabilities they need a message delivered in simple language, or perhaps in not just language but using other media.

Participant observation

Participant observation is my principal method of field research and Burgess (1993) urges that it should be supplemented by other methods, which makes for a more robust approach. Berg (1989) and Jorgensen (1989) advocate the gathering of information from multiple viewpoints which Miles & Huberman (1994) believe maximises the depth of insight. Jorgensen (1989) underlines the fact that in participant observation there are no subjects *per se* but simply situations in which human beings are observed.

Jorgensen (1989:13-14) lists some of the key features of participant observation as

- ◆ A special interest in human meaning and interaction as viewed from the perspective of people who are insiders or members of particular situations and settings;
- ◆ location in the here and now of everyday life situations and settings as the foundation of inquiry and method;
- ◆ a form of theory and theorizing stressing interpretation and understanding of human existence;
- ◆ a logic and process of inquiry that is open-ended, flexible, opportunistic, and requires constant redefinition of what is problematic, based on facts gathered in concrete settings of human existence;
- ◆ an in-depth, qualitative, case study approach and design.
- ◆ the performance of a participant's role or roles that involves establishing and maintaining relationships with natives in the field; and
- ◆ the use of direct observation along with other methods of gathering information.

Whatever approach the researcher adopts there tends to be some tension between being an observer and a participant. Where lack of participation can make researchers conspicuous (Hammersley & Atkinson 1995) the complete participant will enjoy the greatest potential for intimate interaction with the research subjects (Barnes 1992), although a requirement to act in line with role expectations may limit the data collection (Hammersley & Atkinson 1995). The latter approach can lead to an emic (insider) perspective which if negotiated correctly is ethically more defensible than using covert methods. Regarding the issue of insider/outsider locations, in the same way in which some researchers reject a straight forward dichotomy of qualitative and quantitative, so others (Fetterman 1989; Waterhouse 2002) dispute the simplistic divide of emic/etic and others (Spradley 1980;

McCrutcheon 1999; Arweck & Stringer 2002) see this process as a continuum. There is a view that as participant involvement increases so the ability to observe effectively and accurately is diminished, but Jorgensen (1989:56) contends that everyday activities belie this view. Others (Adler & Adler 1987; Hammersley & Atkinson 1998) agree with Jorgensen's insistence that the assumed conflict between participation and observation has been exaggerated.

Burgess (1993) says that the observer as participant is characterised by brevity of contact. The advantage is a lowering of the risk of 'going native' but an increase in the likelihood of rejecting informants' views without really becoming acquainted with them. However, the participant as observer approach permits the researcher to penetrate social situations in order to establish relationships with informants so as to achieve an understanding of their world. This was achieved far more at CGS than at Riverside because of the difference in the degree of 'othering'⁶³ that occurred (which included my own responses). Gans (1968) devised a classification of participant/observer roles which he expected to co-exist rather than being mutually exclusive. They are total participant; researcher-participant and total researcher. These roles allow for varying degrees of involvement and detachment and offer the flexibility needed for fieldwork (Bryman 2004). In this scheme I was more often researcher-participant, in both contexts.

At Kingsway, I was more of a participant who observes. This can be judged to have been successful as on one evening I was mistaken on two separate occasions as being one of the group members, evidenced by being asked which home I came from. Normally I mixed easily with the group members during the refreshment period at the beginning.

At Reach Out, initially I struggled to participate and was more often an observer who participates or even just an observer at the start. Many of the members had multiple impairments which I found difficult as I was considerably out of my comfort zone. Although I tried to take notes as unobtrusively as possible, I became aware that my taking of field notes was drawing attention from some of the leaders who as

⁶³ 'Othering' is a sociological term which refers to a mechanism in the mind by which someone becomes classified as 'not one of us'.

Hammersley & Atkinson (1995:80) warn may see the researcher either as an 'expert' or a 'critic', both of which may have negative effects. I did in fact take notes on a wide range of things, not yet knowing what would become salient and where patterns would emerge. This led to the production of copious field notes although I tried to write in a shortened form that would jog my memory sufficiently to write up more fully on my return home. However, field notes have their own problems. Van Maanen (1988:223-224) puts it like this:

To put it bluntly, field notes are gnomonic, shorthand constructions of events, observations, and conversations that took place in the field. They are composed well after the fact as inexact notes to oneself and represent simply one of many levels of textualisation set off by experience. To disentangle the interpretive procedures at work as one moves across levels is problematic to say the least....

I tried to be as unobtrusive as possible thus utilising a small A6 book. My observations were not based on any pre-designed schedules; rather, I made observations, descriptions and notes that attempted to capture the setting and its interactions. In time, this tension with the leaders led to me becoming more of a participant and this is exactly what Brett Webb-Mitchell describes in his ethnography on L'Arche, Lambeth, where he notes 'the dual roles of being a participant and an observer...was not easily maintained and balanced' (1983:35). However, as I built relationships with the group members it was easier to become more of a participant.

The second research tool I deployed were semi-structured interviews which I will now explain through the related literature.

Interviews

According to Denzin (1970:123) interviews are classified with regard to the degree to which they are structured. Berg (1989:19) believes that they are an especially effective method of collecting information particularly when researchers are interested in the perceptions of participants. The semi-structured interview best fulfils Loftland & Loftland's (1995) claim that the essence of the research interview is 'guided conversation' giving more flexibility than other types of interview. Fielding & Thomas (2001) describe the semi-structured interview as giving the interviewer freedom to vary the sequence of questioning and to vary the depth of

questioning ‘thus adapt[ing] the research instrument to the level of comprehension and articulacy of the respondent.’(Fielding & Thomas 2001:124). The interviewer’s task is to draw out all relevant responses, to encourage the inarticulate or shy and to be neutral towards the topic while showing interest (Fielding & Thomas 2001:129).

There is sometimes a structure to interviews where the researcher has a number of issues to be probed but the structure is loose so as to be flexible so that interviewers can move in directions which they choose and follow up matters that are suggested by their respondents. Berg (1989:17) suggests that interviewers need to digress in order to probe beyond the initial answers to their prepared questions. It is anticipated that subjects may often express their viewpoints more freely in a relatively open context compared to more standardised interviews or questionnaires (Flick 1998:76).

I used my interview schedules (see appendices 2a and 2b) more as an ‘aide-memoire’ as some of the participants were eager to speak and I allowed them to lead off in the directions that they chose yet still ensuring that the questions I wished to pose were included. Interviews with carers or parents followed a different line to the interviews with helpers and leaders as there were questions which focused on the experience of the people with intellectual impairments and one specific question just for parents probing their feelings and experiences. Questions for helpers and leaders also concentrated on their experience with people with learning disabilities but also on their theological framing of the issue (see 2b). These interviews concluded with a penultimate request to comment on 4 statements about disability, framed as ‘disability is...’ which typified 4 of the theories of disability in the literature. The last question invited respondents to add anything they wished to say.

I chose to use semi-structured interviews partly not to impose my agenda but to uncover the subjects-viewpoint and also because of consistency with a feminist concern not to be exploitative of the respondents; semi-structured interviews are preferred by some feminist researchers (Rubin & Rubin 1995). There may be some issues which are resistant to observation and can therefore only be uncovered by interviewing. For this reason I believed that a combination of semi-structured interviews and participant observations would enable me to get a hold on the subjects’ social reality (Bryman 2004:338; Flick 2009:232), insights gained through participant observations being confirmed through interviews (Hammersley &

Atkinson 1995:131) or indeed the reverse: highlights gained from interviews causing the participant observation to be differently construed (Woods 1981).

Goffman makes a number of critical observations; that the interview is a 'social performance'(1959) and that interviewees may employ 'evasion tactics'(1967) to indicate that they do not wish to engage in further discussion on the topic. There is a view that a skilled interviewer must be able to push through resistance at all costs (Berg 1989:26) but since everyday life considerations for face-saving and deference determine that these are respected I would challenge such a view as unethical and be unwilling to adopt such a practice. One of the drawbacks of interviews is that the interviewees may be more concerned with self-presentation than the accurate portrayal of the phenomena under review. (Hammersley 2003:120).Added to this, individuals often have complex and ambiguous, even contradictory, identities (Rubin & Rubin 2005) so simply trying to get to the 'real' person may be a rather naïve endeavour.

A further difficulty with interviewing is the issue of complex and sometimes asymmetrical power relations between interviewer and interviewees. This was less likely to be a problem in my work as the people I interviewed were the leaders and as such were not likely to feel intimidated by me for I was open about the fact that I am not an expert in the field. Nevertheless, it could be argued that in some contexts the role of interviewer elevates that person over the interviewee, regardless of expertise.

Although it is never possible to conduct 'perfect' research Kvale (2008:124) shows how research can be seen as trustworthy and credible based on

The quality of the craftsmanship in checking, questioning and theorizing the interview findings that leads to knowledge claims that are so powerful and convincing in their own right that they, so to speak, carry the validation with them, like a strong piece of art.

Once interviewing has been chosen as a research tactic the next critical question is who should be interviewed? Dean et al (1967:285) list a number of criteria that may be used for selection, the first of which is germane: '*informants who are especially sensitive to the area of concern.*' (my emphasis) Further, in terms of format Spradley

(1979) cautions against asking *why* questions as these can create pressure and convey a value judgement, and I followed this advice.

I conducted 9 interviews in total, with the key players at each site (see table 4.3). At each site I selected both leaders, one carer/parent, and 1 or 2 other helpers. I differentiate between leaders and helpers according to the degree to which they shaped the work or merely helped in its execution. Interviews took from between 45 minutes to an hour and were held during the day in a place of my participants choosing: often at the research site, or at my home if that was more convenient. All the interviews were recorded with an MP3 player and I transcribed them verbatim. Since I recorded over each previous interview there was no problem with storage of data.

Here follows a table detailing the interviewees, 4 from Kingsway and 5 From Reach Out and giving some general information about their background in disability work.

Table 4.4

Pseudonyms of interviewees @ Kingsway	Involvement with disability issues
Greg (Leader)	Over many years, in support roles through his work as Youth Leader initially.
Lisa (Leader)	From decades back - college days and through a career in nursing.
Doreen (helper)	Has always been drawn to marginal groups
Sheila (carer)	Recent involvement through being a carer
@ Reach Out	
Angie (Helper)	Very recent involvement
Carol (helper)	Over decades – teaching children with disabilities in schools
James (leader)	Over many decades – always drawn to marginal groups
Felicity (leader)	Background in teaching children with disabilities

Lee (parent)	Over decades as a mother with a child with Downs Syndrome.
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Taking my main research problem as my pivotal point, I sought to probe issues that helped me to explore in greater detail my main concerns of a) inclusion and b) a theological understanding of the church's relationship to disabled believers. As stated before, I constructed a schedule to be used as an *aide memoire* to allow for flexibility in interviewing. In this way, I hoped to be able to take a reflexive and responsive approach to what the interview participants had to say. Various issues that had surfaced in the literature review formed a good starting point for most of my questions. Those relating to disability and the church were designed to probe critical areas raised by the Disability Movement. This movement has asserted that the Church is, in the strongest form, oppressive of disabled people, or in a weaker form, at the very least, inhospitable and unwelcoming. These topics and critical perspectives were evident in research and writings from outside the church, as with secular writers on disability (Barnes 1996; Rose 1997; Shakespeare 1997, among others) and also from within the Church, from researchers with a specific concern with matters of inclusion (see Eiseland 1994; Webb-Mitchell 1994; Swinton 2001; McCloughry & Morris 2003; among others).

Overall, the questions were influenced by key insights gleaned from the relevant research and these findings were used to start to elicit the perspectives of participants. For example, the interview schedule was constructed round related matters in the research literature such as the pain of parents with disabled children (Featherstone 1981; Kelly & McKinley 2000; Daly 2000). This work was used to help sculpt questions for carers and parents. The question that was designed for leaders and helpers, that asked what in their background aided or hindered them in their ministry with people with disabilities, drew on the insights of Dalpra 2009. This work argued that people with Sunday school teaching experience sometimes had a tendency to feel automatically equipped to teach adults with learning disabilities because of their work in the Church, although this was not always the case in practice. My approach was to use the schedule as a prompt in order to give as much space as possible to my participants to reflect on their work in their setting.

The *disability is* cards that gave four diverse statements on disability for comment, were designed to tease out how the interviewees positioned themselves with regard to some of the dominant views of disability. As stated elsewhere (p103 in methodology) each statement typified a different theory of disability, ranging from a medical view, which sees disability as a deficiency, to a view of disability as gift and blessing as upheld by some disability activists.

Before I started my field work I conducted an open pilot study at a third local church. At this time I was exploring the issue of inclusion in its broadest sense with disability being one sub-topic among others. I attended the morning service at 10.00 at Trinity Church (pseudonym) for 6 weeks and conducted 6 interviews with members of the congregation and also with the Rector of the church. One of the benefits of the pilot study was in my being able to highlight my tone of voice during the playback of an interview which communicated a cynical attitude to the idea of the church wanting to include disabled believers in power-sharing ways (eg in preaching). When I came to do the interviews in the actual study I was aware of needing to express neutrality in my manner.

I now look at a second type of interview, namely, focus groups, which I also deployed.

Focus groups

Focus groups are used ‘to create a candid, normal conversation that addresses, in depth, the selected topic.’ (Vaughan et al 1996:4). Essentially a focus group is a form of group interview but in the literature much is made of the difference between focus groups and group interviews. There are three main reasons for this concern with the differences. Firstly, focus groups emphasise a specific theme, they are about how people discuss an issue or a topic as members of a group and unlike group interviews they are not used as cost-cutting measures. However, in the literature the terms focus group and group interview (where people are interviewed en masse but invited to respond individually) are sometimes used interchangeably. Bryman (2004:346) offers some clarification.

The focus group method is a form of group interview in which: there are several participants (in addition to the moderator/facilitator); there is an emphasis in the questioning on a particular fairly tightly defined topic; and the accent is upon interaction within the group and the joint construction of meaning.'

One of the drawbacks of focus groups are their labour intensity in terms of recording and transcription, difficulty in analysing data, problems of organisation and for some researchers (though not in my case) a loss of control over proceedings. An advantage, to my mind, is that it gives the participants the opportunity to take considerable control.

I now give some details of the 6 focus group participants giving pseudonyms as before.

Focus group participants

Table 4.5

pseudonyms	Background in disability ministry
Lisa	A church pastor from CGS with former nursing experience and involvement with disabled people through a friend mentioned in interview.
Felicity	A former teacher for children with learning disabilities over many years. From Riverside Church
Patrick	Former Chief Executive of a charity for people with learning disabilities and Adviser to the Bishop on mental health issues. From the Diocese.
Wanda	Diocesan adviser to the Bishop on matters relating to people with learning disabilities and also a former leader of a theatre group who travelled with young people including several with Downs Syndrome.
Patsy	Involved in pastoral work with husband Patrick over years with people with learning disabilities and also those with mental health issues.
James	Deacon for Social Concern involved in a range of ministries to people on the margins of society (and with Felicity) leading a group for people with learning disabilities for over 20 years. From Riverside church.

I attempted to create a fairly unstructured setting in which the participants' views and perspectives could be drawn out. I invited the respondents to come to my home for the discussion in the living room followed by a 'thank you' dinner in the dining room. I expected them to have at least a passing acquaintance with each other from their local involvement in this specific ministry to people with intellectual

impairments, yet I was confident that none was in any kind of power relationship which could inhibit their contributions. Of the ten people that I invited I was only able to find a suitable date to accommodate six individuals drawn from both settings and elsewhere. One of the leaders of the group at Church of the Good Shepherd called Lisa in the interview was able to attend and the two leaders, James and Felicity from Riverside were there. Three of the other people in the focus group were not from either of the two research sites but two of them were attached to the Diocese. Wanda was at that time the Adviser to the bishop on learning disabilities and had travelled for a number of years with a theatre company which had some young people with Downs Syndrome among their number, and the other couple (Patrick and Patsy) also had a life time's involvement with both mental health issues and learning disabilities.

I also undertook a focus group at my home. As with the individual interviews I had a number of issues I wanted to probe but was happy for the participants to take the discussion off in any related direction. The discussion started unexpectedly, for after I had set the scene, welcoming everyone and explaining the purpose of the focus group, Wanda asked if I could read out all my questions so that they knew where they were going. I agreed to do this but with the proviso that I was not necessarily going to cover those questions but might want to go off at tangents that arise from the group. (See.2c).

The focus group discussion lasted for just over an hour and then we were all able to fully relax over a meal downstairs. I now move on to look at a number of ethical concerns.

4.7 Ethical considerations

Ethics is always an important issue where research on human subjects is concerned. However, where the area is especially sensitive this is even more the case. I started my work in 2003 when the ethics committee at Kings had not been established. With hindsight I can see that this input would have been helpful.

Ethics is a question of principled sensitivity to the rights of others and self, which consequently is likely to limit the choices researchers have in the way research is conducted. Bulmer (2001:46) asserts that researchers must preserve the rights and integrity of their subjects as human beings, even at the expense of remaining ignorant of the matters that may be under review. In this section I will look at the question of who is entitled to do disability related research, issues of consent, the question of anonymity and confidentiality and finally reciprocity.

Who can research disability issues

A central question for this thesis, is who can research disability issues. Moore et al., (1998:14) highlight the need to be

Critical of self in terms of values, presuppositions and practices [as] an essential part of developing a critical disability research process, particularly when reflections can be made in association with others and in relation to the voices of disabled people

There is one key ethical issue that relates to the substantive research area of disability. In some quarters it is argued that non-disabled people are less well placed to undertake research in this area. Ethically it is argued that there may be concerns about the 'control' of this area by non-disabled people. For example, according to Oliver 1992; Abberley 1992; Hirst & Baldwin 1994 and Gregory et al., 1996, much of the research that has been conducted by non-disabled researchers has been considered by disabled people to be either futile and/or to have, negative consequences, undermining the agendas of disabled people. This has led to essentialist claims for the value of this type of research only being conducted by researchers with disabilities. However, Barnes points out that 'analytically the experience of impairment is not a unitary one.' And going further he notes,

'having an impairment does not automatically give someone an affinity with disabled people nor an inclination to do disability research.... Indeed I have met many people with impairments who are unsympathetic to the notion of disability as social oppression and many able-bodied people who are. (Barnes 1992:121)

Barnes also notes that matters of age, class, race, etc are equally important to the issue of empathetic involvement. While there are ethical issues involved in who can speak for, or on behalf of, another person, ethical concerns of power, ownership and control, nevertheless, in my research, while I recognise the need to remain vigilant in

respect of these aspects, my intention is to produce work that will be useful for church groups who work with/for people with disabilities.

Before moving on to look at consent, confidentiality and anonymity, and reciprocity, I consider the four main areas of concern highlighted by Diener & Crandall (1978) and alluded to by Bryman 2008.

- ◆ Whether there is *harm to participants*
- ◆ Whether there is *lack of informed consent*
- ◆ Whether there is *an invasion of privacy*
- ◆ Whether *deception is involved*

Harm to participants can mean anything from physical harm to loss of self-esteem, harm to participants' development or causing stress, or 'inducing subjects to perform reprehensible acts' as Diener & Crandall 1978:19 articulate it. The other three categories are self-explanatory and the issue of consent is discussed here in some detail. Of course there can be some overlap of these categories.

Consent

It is axiomatic that a key ethical concern must be to ensure that, wherever possible, and as far as possible, participants should give their informed consent to the researcher (Bryman 2004). Furthermore, research participants must be aware that they have the right to withdraw from research contexts if they do not wish to participate (Bulmer 2001:49). Moore et al (1998:23) urge that

It is important to recognise that when professionals in positions of power dictate to others that they will be involved in a project, and how, those who do become research participants may not have done so of their own accord.

My observation was overt, although Jorgensen (1989) points out even when an overt strategy is employed not everyone knows about the true purpose of the research. This issue is complex for, in reality, overt and covert approaches can merge into one another, so that most observational work, as Adler (1985:27) argues is 'a delicate combination of overt and covert roles.' The issue of consent is similarly complex. In both places where I conducted research, consent had been negotiated with the gatekeepers (in this case the leaders), and as Fielding (2001:150) cautions 'you

should allow for the possibility that the gatekeeper's permission may be given without the knowledge or consent of the others being studied.'

At CGS and at Riverside church, verbal consent to conduct participant observation was given by the leaders but a decision not to do consent slips with the members was taken because of comprehension issues. *The Social Science Research webpage* on Vulnerable adults and groups states 'in institutional settings, where conformity and compliance are rewarded, people may not feel they have a *real* choice' It adds that 'refusals should not result in sanctions, adverse criticism or the loss of privileges,' which historically has sometimes been the case. All in all, the issue of consent may not be an easy one to raise with people with learning disabilities. Withdrawal was not discussed but since it was a public setting and people came on a voluntary basis it could be argued that it was quite possible not to attend if anyone wanted to withdraw.

Consent was individually negotiated with interviewees as I often spoke to them during the participant observations times so I was able to ask them informally if they would be willing for me to interview them. I was in regular contact with the participants of the focus group who were members of the Diocese and not from either Riverside Church or Church of the Good Shepherd, so it was also quite natural to raise the question of doing an interview. Of the ten I invited to the focus group, only six were able to come which raises the possibility that some people used their right not to participate.

Confidentiality and Anonymity

Although popularly used as synonyms, the two aspects of confidentiality and anonymity are distinct. Confidentiality refers to the attempt to remove from all data anything that could lead the subject to be identified, and anonymity, simply to the obscuring of the subject's or place's name. Berg (1989:138) cautions 'in most qualitative research, however, because subjects are known to the investigators... anonymity is virtually non-existent. Thus it is important to provide subjects with a high degree of confidentiality.'

It is common practice to use pseudonyms instead of actual names but it would be naïve to assume that this is sufficient to obscure the identity of the person concerned as it is sometimes possible for participants at least, to identify individuals from other clues, in conjunction with place names (Gibbons 1975). In my study, place names were obscured as were the names of the churches I attended. I needed to protect the interests of all parties (Hammersley & Atkinson 1995:66) including the leaders who I realised were anxious to safeguard their reputations. I use pseudonyms for the two churches and while I say they are located in the same county I do not mention the county other than to say it is one of the prosperous Home Counties.

Reciprocity

In order for the research to be ethical, researchers sometimes perform services or make small payments in exchange for information.(Jorgensen 1989). My work did not so much require me to make a contribution for information so much as to play my part in all the work involved in these ministries. Jorgensen (1989:72) says 'morally responsible participant observation requires that you be alert to ways of providing something of value in exchange for what you get.'

At Riverside I immediately offered to make some cakes for the tea and when I was told that some of the members were diabetic, I decided, in a spirit of inclusion, to seek out some good recipes for cakes that could be eaten by those with diabetes. I also made a dessert for the house group dinner I attended at Riverside.

At CGS, partly to make a contribution and partly to help build my relationship with the members of the Kingsway group, I made popcorn with them, having previously established that they liked popcorn. One group member started to call me *the popcorn lady* which pleased me as Johnson (1975) reminds that data is improved where good field relationships are established and sustained. The Christmas service and tea was a big catering event so I make cakes and helped clear up afterwards. At CGS, I occasionally gave lifts after the meetings. Since it is known that the position of the researcher is likely to impact the research I give an account of my location as follows.

4.8 Location: positioning myself in the research

My own motivation to encourage widening participation in the church, undoubtedly arises from a number of personal experiences of exclusion based mostly on embodiment, being a woman. As a single woman in the ultra-conservative Restoration Movement, I experienced a high degree of marginalisation as a woman's gifts were largely seen as latent and only of value to the Kingdom of God within marriage; because the man was the key mover. Restorationists did not overtly teach the Augustinian⁶⁴ view that woman is only fully human when united with her husband but the underlying assumptions were consonant with that. In this environment, depending on the level of insecurity of the leaders, I was sometimes denied the right to think my own thoughts and articulate them without being 'demonised'⁶⁵. As an intelligent woman with a passion for the church I had a lot to say about the church and although, looking back, apart from believing that women have a right to an opinion like everyone else, there was nothing subversive about my views. Had I been a pastor's wife this would have been acceptable as leader's wives are often treated with less suspicion. Nevertheless, it is as well that I was not, for I have no doubt that I would have been incapable of grasping why anyone would want to question the status quo if I had been affirmed within the mainstream, as married women are.

The fact is, that it is those on the margins of society, rather than those at the centre that are likely to have the most insight into social exclusion and for this reason I have learnt a huge amount from feminist and gay sources. Although I am a committed Christian and a regular member of an Evangelical Anglican church, with a charismatic background, this should not imply that I am uncritical of the Church and particularly in its practices when it comes to issues of social inclusion.

⁶⁴ In *Misogyny and the Western Philosophical Tradition*, Beverly Clack summarises Augustine's view of the Imago Dei: 'man is completely in the image of God whereas woman is only in the divine image when in partnership with her husband (Clack 1999:63) This view is corroborated by Sarah Coakley (1990:350) and Grace Jentzen (1990:341)

⁶⁵ This is not the exclusive experience of women as clear-sighted men are often maltreated in such environments where they are regarded as a threat and are habitually side-lined although often in covert ways so as not to acknowledge the truth or be accountable.

From within this thesis the writers that I quote from who are closest to my own position are Miroslav Volf, Jane Williams, Stanley Hauerwas, Serene Jones, Jean Vanier and Mary Grey. Clearly no two people ever hold exactly the same position on all matters, and indeed, if we are open-minded individuals we should not, necessarily, hold the same views ourselves from one year to the next, but the central thrust of these writers resonates with my own.

Through such organisations as the Anglican WATCH (Women and the Church) and the Evangelical Men, Women & God I found like minded men and women and sometimes found voice through writing for their publications: Outlook and Double Image, respectively. I also attended a feminist theology group run by my local branch of WATCH. Feminism then, and specifically Christian feminism restored my self-esteem which the conservative and male-dominated church had severely damaged: I was not wicked for believing that God had given me gifts to use in his church and aspiring to do so. I believe that in no small measure, I owe my sanity and the survival of my faith to Christian feminism and pro-feminist, Christian men.

Later as a married woman and a mother within Evangelical, Anglican circles in a conservative geographical location, I encountered a different form of exclusion based upon stereotypes of what God would ordinarily be calling a wife and mother to do. Motherhood was a form of gate-keeping that kept women in clearly prescribed locations and certainly failed to offer affirmation for venturing beyond those bounds. Somewhere in the middle of these negative encounters however, I (a single woman of 31) had a wonderful and quite prolonged experience of complete inclusion in a church that I now realise has a long history of inclusive practices.⁶⁶ I had not been there long before the pastor invited me to lead a house group. This was an extraordinary experience for me as it signalled that he was able to see a person behind the fact that I was unmarried. I was being defined by what I was rather than what I wasn't and these are issues that people in the Disability Movement raise. On the basis of this experience of prejudice I am arguing for an experience of exclusion based on embodiment. Although I am not an insider to the Disability Movement, I

⁶⁶ For example in the 1950's when most churches were battoning down the hatches to immigrants, this church welcomed in an Indian family and made the man an elder in the church.

feel I have encountered prejudice, albeit the types of prejudice that a person with intellectual impairments is likely to experience is on a different level from my own exposure.

With so much negative experience behind me it could be feared that I would be looking for phenomena to confirm my jaundiced view of the church's attitude towards inclusion. Interestingly, the engagement with my fieldwork sites had quite the reverse effect, especially at CGS. While I note a negative first impression at Reach Out, my awareness of the unreliability of first impressions and my concern to keep checking impressions against the full data, led me to modify my initial response and again to register some very positive impressions that went some way in overturning my historic presuppositions about the Evangelical church with regard to inclusion of those on the margins. As noted earlier my interviews during the pilot study made me aware of this jaundiced attitude (communicated through my tone of voice) towards the church and its willingness to allow disabled people to participate in active ways.

4.9 Data analysis

Once a large data set is gathered the task is to bring some kind of order to the data, organising it into patterns. Patton (1990:382) states that 'simplifying the complexity of reality into some more manageable classification system is the first step of analysis.' Miles & Huberman (1994) argue that coding is the process that enables the researcher to identify meaningful data and sets the stage for interpreting and drawing conclusions. The field notes, interviews and focus group were initially open coded to identify and compare the emerging issues. I coded the focus group transcript with the interview transcripts as many of the same people participated in both.

The first step was to open code and these codes were then organised into overarching categories. The data were re-analysed to check that they still fitted the issues and concepts that had been collapsed into categories. This entailed making decisions about which text segments were relevant to a particular category.

I coded my data according to thematic analysis. However, Gomm states that insofar as themes suggest themselves to the researcher as a result of reading the data, this can be described as grounding theory, which means that theory is not imposed on the data.

‘However, the contrast is not so sharp as the words imply. The difference is really one of *timing*. Even with thematic analysis there comes a point at which the analyst imposes a structure on the data. It will only be one of many structures he or she might have imposed.’ (Gomm 2008:248)

But wherever the themes come from, the mechanics of thematic analysis are similar. Gomm summarises these steps as, deciding what themes will be and what will count as evidence of a theme, coding the transcript to indicate that a passage is an example of one theme and not another.

I followed a Straussian (1987) data coding method. Open coding allows the researcher to identify categories, their properties and dimensional locations, and the next procedure which is axial coding reassembles the data but in new ways making connections between a category and its sub-categories (Strauss & Corbin 1990:97). Axial coding is considered to be part of the analysis and interpretation stage. Silverman (2006:97) goes further in stating that ‘observation’ itself ‘is theoretically impregnated’ which is to say that analysis occurs before any coding is done. An example in my data where a cluster emerged was identified from respondents talking about disability in very different terms. It soon became apparent that these different perceptions clustered around two contrasting, even conflicting models of disability, thus models of disability became a major category. According to Bryman (2008:551) once coding has been done the researcher might see how the emergent categories link with theories from the literature and in this thesis conflicting notions of disability theories is constant throughout. Some of the more negative responses to disability can be interpreted as the result of influence from the prevailing models of disability as explored in Part One. Conversely, the positive responses which were abundant were interpreted theologically as explored in Part Three.

Silvey (1975:16) states ‘research ultimately must be based on comparisons, whether it be comparisons between different groups of cases, between the same cases at different points in time, or even between what is and what might have been.’ The two

sites that I researched became a comparative study, sometimes the comparison being between sites and sometimes within each site.

Initially I used a rather basic ethnographer's approach of cutting and sorting manually which is the traditional technique of cutting up transcripts and collecting all those coded the same way into piles, envelopes or folders or pasting them onto cards. These scraps are then laid out together and re-read together as an essential part of the analysis. Of course some chunks of text can represent more than one code and these are called re-occurring codes and a number of these occurred in my coding. In order to demark the codes if more than one was necessary I highlighted the whole chunk in one colour and coloured the first and last words of the text in the second colour code that applied to the whole chunk.(See 2d) So as not to lose sight of the context of each snippet I kept whole transcripts which I marked up with the parts I had colour coded and cut up, so they could be traced to their original context if necessary for clarification.

While grounded theory does not impose pre-existing theories onto the data, a major criticism of this concept is that it does not acknowledge implicit theories which guide the work at an early stage (Bryman 1988; 83-7; Silverman 2005; 232-7). I cannot claim that a prior awareness of, for example, the controversy over conflicting models/theories of disability did not inform my analysis.

A further criticism of thematic analysis is that it fractures texts. Riessman (2003) found this to be problematic when conducting interviews with divorcees who often gave lengthy and intertwined accounts. This was not the case in my study as interviewees did not give any lengthy or intertwined accounts so thematic analysis was not a problematic analytic tool.

4.10 Summary

In this chapter, I set out my methodological approach to this thesis. I selected qualitative research methods as most suited to this study and I considered a critical disability research model and a discussion of linguistic preferences outlined by the

Disability Movement from which I explain my choices and usage. Next, I outlined the study design, moving on to look at the research tools. Then, settings, sample and access were described and a table depicted what data was gathered. Next there is some discussion of ethical matters including a section on the location of the researcher. Then finally a section attending to data analysis.

5. RESEARCH FINDINGS

This chapter describes and details the findings from the two settings where I conducted interviews and observations over the period of the fieldwork. In this chapter, I report my empirical findings from two Churches focussing on their provision of specialist ministries for members of both congregations who have various learning disabilities. I start with *The Church of the Good Shepherd* (CGS) and the Kingsway group, and then detail my findings from *Riverside Church* and *Reach Out*. Over the period of my fieldwork (see chapter 4) I collected a large set of data. Thus in making a decision about how best to manage and report these findings, I decided to concentrate, in this chapter, on providing an account that provides a rich description of the perceptions of key workers in both sites as well as a detailed account of my observations of practices that were observed in each setting. The intention in this chapter is explore my illuminative data set in order to provide a strong profile of provision and practices in each of the research settings. In this chapter, I relate my interview data and observations to the research questions that frame my empirical research. These are:

1. To what extent does Judeo-Christian faith and therefore the Christian church, represent a form of oppression for disabled people, as claimed by the Disability Movement?

2 In what ways, does the church include people with disabilities, especially those with learning disabilities, and are they encouraged to participate in the ministry of the church?

3.To what degree are people with impairments included in the mainstream social life of the Church fellowship?

4. Are they respected as adults and encouraged to be self-determining? Also, are they supported in such adult areas as employment, independent living, bereavement, marriage and parenthood, as members without disabilities are likely to be?

5 What elements in the culture of a given congregation are conducive to the full inclusion of people with various disabilities?

In what follows, I set out my findings grouped around the key themes which emerged from my reading of the literature as well as coding and analysis: models of disability, personhood, theology, modes of engagement, seeing the members as the same as others or different (in both positive and negative ways) and finally, inclusion. I report the data drawing on the small set of interviews, and one focus group but, primarily, from the wealth of material from my field notes. In some places I include vignettes that illustrate some of my key findings. The section on inclusion incorporates indications of social inclusion in the ethos of the church: in relation to gender, age, race and disability. Since, these areas are outside the research focus of this thesis I highlight some areas of inclusive practice at each site to demonstrate practices of social inclusion that make up each setting. For example, inclusion of the Deaf Community at Riverside Church. I begin with the research setting *Church of the Good Shepherd* (CGS) and their group for people with learning disabilities: *Kingsway*.

Church of the Good Shepherd (GCS)

In this section I will draw on interview data with key workers and leaders who participate in The CGS and its Kingsway group. (see table 1 for participants)

Table 1 participants at CGS

Leaders and helpers	Role in the Kingsway group CGS
Greg	Primary leader and initiator of events
Lisa	Main role as church pastor and also co-leader of Kingsway
Doreen	Plays piano and teaches
Sheila (Carer/helper)	Helps generally and especially with the two men she is carer for.

5.1 Models of disability

In this section, I explore the models or theories of disability that were operating albeit, sometimes as a ‘practical theory’ (that which has been internalised from the practice they have experienced (Handal & Lauvas 1987), at the time I undertook my fieldwork.

Towards the end of the interview I introduced 4 cards with various propositions about disability. These loosely relate to some of the major theories of disability, so I was seeking to surface the theoretical foundations that each individual was working with. They are ‘disability is:

1. a sign of God’s goodness and blessing’
2. a social construct’
3. the result of some deficiency’
4. the consequence of sin’

Proposition 1, that disability ‘is a sign of God’s goodness and blessing’ was mystifying for most and many of them needed to rephrase the proposition to embrace God’s goodness being evident *despite* the disability and Greg said he would say ‘Life, is a sign of God’s goodness and blessing.’ Lisa said ‘I don’t think it is God’s goodness or blessing but we all have some disability, some hidden deep down and some more obvious.’ Doreen said ‘not so much a sign of God’s goodness and blessing but he makes it so by helping people to cope and in what it draws out in others.’

Proposition no 2, that ‘disability is a social construct’ also caused some confusion: Lisa changing ‘construct’ to ‘constraint’, thus altering the proposition. Doreen says ‘in as much as society has labelled it and classified it’ and then re-iterates ‘people are different not **dis** anything.’

Doreen said.

Being with this group I have realised how deep people are and how much they can understand. Before I would have thought if someone couldn’t speak clearly – I wouldn’t take great pains to get to know them as I’d think they

probably wouldn't understand. I know the Lord can use absolutely everyone with or without disabilities.'

Regarding proposition 3 no-one disagreed with the view although Greg use the word 'defect' and immediately seemed uncomfortable and added 'defect itself suggests what society thinks'. He added 'I don't think I'd say a deficiency so much as people are different.' He used the term 'handicapped' once in speaking about an institution for people like 'S'(who was the founder member of Kingsway). 'It was full of people in the main more handicapped than him.' Doreen states that 'People aren't **dis** anything really.'

Some struggles were evident over use of the old medical model language which sees disability in terms of deficiencies. Doreen said 'mental handicap, as they used to call it' and on another occasion started with 'handi...eh ..eh.. learners.' Lisa said 'more able, I hate to use that word!' In the focus group discussion she also said 'I hate that word who is normal – no-one!' Lisa concluded 'people aren't **dis** anything really', echoing the same sentiment expressed to me by Doreen, and remarked 'we have moved away from medical models...as we all have some disability of some sort.'

Regarding proposition 4, that disability is the result of sin, everyone emphatically disagreed with this view. There is evidence that the medical model is being displaced, in what is said by a number of people at CGS. However, there is no well theorised alternative being used in this church, although many people interviewed were reaching for more life affirming ways of talking about disability.

5.2 Personhood

The theme of personhood in this thesis refers primarily to the theological concept of *image Dei*: a belief that all persons are made in the image of God thus rendering people of infinite value regardless of their function or utility. (See chapter 8 for a fuller exploration of this topic). I have also included data here that demonstrates treating people with a strong sense of the person as this is relevant to the scope of my enquiry.

Greg started off our interview by sharing some photos of his group members to set the scene. When asked how he worked with people with disabilities he replied, 'If you can personalise it, that is the way to come to terms with things because we are all individuals and I found that was the best way to relate to people.' Doreen singled out a woman for whom she has great respect and remarked, 'in the ordinary way of things you wouldn't get a chance to get to know someone like her.'

The Kingsway group and the main church emphasise observing birthdays. This is quite a time-consuming part of the Sunday service (they seem to prefer to keep the sermon short to allow time for this). The former minister had introduced birthdays and Greg comments 'that it is very personal'. Another personal touch that was observed was the way in which they organised the Remembrance Sunday service. There was a section in the service sheet on local men who had died in both World Wars and there was a short account of each man. During the prayer time the cubs and brownies called out the names to be remembered. [field notes April 2006]. A very realistic and accepting approach to how people are was evident. For example, two children are invited to come and hold the bread and the wine while the vicar explains the elements. One little girl can't stop giggling and no-one reprimands her – she is probably just nervous being at the front. Also, addressing adults, the vicar preaches on the need for intimacy in an over-sexualised culture and says 'we look for people who will affirm our personhood.'

Lisa tells me about her friend's father who had taught her about disability. She says he was 'appalled' at how people with disabilities were treated as if they were ill and he showed her round his workplace to show her some better practice.

Doreen, related her pleasure in her work at Kingsway.

We used to live in Chile and go round various churches helping- sometimes with children, sometimes with older people and sometimes [with] the people who lived up in the hillsides who had virtually nothing. This group has the same kind of feel to it. All very basic and simple and lovely – how people are – straight.

Greg believes that institutions for people with learning disabilities were 'o.k. in their time but probably went on for too long'. He argues that 'people have been able to develop as full human beings more as they have been living in the community.' Greg

is keen for *Kingsway* to do the Bible study course that the church has been doing which is ‘all about being accepted by God that you are a saint who sins rather than just a sinner.’

A strong sense of the person is frequently drawn out by these leaders and helpers at *CGS*. One of the helpers relates how a man she is carer to had once lost his job and the whole workforce had gone on strike until he was reinstated. She concludes simply ‘well, he is such a popular bloke.’

The group members have to deal with death more often than most people as some of their peers with learning disabilities die younger. Lisa tells me about a funeral they attended and how the group had responded - ‘All the group just sang ‘This is the day the Lord has made’, quite spontaneously and they just said their goodbyes very simply.’

At the annual carol service for people with learning disabilities, one man with Downs Syndrome, George, is on the stage with the group leader, Greg. Greg tells the congregation that George keeps him in check and makes sure he does not make any mistakes. He then makes a mistake and quickly puts himself down as being a bit slow to understand; thus turning the usual power relations upside down. Greg also makes a comment which is relevant to a theology of personhood, in terms of a Trinitarian understanding of how persons are made: to be outer directed. [Field notes Oct. 2006] Later, Greg says, in interview, ‘so much of their life is about their own basic needs. People with learning disabilities, and probably everybody, are at their best when thinking about others.’

5.3 Theology

Three themes emerged from coding and analysis: ‘tough’ theology: a theology that does not see the Christian life as one long round of wealth and worldly success; a theology of weakness and vulnerability: being realistic about the human condition in general; and finally, a theology of diversity: which sees difference and diversity as part of God’s design. I deemed areas such as these important in exploring research

questions 1 and 5. How the prevailing theology might impact people with impairments in a church community, was a major concern of mine so the underlying theologies were teased out.

Tough Theology

In this section I draw on various field notes taken from my observations of preaching. These field notes illustrate tough theology: that is, an emphasis on, the reality of life being tough for human beings in general which then tends towards inclusion of people with disabilities who *may* have a rough ride in society. CGS has a host of different people preaching from week to week so the notes that follow come from my observations of a wide range of speakers. For example, an emphasis on the way of the cross exemplifies a very tough theology. A local school teacher who preaches regularly talks about lenses and having poor lenses and concludes ‘the cross is the best lens to see things through’ [field notes Feb. 2005]. On Palm Sunday the vicar speaks about the need for endurance. He contrasts Palm Sunday with Easter and says ‘enthusiastic Christians are in danger of stopping at Palm Sunday – we want Jesus without the cross’ [field notes March 2005]. He underlines that the path of the cross is essential to resurrection. Also during the time of worship there is talk about bringing the sacrifice of a broken heart.

On another occasion the preacher says that Jesus does not choose his followers on the basis of perfectibility. He quotes the popular Christian writer, Philip Yancey, saying that Jesus seems to prefer to pick unpromising material for his disciples. After the sermon the speaker prays, reinforcing that ‘unpromising and dense people are accepted in Christ.’ The vicar illustrates this point by telling the church that when he was at school he was the kind of boy that no-one ever chose for the football team as he had poor eyesight. He adds that Jesus came for people like himself that no-one really wants on their team [field notes Sep.2004]. In this example, there is a strong emphasis on God looking on the heart and not the outward appearance. The speaker says that our security is in God’s love and not in what we earn.

The school teacher preaches on another occasion and points out that the stories of Jesus are: subversive, important and have power. She talks about ambitions and states that Jesus' ambition was to die on the cross. She asserts, 'as Christians our aim is to get as low as possible and not as high but we don't believe it because society is telling us something else.'⁶⁷ She concludes that 'the law of the kingdom is the opposite to the world' [field notes Feb.2005].

There are other examples too of tough theology. A senior person in the Diocese comes to preach and talks on Kingdom citizens. He says 'In the kingdom there is a mixed multitude because we do not control the borders of the kingdom. There is intimacy of relationship with the King and all his citizens' [field notes Oct.2006]. Mother Teresa is quoted in the talk one morning: 'The poverty of not being wanted, not being loved and not being cared for is the worst poverty there is.' In the Kingsway group Doreen explains how bad things come from the heart, for example jealousy. She urges that we must not get upset if people do not think we are important. She concludes that Jesus is pleased when we serve and do not look for the limelight [field notes March 2005].

These extracts under tough theology are relevant to my research questions as they point up that human life, in general and the Christian life, in particular, is not easy for anyone, thus embracing and including all persons in the struggles of life.

Theology of weakness and vulnerability

In this section the field notes focus on observations that highlight the inherent weakness and vulnerability of human beings. This is important as it tends towards inclusion of those often excluded on account of their perceived weakness. The South African woman leading the worship this Sunday morning, prays for us to be more vulnerable. She also does a trick thing asking for 'hands up everyone who is fine.' After the majority put up their hands she explains what 'FINE' means – Fearful, Insecure, Neurotic and Emotional and then asks the question again, perhaps hoping

⁶⁷ Dutch, Catholic priest, Henri Nouwen, talks about the kingdom being about downward mobility (2007).

that people will now self-identify as those who have these qualities, yet, people are less keen to put up their hands this time round [field notes Jan. 2005].

The vicar explains what fellowship means, linking it to the reality of human weakness. He says ‘fellowship isn’t friendship. The heart of fellowship is mutual acceptance of each other’s weaknesses. Acceptance is not about liking but the hallmark is lack of prejudice.’ He tells the congregation that Gandhi refused to become a Christian because he was unimpressed by Christians, as they did not live out the radical teaching of Jesus, to love their enemies and to turn the other cheek.’ Before the sermon the vicar prayed ‘Lord we come to you as weak and broken people’ [field notes Nov. 2004]. On another occasion the service focused on pain and weakness.

The vicar says that Ephesians gives an image of the body as *all* (speaker’s emphasis) having something to bring. He talks about a non-hierarchical view of leadership that releases the diversity of the congregation. He says that what builds us up is not our teaching or our programmes but our love for each other. He closes with a heartfelt prayer that the church will be a community where the widowed and divorced, gays and single people and people in difficult marriages can find intimacy in a pure way.

This section reveals the value that CGS places on people being real, owning their human frailty and vulnerability and thus providing a fertile environment for inclusion for people from all walks of life.

Theology of diversity

The leadership of CGS value diversity as so many people preach and generally contribute to the services. This includes men, women, and children and people of minority ethnic heritage as well as some persons with intellectual impairments. Two young men with learning disabilities regularly serve communion. A number of senior black clerics come to this church from time to time and they are often requested to give the final blessing or preside at communion.

The respect *CGS* gives children is noteworthy. On one occasion a child of about ten did a Bible reading and then made a comment on the passage [field notes Oct.2004]. Another example was where the notices have been pre-videoed with the children reading them and then shown on the screen. At communion parents are told that they can take extra bread to give to their children if they wish, thus treating them as full members of the Body of Christ. One Sunday when there is a church BBQ after the service the vicar says that the children will be fed first as it will be rather late for some of them. Children are not expected to be little adults. In one service the vicar's opening prayers are drowned out by the happy singing of children in the Sunday School. He simply keeps going and thanks God for the children asking for a blessing on them [field notes Jan. 2005].

One Sunday the vicar speaks on marriage and having children and he is sensitive to the fact that not all members of the congregation are married or have children and he directly acknowledges that some are single or divorced thus showing sensitivity to the diversity of the Body of Christ. Sensitivity to people without partners and/or without children, is sometimes lacking in the Christian church. What I am suggesting by including these examples is that *CGS* values difference and seeks to be inclusive in general terms.

5.4 Modes of Engagement⁶⁸

At both sites, people with learning disabilities were sometimes responded to as if they were children and sometimes as adults. One of the major findings of my research was that at *CGS* and *Kingsway*, the people with learning disabilities were invariably treated as full adults, and there was a conscious attempt to ensure this mode of engagement. In what follows in the next section, nearly all the examples of engagement are drawn from the Kingsway group and only two from the main church service.

Engagement as adults

⁶⁸ To recap this refers to whether the members were treated as adults or more like children.

One of the servers at communion who has Downs Syndrome is working in tandem with another person thus being treated as an adult. One of the people from the Kingsway group prayed aloud in church during a time of open prayer. This shows the freedom for those adults with disabilities to contribute with all the other adults.

In the teaching time at the Kingsway group, Doreen elicits quite a lot of discussion and asks some challenging questions. One day she drops a book and asks someone to tell her what happens and why. She elicits 'the law of gravity'. She then goes on to talk about aeroplanes and tries to elicit 'law of aerodynamics' She has to supply that information herself but she gives space for anyone who knows it and then says that she does not fully understand it herself, simply that it is stronger than gravity. She builds a bridge from this discussion into a chapter they are doing in a book called 'Freedom in Christ'[field notes May 2006]. Doreen, usually gives out a text with some simple drawings. They always have a section with capital letters which indicates choral reading. The group members take the paper home to review the lesson and there is never any suggestion that anyone might want to do some colouring in.

Features of the adult world are not screened out for the group. For example, Greg talks about a funeral that some of them had been to. He does not seek to shield them from the reality of death which is arguably more pronounced in their case than for others as some of their own friends have died relatively young. Equally Kingsway people are not treated as asexual beings as children are more likely to be. One young man tells Greg that he doesn't have a girlfriend and hastily adds that he is not gay. Greg responds 'I didn't think you were gay.' Two members of the group have been engaged a large number of times. Greg announces that he has seen a man who used to come to the group and who got married on Valentines Day. One of the group says 'That's good'.

Kingsway members are actively discouraged from acting like children. On one occasion they had a meeting in the Sunday school room. Some of the group started to find some toys and play with them. Greg says wryly 'Oh if I'd known how excited you lot would be by the toys we would have it in here every week!' A man with

Downs Syndrome then picks up the baby gym and Greg remarks ‘How old are you, 27 or 7 months?’ Everyone laughs. On another occasion this same member of the group appears with a toy pushchair with a teddy in it and one of the group reprimands him playfully saying ‘Oh grow up!’

Each year the Kingsway group have a number of social activities, marking special dates, for example, on Shrove Tuesday, they have a pancake evening where the group leaders involve the members in tossing the pancakes if they wish. Initially they used to let them make the batter but it became messy so, with experience, they now bring the pancakes readymade and let the participants heat them in the pan and toss them. During this evening Greg mentioned to me that he had hired a local Night Club and held a Valentines Disco for 200 people with Learning Disabilities in the area.

I made a note one evening that *Kingsway* has the feel of a Youth Club. Later, in interview, Greg tells me that he first came to this ministry in his capacity as Youth Club Leader and I share my observation with him. He agrees that the group has something of that feel. A man in his fifties is sitting with his arm round a woman in her sixties. Sometimes they hold hands. As far as I know, they are not a couple, but this is one of the features that reminds me of a youth Club. Greg never discourages this as he tells me that the containment and segregation of males and females in institutional homes was an artificial situation. The members of the group have responsibilities such as putting out the tables, giving out the books etc. There is a jokey repartee among the members of the group. One day Greg asks a young man who was working in a zoo what birds liked to eat and he replied ‘Seeds’ Greg probably choosing to mishear said ‘Cheese! I didn’t know that birds liked cheese’ Everyone laughs uproariously. One of the older men is playing his electric guitar but he is in the way. Greg says very naturally ‘Stand back mate’[field notes Nov. 2004].

The prayer times are very open. Greg gives an update on one member who is in hospital with a heart condition and that leads into prayer. They all pray for a woman helper from the group (she is carer to two of the men) who has suddenly lost her adult daughter. They express compassion for her distress. One of the members asks for prayer as it is the birthday of her late mother and she is upset. The group also

requests prayer for other people they know and for job interviews and the sort of thing that many groups would pray about. Some of them stand in the middle and pray confidently. The register is a strange mix of natural informal speech and Anglican liturgy. One man says 'Christ is rose again' periodically.

While there is a lot of autonomy as one would expect of adults, there is also some cautious concern. A young man buys a 't' shirt that he likes which is advertising a ministry for people with learning disabilities. He wants a baggy one but his carer points out that if it is too big it will look like a dress and he might be teased. He still wants the very big and long one, so she backs down and respects his decision. In an interview with this carer/helper, Sheila, she tells me that they like coming to the group as they enjoy having some responsibility; they put the tables out each week.

Each year there is a Carol Service for people with learning disabilities and people come from all around. One of the Kingsway group, George, was dressed as a bishop as giving the benediction was his particular metier. The new vicar was not to know this and he came up and said some things and then automatically gave the final blessing. This was a tense moment and Greg let it go so George was not able to do his usual blessing. In the midweek meeting this sort of thing had occurred when Greg had already given a closing prayer and a repeat benediction had been permitted. Greg treats this man as a person who has to learn to grow up and accept life's disappointments just like everyone else [field notes Dec.2004]. As with all the observations that are included in this section, there is consistent evidence of an adult to adult mode of engagement.

Engagement as children

I found little evidence in the interviews and observations of models of engagement that were of an adult to child nature. However, it is necessary to distinguish between treating people as children in an old-fashioned and patronising fashion and treating people as children in the more modern sense of respecting them as persons, expecting them to do things for themselves, taking initiative and not being passive yet paying attention to their particular needs and vulnerabilities.

At the annual Carol Service which is a major public event with the Mayor and Mayoress present, Greg does a game from the front in which the congregation have to guess what is in the presents. He tells them not to shout out but to put their hands up if they have an answer. This could be regarded as treating the congregation a bit like children although in this context it could just be crowd control.

Lisa cites an example of how vigilant they are about not treating Kingsway members as children. She reports that there is a person who likes cooking who she will not use any more on functions involving people with learning disabilities as this woman rations their food and treats Kingsway members like children believing they will take too much if allowed to serve themselves. Lisa accounts for her behaviour by explaining that she used to teach children with learning disabilities, thus highlighting a tendency for some people to treat adults with learning disabilities the same as they might treat children with or without learning disabilities.

5.5 Members seen as same or different from others

People with learning disabilities were sometimes regarded as being the same as other people and sometimes as being different. Within both of those categories there were positive and negative aspects.

Same as others in positive ways

Much of the data in this section relates to research question 4, and marks some of the most significant findings at CGS, namely, that people with learning disabilities are treated in very positive ways.

Holidays are an area where group members are treated in the same way as others. Greg tells me how he first became aware that many of the group had a lot of money yet never went on holidays. He asked them where they would like to go and they said Lapland. So one Christmas he took them to Lapland and then he did two trips to America with them. A more local trip was to Devon and he arranged for some of the stronger swimmers to take a two-hour surfboarding lesson. When they go on holiday the photos are a big excitement afterwards. A man comes round one evening

showing the photos of their trip and taking names for those who want to order copies. Further, at church one day the notices state that Lisa has taken a group of older people on holiday and it is mentioned that P (an older church member with learning disabilities, not from the Kingsway Group) has gone with them.

Kingsway members are treated like any other group of people. For example, both Greg and Doreen ask questions of the Kingsway members. When individuals make requests for songs, Greg asks them why they have made that choice. Doreen also asks many questions when she is teaching. In common with the rest of the groups in the church, The Kingsway group have a special meal each year, just for themselves with all the same attention to detail as given to the other groups. Greg addresses some of the men as ‘mate.’ in the way he might speak to any peer.

Doreen, says she loves the Kingsway group because it is ‘very basic and simple and lovely – how people are – straight.’ She says ‘being with this group especially I have realised how deep people are and how much they can understand.’ She talks about going to Spring Harvest (a Christian conference) so she can be involved with people with learning disabilities and says ‘other people came just like me for friendliness, just to get to know them.’

The most significant example of sameness as positive is given by Doreen, who in teaching about the spiritual gifts in Ephesians 5 raises the possibility that any one of them may have prophetic gifts and then offers practical advice for such a situation.

Different from others in negative ways

However, there are some instances, where negative points are raised regarding people with learning disabilities. Greg talks about the old institutions for people with learning disabilities and concludes ‘in the main they denied people their full human rights.... Meals at set times bedtimes set. Supervised trips out, contained and segregated by sex. - an artificial situation.’ This situation no longer exists but the weather leads to another aspect of difference that Greg also points out to me. ‘Since

most, if not all,[members of Kingsway] cannot drive, their church attendance is rather weather permitting as it might be a 15 minute walk.’ He explained that this sort of ministry needs a lot of transport support, otherwise the Kingsway members cannot be included in the life of the church. Although both these examples show awareness of negative differences between people with learning disabilities and others none of the observations revealed any negative treatment of the Kingsway group members.

Different from others in positive ways

However, some significant differences marked by positivity are highlighted by both Greg and Lisa, both of whom identify the responsiveness of some people in the Kingsway group. Greg observes ‘tactile behaviour comes a lot with people with learning disabilities and that can be a shock for the British’ [field notes Aug. 2006]. In addition, Lisa tells me in her interview and again in the focus group about an incident where her friend had not come to church for some weeks due to a bereavement and one of the Kingsway group noticed and asked after her and then promised to pray for her. Lisa comments ‘Nobody else in the entire church asked me where my friend was.’

To sum up this section, there are examples of seeing the members as same and different in positive ways at both sites. However, at *Kingsway* there are no examples of same as negative and many examples of same as positive.

5.6 Inclusion

Although I was primarily looking at the issue of inclusion in relation to people with learning disabilities it seemed useful to see how inclusion was worked out more widely. Thus at *CGS*, in the main church service, inclusive practice was noted with regard to race, gender and age. (Originally I included laity too, but since this was not a relevant category for *Riverside*, being a ‘free church’ I decided to drop this area) There did not seem to be any one privileged category of people. With regard to

research questions 3, 4 & 5, people with learning disabilities, at CGS, were often fully included in the social and ministerial life of the church, as well as there being good indicators of inclusive practice with other groups: age, race and gender. To illustrate this point, I include two vignettes that illustrate the forms that social inclusion takes at CGS.

Children and Young people

Children and young people have a vocal role in this church. On one occasion, during a worship time a South African woman who was leading, handed over to a group of children to teach the congregation some choruses. Lisa came and pointed out to me that one of the children teaching had learning disabilities. In addition, a young boy of about ten, did a reading one day and then gave a comment on the scriptures he had read. On a different week, the Youth Pastor addressed the congregation about a community project they had been involved in. He invited a big group of his young people to come up and speak. One by one they talked to the congregation and their language was characteristically peppered with 'really, like and cool' indicating that they did not feel any pressure to speak more formally.

Black and Minority Ethnic (BME)

There was a marked number of contributions from Black people. I was told that some senior African clergy attended the church from time to time and I saw that when they did they were invariably invited either to give the closing benediction or to preside at the Eucharist.

In addition to this there was a minority ethnic Youth Pastor and another minority ethnic man in the music group. On my first visit there was an African music group from Scotland visiting the church. They sang at the beginning of the service and again at the end. They came up onto the platform and one of the vocalists noticed a young man with Downs syndrome sitting on his own at the front and he stepped off the platform and took the young man's hand and led him up onto the platform where the other vocalist took his other hand and he boogied away with them contentedly.

People with learning disabilities

There are two main themes here in relation to inclusion of people with learning disabilities. Firstly, there is evidence that they are encouraged to be fully included in the social life that others enjoy and secondly they are included in the life of the congregation. This first point was evidenced through their conspicuous absence on some occasions when I was told some of the Kingsway group have gone to a cricket match, was doing a cyclothan or have gone on holiday to Spring Harvest.

Lisa and Greg explain some issues concerning inclusion. Lisa tells me, that with regard to the general congregation there are 'more that accept than include'. She adds 'I am sure we can include more'[field notes Sept. 2006]. Greg explains to me why they all sit together at the front in a block, rather than being more integrated in the congregation. 'Often their faculties are not that great. They often depend on visual skills because a lot of them can't read...some sit at the front so they can see.' Also, Greg talks to me about the need for a balance of inclusion and segregation. 'Separation versus integration is the big debate: it runs through education and the whole of life and we are trying to hold a middle ground today – it's half and half, I think'[field notes Aug.2006]. Lisa expresses some of this tension in the focus group. She explains

Our group for learning disabilities is growing so fast that it can't go on unless we do something else. So the leaders of this group said we want to integrate some of them in the house group. And it was all so fast and we said that we needed to go away and pray about it. So we have a short term option, some of them that the leader will choose are going to be linked to a 'normal' house group. I hate using that word for who is normal? – none of us! But at least they can be part of it for social events and people can come up to them and speak to them and know them [field notes Nov. 2006].

Others who speak on inclusion include a senior member of the Diocesan clergy who I hear preach one week. He says that 'Inclusion is the reality of the Kingdom so we need to be changed in order to be able to accept people radically different from ourselves.' He then asks the congregation if their church demonstrates that. Greg talks about inclusion more widely as part of the Christian Gospel. He says,

I see it [inclusion of people with intellectual impairments] as the principal difference between Christianity and Islam and why I think the Christian

church has got so much to offer people with learning disabilities and a principal way of witnessing to Islam...I feel so passionately that the church should really go the extra mile and reach out to people with learning disabilities because we have something so much more positive to offer rather than seeing it as the consequence of sin either of themselves or their parents.

There is a time of open prayer and sometimes one of the people with learning disabilities prays aloud. Sometimes the open prayer time is structured as one line prayers, (or just one line praise prayers) which facilitates participation for all sorts of people including those with intellectual impairments. When there is time for prayer for special days coming up one of the men with Downs Syndrome asks for prayer for his friends who are getting married in several months time. This could be considered as an inappropriate request at this point in time, but the woman leading includes his request and points to him and says his name in honouring this request. Presumably the congregation know who he is and will understand why they are praying for something so far in advance.

Coming to *CGS* in the gap between the 9.30 and the 11.00 service allowed me to observe the interaction between the congregants and the Kingsway group. One of the older women from the Kingsway group is well integrated into other groups for older people and she is greeted warmly by an older man who kisses her on the cheek. She and the younger man with Downs Syndrome who serves at communion are also greeted by a number of congregants. There are a number of gestures of physical affection from members of the congregation; either a kiss on the cheek or a warm squeeze of the shoulder or the arm, or a hearty handshake. The older man with Downs Syndrome who used to do the final blessing in the Kingsway group (George) seems well known and I observe people greeting him by name and shaking his hand.

Two other examples of when the Kingsway group experience inclusion are noteworthy here. The first Sunday of the month is communion where it is possible to watch the dynamics during 'the peace of the Lord'. The two older women who come from a local home and sit together by the pillar were fully integrated during this activity. After the worship time and just before the sermon begins, a number of people who have been ministering from the platform sit down among the

congregation. It is noticeable that many of them (especially the vicar) choose to sit with the Kingsway people at the front.

There are two things which relate to inclusion generally: first, the introduction of birthdays by the previous vicar which Greg says is very personal and inclusive for everyone. Second, the seating is in an informal amphitheatre layout, conducive to general inclusion and participation. Each year the Kingsway group has its own carol service, and I was there the week they began organising it and attendance was noticeably higher than usual. Sheila, a helper, told me that it was probably because they wanted a part in the carol service. There was a little drama, five readings and a number of prayers to be done. There was great excitement about getting a role and it was clear that everyone was encouraged to play a part, some vocal and some not, namely, to give out the carol sheets.

The Kingsway group is not exclusively for the church at CGS. Greg explains that the group is open to any church and people from about six different churches come so it is not possible to tie the teaching in to what the main church is doing. 'One of the driving forces was to teach' He says that although the church service is fairly visual, he does not imagine that many of the group members understand the sermon. So an aim of the group is to provide relevant teaching in an accessible way. There is a great deal of participation in the meetings from setting out the tables, giving out the books and the teaching handouts, to extemporary prayer, opportunities to share and request songs or hymns, choral reading of key texts for the teaching time and making prayer requests. Initiative taking is encouraged, yet because Greg has a strong sense of boundaries, this is never a free-for-all. He is in charge and if challenged he will make that plain. One evening a young woman says 'Oh why are we doing this again?' And Greg responds 'Because I am in charge!' One woman misbehaves one week and he tells her that he will take her home if she will not behave. She threatens to push him over. However, Greg stands his ground and eventually she apologises to the person she has upset. There are tears all round and everyone is reconciled.

Greg also handles the group in face-saving ways: he tries to accommodate their requests but may have to say 'no'. On one occasion he tells a member that they will have her hymn if there is time at the end. Right at the end he turns to her and says

‘Well there is time for your song now’ and they all sing it together. On another occasion someone requests a hymn after Greg has concluded the evening. He does not ignore her but says kindly, ‘Yes, that is a nice one isn’t it,’ but clearly with no intention of having it there and then. Sometimes when one of the members makes a request, a question may be asked to draw them out more, for example ‘Why did you choose that one?’ or ‘Why do you like it?’ The members soon become aware of one another’s favourite hymns and sometimes a request will prompt roars of laughter and comments of ‘surprise, surprise!’ However, some of the group need help in finding the numbers and probably most of them sing from memory. My initial impression was that they could all read, a point that Greg disconfirms.

Some of the men with Downs Syndrome have vocal roles. One of the older men gives a formal benediction at the end of the meeting, standing to give the sign of the cross in full Anglican fashion. After he stops coming to the group through ill health one of the younger men with Downs Syndrome takes over this role. He welcomes me on my first visit and says they should pray for me. Greg says ‘no’ and gently but firmly puts his hand on his knee. However, when they pray he does indeed launch into praying for me. On another occasion the same man gives thanks for a visitor coming and he manages to move directly from this man’s name into ‘and the Father and the Son’ thus making him part of the Holy Trinity. No-one seems to mind, yet I notice that when they have the public carol service, his prayers are scripted and read aloud.

The group’s prayer times are completely open and include requests for healing for a friend, girl/boyfriend or family member, prayer for a job, prayer for those they know getting married, prayer for friends who have been bereaved. Greg tries to give freedom but does not encourage anything super-spiritual or inappropriate. An example of this is when he asks one member to say ‘thank you’ to a person who has worked hard to give them a pancake evening. The man he asks then launches into prayer thanking God for this woman and then saying how much they have enjoyed themselves and then requesting another one next year and all of this is wrapped up with, ‘In the name of Christ, Amen.’ Greg turns to me and says ‘Extemporaneous prayer has a lot to answer for’ and to the man concerned he says, ‘you could just go over and thank her!’

The prayer is also reciprocal: members of the group praying for those leading the group and vice versa. One man in the group prays for the older lady who does the teaching and another person puts his hand on Greg and prays for him. Lisa told me that when the vicar left, one of the Kingsway Group got up and put his hand on his shoulder and prayed for him in front of the whole church. She said there was a tense moment as everyone wondered what he was going to say but finally, it was felt that there had been no cause for alarm. When one of the carers suddenly lost her adult daughter the group were very concerned to pray for her and revealed compassion.

One remarkable aspect on the spiritual side was Doreen's expectation that people with learning disabilities are fully included in the main spiritual ministries as set out in Ephesians, chapter 5, exactly the same as anyone else.⁶⁹ Another area where full inclusion is seen is where the church has been collecting to buy water filters for Africa. The Kingsway group are told that they have raised enough money to finance 2 of the 16 water filters that the church is now giving to Africa.

One of the other significant findings that evidences inclusion is the way in which the general congregation owns this ministry and accepts the people from *Kingsway*. One of the church wardens sometimes comes to the group to see what is going on. Lisa tells me that this church warden would like to show the video of the carol service to the church prayer group to encourage them to pray for the Kingsway group. Another of the helpers asks me for a copy of the video so that her husband can see it as he had been abroad and did not want to miss it.

Riverside Church and Reach Out

I will now report on and describe the data gathered from this second research site using the same six headings as I used with *CGS*: models of disability, personhood, theology, modes of engagement, seeing the members as same or different, and inclusion. I include a table of the participants and their roles at the site and I seek to

⁶⁹ This shows that Doreen understands what Brad Jersak (2006 in part one) has experienced of people with learning disabilities having prophetic gifting.

link the data to the research questions which are reiterated at the start of this chapter. Further I will draw on data from the respondents included in Table 2.

Table 2 participants at Reach Out

Leaders and helpers	Role in <i>Reach Out</i>
James	Leader
Felicity	Co-leader and main participator
Carol	Helps to lead and teach
Angie	Helper more in the background
Lee	Helper and mother of a boy with Down syndrome.

5.7 Models of disability

In this section I will describe some underlying models or theories of disability, by examining the comments that participants make, mostly through interviews. From the ‘disability is’ cards at the end of the interviews, Felicity was concerned that the statements were contentious and at the end asked to simply state what she thought which was welcomed.⁷⁰

Proposition 1 caused dismay and Angie said ‘I don’t think a disabled person would say that!’ Felicity said that God ‘can use disabled people in goodness and blessing’. Also proposition 2, disability as a social construct, caused confusion and James said ‘I can’t begin to frame that’ and I suspect that was true for many of them. However, to clarify I gave an example of Deafness as a social construction⁷¹, When talking about proposition 2, a clear underlying medical model came to the surface. For example Angie said ‘I can’t see how society could have caused it as you are born with it.’

⁷⁰ Felicity said ‘That if someone is disabled or difficult or perfect (in our eyes) they still need God’s love, but that doesn’t fit anywhere.’

⁷¹ I unpacked the phrase in order to explain its meaning and illustrated with the situation researched by Groce (1988) at Martha’s Vineyard where Deaf people were a significant minority so that the population learnt to sign. Thus Deaf people were not disabled but could use sign language in most public places and be understood. Further, I had left the phrase as it was expected to signal who was familiar with the literature from the Disability Movement where it is in common use.

The concept of disability as a deficiency (proposition 3) was only challenged by Carol who gave an emphatic ‘no’ yet elsewhere in the same interview she talked about ‘disability being a fluke of nature’ thus undermining her commitment.’ Angie said ‘yes, that is true for most people’ and Lee remarked, ‘ I think I’d go along with that’.

Regarding proposition 4, that disability is the consequence of sin, all respondents disagreed robustly to the notion of disability as the result of personal sin but Felicity gave an overview commenting ‘Sin is endemic in us as human beings and the Fall indicates that things will not be perfect.’

Many of the leaders and helpers at *Reach Out* used words like ‘needs’ and expressed a desire ‘to help’. James said ‘The love of Christ compels us to want to help people.’ He expressed his conviction that ‘it is not going to be the whole church that suddenly comes in to help people.’ His wife, Felicity said of the group, ‘they will always need a little more understanding and support’, underlining a helping perspective.

While many of the participants used language which belongs to a medical model and suggests a deficit view of disability, they often express discomfort at using such terms as they have a high regard for their members as persons of value. James used some terms, ‘mentally retarded’, ‘mental handicap’ and distanced himself from them as ‘old terms.’ yet revealed a struggle to express disability in more positive ways. In my interview with him he said ‘people struggle over the language ‘mental handicap’ and get round it with weasel words but the words don’t make any difference, that doesn’t change reality.’ This is a popular misconception about language.⁷² However, he continued ‘the problem is imputing things to people’, and indeed that is where the importance of lexical choice comes in to play.

Reach Out helpers also used many words to denote a deficit view of disability. Carol said that she couldn’t believe that God wanted ‘them to be lacking’, Lee talked of ‘a

⁷² Linguists, (See the Sapir/Whorf hypothesis (Penn 1972) tend to take the view that reality is socially and discursively constructed (some preferring a weaker and less deterministic form of the hypothesis) so that language is itself a component of the social construction of reality and actually part of imputing things to people.

hindrance'. When presented with the notion of disability being a deficiency, Lee reinforced this view with commenting: 'that's true isn't it? If you have a lower IQ it is a deficiency'. James was quick to point out 'there are certain deficiencies in all of us.'

James also noted that 'deficiency' is a reason why, in his view 'they' cannot be incorporated into house groups in the church. However, he asserted a different view when he said 'we are in danger of comparing people with learning disabilities to some norm which doesn't exist.' [field notes March 2005] This further underlined the tensions involved in using deficit language drawn from medical model concepts while reaching for something more life affirming.

The leaders also expressed some concerns about disabled people being dismissed. James said, 'another thing I am very uncomfortable with is when special needs folks are talked down to and that happens quite easily.' Felicity also said 'if someone is disabled or different or perfect in our eyes, they still need God's love.' In these comments the leaders are building towards a conception of equality between all human beings. Some of the other comments from helpers suggest a view which is less deficit in nature. For example, in discussing the faith of people with learning disabilities Carol said, 'I am sure they can have faith at their level of understanding' and Lee remarked 'people with learning disabilities have the capacity of being a believer.' Felicity talked about having 'a glimpse of their spirituality' and refuted any view that people with learning disabilities don't need salvation for she asserted, 'they are whole people.' Carol told me 'I see them as people – they have personalities. I take them as they are.'

The following comments from two helpers illustrate some moves away from a deficit view of disability. Angie speaks of learning from people with disabilities as well as helping them: 'how they can teach me to understand them better and love them better and be more patient.' [field notes Oct. 2006] Lee, a helper who is also a parent of an adult son with Downs, notes 'if we were with people with learning disabilities all the time and we just accepted them, it would be different.' This comment signals a weak version of a social constructionist concept of disability seeing the problem as being more about society than 'them'.

Felicity edges towards a minority culture view of disability (as set out in chapter 2) when she discusses inclusion. She highlights the tensions involved in the need to recognise and respect difference as well as dealing equitably with everyone. She says

There is always a tension between being inclusive and anyone can come and being specifically helpful. It's like cultural things. Should we have a Chinese Fellowship or just all international students together? There is a place for people of a specific culture to build together.' [field notes March 2005]

These respondents reflect a shifting view of disability in what they say that suggests that the leaders and helpers are caught up in an early model of disability which they have outgrown through their own perceptions, experiences and concerns.

5.8 Personhood

Turning to the second key theme of personhood; this relates to a theological concept which Mauss (1979), writing on secular sociology and psychology, acknowledges owes its metaphysical foundations to Christianity, (see chapter 8). The concept of *Imago Dei* denotes that humankind has infinite worth regardless of function, by merit of being made in God's image. The data also contains some evidence of respondents having a high regard for persons as it relates to research question 5.

Giving flowers, or other gifts, remembering birthdays and addressing people by their name could all be considered acts which affirm the person. At the beginning of *Reach Out*, people were checked off on a list and their name was put on a sticker which they wore for the duration of the meeting. There was usually a slot to acknowledge people's birthdays and to sing 'Happy Birthday' to them. At the end of term, one helper was leaving after being on the team for many years. Felicity said they had something for her and then coughed conspicuously until Suzie remembered the bouquet of flowers by her side and jumped up to give them to her and kissed her. In the main service at *Riverside* someone was leaving the staff after a long period of service. The pastor presented her with a bouquet of flowers as a 'thank you' and a mark of affirmation for her contribution to the life of the church. The pastor hugged her and prayed for her. All these small acts underline a sense of the personal. Furthermore, when I first met the leaders of this ministry to talk to them about their

work, they also shared with me lots of photos of their people (as Greg had done at CGS), which set a very personal scene.

Carol drew out some dangers in not taking people with intellectual impairments as they are and perhaps having inappropriate expectations. She recalled how she had once met a vicar who was doing school assemblies at a school for children with learning disabilities and he was struggling with it. She recounts

He asked me how I treated these people. ‘Do you just see the potential they would have had?’ he asked. I said ‘Oh no, I see them as *people*. They have personalities. I take them as they are. No wonder he was struggling! Never do I think ‘ooh they could have been so fantastic at that.’ [field notes Sept. 2006]

Later on in the interview, Carol says:

Well disability is no respecter of persons. I don’t think anybody knows why it happens. Almost a fluke of nature... I struggle to believe that God gives certain people disabilities, but I think that whatever state they are in, God is there for them in whatever way they need him and can respond to him.’

Here the focus is on God being there **for** them rather than **in** them, which would tend to indicate a non-reciprocal relationship with the church, (what I elsewhere refer to as ‘one-way street thinking’) which can have a limiting effect on the way in which people with learning disabilities are regarded in the church. However, there is nothing patronising in what Carol says as she concludes with, ‘it is a great privilege to be able to do this.’

Some of the worship carries a strong sense of the value of persons. At *Riverside* they sing a song called ‘The dance of Glorious Diversity’ which is linked to the theme of the mystery of the Trinity. This song is rich with notions of personhood and the value of difference and diversity. One day when the pastor is dedicating a young baby, he makes the point that if Jesus were to come and identify the most important person there he would be drawn to the smallest and the youngest and that this baby girl would be such a person. He walks around the church showing her off and reinforcing the view that Jesus loves the weakest and the least and values each one as an individual and takes us all seriously.

5.9 Theology

In this section I attempt to describe the theological tenor of the research settings. The three sub-topics of ‘tough theology’, ‘theology of weakness and vulnerability’ and ‘theology of diversity’ are pertinent to my exploration of research questions 1 & 5 and will be used with reference to my findings at *Riverside Church* (as with *CGS*).

Tough theology

Tough theology raises the expectation that this life is not likely to be trouble-free, in contrast to a triumphalist theology prevalent among some American television evangelists (McArthur 2009), who give the impression that the Christian life should be an uninterrupted experience of wealth, health and success. A triumphalist theology, unlike a tough theology, is inclined to marginalise people with impairments as they are less likely to lead a carefree life, and are often among some of the poorer members of society (WHO 2005).

One Sunday morning at *Riverside*, I heard a preacher unpack his view of the Gospel as much more than being a good citizen and about going beyond our comfort zones, loving our enemies etc. The worship leader talked about the Christian life as a journey. The worship group do a little sketch with people carrying heavy loads and bumping into things. She says we need to put down our heavy loads to see where we are going [field notes Jan.2006].

On another occasion, a new elder preached and he said that it is fallen nature to be against those who are different from us. He talked about the Eastern concept of hospitality and receiving angels unawares. He explained that an angel is a messenger of God and as such, that strangers can bring a message from God as they have no agenda or vested interests as most human agents do. This emphasis reminds us that we have to work against our fallen nature in order to embrace one another with our manifold differences.

James is critical of the notion that our worldly success gives us any true importance and hates seeing people with learning disabilities put down by that value system. He tells me in an interview that ‘everything of importance comes from within us.’

At *Reach Out*, the worship songs often underline the fact that we will need God’s help in our lives. They sing ‘Lord I need your help’ and later ‘Send your Spirit to help me Jesus’ and in this context the members talk about what they do when they are scared. The leader says ‘when we are scared we need to know that God is greater.’ One day in talking about the story of Moses when he tries to get Pharaoh to let his people leave Egypt, Carol says that things are difficult but that they are going to get worse. This leads into singing ‘When the road is rough and steep fix your eyes upon Jesus.’ All of this creates a robust theology which is not resistant to acknowledging the hard realities of life, and which makes links between inclusion and tough theology.

A theology of vulnerability and weakness

In some respects, a theology of weakness and vulnerability, might insist that all members of the congregation are in this category on account of their humanity, irrespective of any disabilities or worldly achievement. This theological stance, superficially at least, tends towards greater inclusion of people with impairment. As already mentioned at *Riverside*, the pastor paraded a young baby around the church one day, highlighting the fact that Jesus values most those who are not powerful in society and he challenged the congregation ‘Have we welcomed the weak, given priority to the poor?’ . Here vulnerability and weakness, individual characteristics, are transformed into structural concerns as he talks about structures in society [field notes March 2006].

At *Reach Out* they sing ‘Even in my weakness you consider me lovely’, and the worship leader says ‘he does delight in us **all** (speaker emphasis) doesn’t he? They sing ‘Send your Spirit to help me Jesus’ which appears to be a favourite of theirs.

A theology of diversity

In theory, a theology of diversity should be comfortable with a challenge to the *status quo* and should not assume that there is one right way for human beings to be. At the end of the service there is prayer for the church community to span a variety of cultures, ages etc thus showing awareness of societal diversity. Felicity points out that all the disciples were different and underlines the importance of diversity to the creator God. James says in an interview ‘I see people with disabilities certainly as created in the image of God.’ One of the helpers says in her interview with me ‘I think disabled or not, every person is loved by God and he died for each one and his love is the same.... God is no respecter of persons.’ However, my data analysis did not yield a great deal of evidence that reflected strong and overt concerns with diversity in *Riverside Church* or *Reach Out*.

5.10 Modes of engagement

As at *CGS*, the data that I report under this heading relates entirely to the afternoon meetings. It became apparent to me that, at both sites, people with disabilities were treated sometimes as adults and, at other times, as children. Nevertheless, the most striking finding at this research site relates to this theme of engagement and in particular to a tendency to respond to adults with learning disabilities as if they were children.

Engagement as children

In the group meetings there was an emphasis on colouring in as a major activity. It was always offered as an option for the activities before tea and was popular. (On one occasion a helper asked me if I’d like to do some colouring in!) Sometimes the leaders say and do things which are reminiscent of children’s programmes. At one meeting the woman presenting the topic starts with ‘I hope you have lots of fun today’. This sets up a rather Blue Peterish tone and then she says ‘And here is one I made earlier, just like in Blue Peter!’ Sometimes the participants are told to put their hands together and close their eyes to pray. On another occasion a helper asks ‘Are

you sitting comfortably?’ which is neutral enough except that for many people, of a certain age, it carries the connotation of ‘Watch with mother – a 1950’s children’s programme. Once some dried pasta is handed out and Felicity notices that one person starts to put it in her mouth and she says ‘oh don’t eat it darling it will give you tummy-ache!’ Although it was said very lovingly, essentially this is talk used with children more than adults[field notes March.2005].

Sometimes the members do not understand the ‘real’ world. This was evidenced on two different occasions. The teacher was trying to communicate how sometimes things go wrong but then God makes it come right again in the end. She started by making some pastry for jam tarts and made a total mess of it. She was taken off by a helpful friend and later, as if by magic, returned with some perfect jam tarts. Of course in the real world pastry can’t be rescued like that. Failed food items can be made into other items, for example, failed sponge cakes can be ground and used to make rum truffle cakes. Similarly, God can turn disasters to good in ways we had not imagined.

Another incident reveals an expectation that group members will not understand or be at home in the adult world. The topic of the lesson is the weeping woman in Luke 7. This story is demonstrated through a mock telephone conversation and one speaker says to another, ‘we know what sort of woman she is!’ Whether the members were expected to pick up the nature of her misdemeanour from the tone of voice was not clear, but later one woman suggests that ‘the weeping woman’ was a witch and the helper says with dismay ‘No, I don’t’ think she was a witch.’ She does not add that she was a woman who sold her body to men. In one of the early sessions, a woman was invited to tell the group about something exciting that had happened to her. She told them about her trip to see Santa Claus that week. She had been taken there by another organisation but this incident highlights the inclination for some people to treat adults with learning disabilities as children. A story told to me by Lee, a helper with an adult son with Downs Syndrome who attended *Reach Out*, underscores this point. Her son was not able to understand what was happening at church (not the church in this study) so he had been invited to go and sit with the little children. His mother comments, ‘as they get older, it really isn’t appropriate.’ In the summer there was a garden party at *Reach Out* with different activities to

choose from. It was an extremely hot afternoon and one activity that was conducted under a gazebo was flag painting, where a flag of choice could be painted on the hand or face. At the time the Olympics was on and a flag could be chosen from any of the participating countries. One young man commented that he wanted the Spanish flag as he always went to Tenerife on his holidays. An elderly woman came over and was offered a painted flag on her face. She declined the offer, so she was offered a flower on her hand instead but she still insisted 'no thank you.' She may just have wanted to enjoy being in the shade with no intention of having anything painted on her at all.

In my interview with Angie, the reference to working with children came up twice in the context of what helped in being able to serve in this ministry with adults with learning disabilities. Angie said 'obviously when you are a teacher you have contact with children who have disabilities.' Later, she said 'I didn't specialise in learning disabilities but I taught in an infants school: five, six and seven-year olds.' She offered this experience of teaching infants as a good preparation for this ministry with adults with learning disabilities. [field notes Oct. 2006]

I now discuss an incident that happened early on at *Reach Out*. It must be stressed that the events of this particular afternoon were never repeated by any leader or helper in the time I observed the group. Thus the events outlined below are not representative of the way in which the members were ordinarily treated. The person who led the teaching was chivvying the people along to get the answers she wanted. She said

Did you feel welcomed when you came in here today? Yes, you did, didn't you and what made you feel welcomed? [slight pause] We call your name and you get a name tag and are shown to a chair and we talk together.'

In discourse analysis, this type of speech is called 'B event discourse'⁷³ and is regarded as a tool of institutional power. It is characterised by A making propositional statements about B which B would find harder to disagree with than if the utterance had been an open-ended question. In the example above, another person took over and led a time of confession. She asked, regarding the Christmas season, 'Why do we have presents? What did God give us at Christmas? [pause]. A woman

⁷³ See Fairclough 1989. *Language and Power: an introduction to Institutional Discourse*.

in the front row said ‘toys’ and the helper said quite sharply ‘no, he didn’t, he gave us Jesus.’ This practice of expecting people to read one’s mind and parrot back the expected response is called ‘right answerism’ (Holt 1969) in education and is regarded as bad practice. More alarming was the way in which the woman in the group had been publicly rebuked for offering a reply other than the desired response.

Later I observed the same helper, Angie in the small group when the participants did the pre-tea activities. She was helping with a task where the members had a piece of A4 paper with the Bible verse printed but well spaced out, and they had to find the same words on coloured pieces of paper and stick them in the right place to recreate the Bible verse as a colourful collage. It was also expected that they would glue the Bible reference at the bottom of the page. The members were all being very heavily led by the carers who were almost doing the work themselves. One member however, was determined not to have it done for her. Later, when her work was not perfect, Angie commented to the other helpers ‘she has obviously done it herself,’ as if that were thoroughly unacceptable and not the intention of the task. The helpers then tried to make this member paste the reference on the bottom of the page when someone noticed that she had pasted it on the back of the page. Angie, remarked a second time, ‘oh because she did it herself!’ At the end, when the members were invited to come to the front and show their work to everybody, the woman who ‘had done it herself’ was more eager to come forward to show off her work than the others who may have had perfect work in front of them which they had not actually done themselves. The helpers were enthusiastic for these people to take their ‘wonderful’ work home but, I noticed, the members seemed less thrilled with ‘their’ work. [field notes Nov. 2005]

This afternoon had been the first time I had visited the group. Over the following twelve months I saw that this first session was not at all representative. I also interviewed the helper, Angie, later on and she was the sole person at this site to say that she could learn from people with learning disabilities. On this first occasion she did not appear to have much regard for the members as adults but this first impression was not borne out in any other encounter over the 12-month period that I attended *Reach Out* nor, in the interview that I conducted with her. Psychological studies of first impressions (Hamilton et al 1980) confirm the fact that first

impressions are subject to existing schemas which can become a template from which other experiences are made to fit. I therefore had to resist that tendency and, since my work was systematic, I was able to see that my first impression was unrepresentative and was able to modify that first impression to create a more accurate new impression of the work at *Reach Out*. However, what does remain is one powerful, albeit, discrepant case, where the members were being infantilised.

Engagement as adults

Many of the examples collated that would fall under this theme came from the house group that I was invited to attend but once. However, I decided not to use this data in my thesis for ethical reasons. The members were not in a public setting and it would be reasonable for them to expect privacy. Nevertheless, it should be noted that the house-group gathering was conducted in a much more adult to adult mode than the *Reach Out* meetings. Members told me over dinner about social activities they had done over the years, such as, going sailing and having a fish and chip supper on the way home. There was always a Greek evening in the summer and other international evenings throughout the year, including curry evenings. Alongside the social events there were a number of spiritual activities, including Bible studies and times of worship. I noted, as I had done at Kingsway, that this meeting was more like a youth group as they were being treated more as young adults. Lee, the helper with the son with Downs Syndrome pointed him out to me as ‘the one with the horrible black ‘t’shirt on.’ Thus revealing her adult treatment of him, letting him choose what to wear as any adult would hope to be able to do.

Another incident where the engagement was on an adult level, but perhaps with worrying consequences, was when members role played the wedding at Cana. A modern wedding was simulated with the wedding march playing and a ‘father figure’ came in with a bride on his arm. This woman was then presented to a man with learning disabilities who was playing the role of the groom. It was repeatedly emphasised that this was not a real life situation yet, even so, I wondered how the ‘groom’ was faring with his adult emotions in a situation where a real life scenario was being so effectively evoked.

In sum, in my field notes of observations, there were rich examples of moments and incidents where the group members were engaged with in an adult to adult style, many from the house-group context and at least one of the examples from *Reach Out* with worrying consequences.

5.11 Members seen as same or different.

The perceptions of leaders and helpers regarding people with learning disabilities varied: sometimes being regarded as the same as other people yet sometimes as notably different and within both of these categories each factor having positive and negative aspects.

*Same as others in **negative ways***

Starting with examples of others seen as the same as others but with a negative slant, James says in interview ‘there are certain deficiencies in all of us – none of us is perfect.’ Later he says with regard to disadvantage ‘ I wouldn’t want to separate out people with special needs.’ These comments can be construed as seeing people with learning disabilities/‘special needs’ as being the same as others in negative ways: all sharing a nature that is deficient ; being lacking in some way.

Lee, says ‘all children rebel and that happens with people with learning disabilities.’ She talks about her son ‘He is very aware that he is different and hates people staring at him and treating him as different, but then he doesn’t like to be ignored.’ Lee’s son feels different in negative ways that draws unwelcome attention yet he is also the same as others in that he does not wish to be ignored and may rebel like any other child.

*Same as others in **positive ways***

The data here denotes sameness with a positive inflection. For example Felicity leads one afternoon and starts by saying ‘I’m going to test your brains first – have you brought them?’ thus highlighting the fact that she knows they have brains. The

worship leader asks the group what we need to do when we are frightened. The assumption here is that everyone gets frightened at times.

Being treated the same as others has good and bad sides. On the positive side, when a young man asks to play his new pop music and dance to it there is no objection. On the other hand, a young woman tells me that she has got into trouble with one of the elders for practising the drums too loudly in the church. Clearly this elder had treated her just like any others member of the music group, which could be considered positive yet with the negative consequence that she was reprimanded, just as anyone else would be. While treating people with intellectual impairments as the same with a positive bias, may lead to negative consequences, as in being reprimanded, this data here still underlines a positive view of sameness.

Different from others in negative ways

This section introduces a bias towards regarding people with learning disabilities as different and the focus is first on negative ways of perceiving difference.

Some examples taken from Felicity and Carol follow. Felicity talked about a seminar she had been to on autism: ‘they need to be helped to live the life as we know it, so they have to be seen as different.’ Further, Felicity talks about a dilemma; the problem of inclusion in church. She says ‘how to meet the needs of those who didn’t have the academic abilities of probably the majority...’ Elsewhere she says ‘certainly in most big churches there are people with learning disabilities, perhaps not as marked as some of the people who come on Sundays (meaning *Reach Out*) but who have difficulties accessing the teaching and need encouragement’ [field notes Sept. 2006]. Another helper, Carol, in puzzling over the same issue remarks ‘why shouldn’t they be given an equal but adapted to suit them, treatment in society. I’m sure that although possibly we might not understand it, that they have a faith at their level of understanding.’

In interview James comments on ‘the simplicity of their communication’. Later he talks of the problem of inclusion for some of the group members, saying ‘they can’t be incorporated into regular house-groups because of their deficiency.’ One young woman who is starting to help with this ministry comments to me over tea that she

doesn't really know what she is doing as she has no special needs training, thus giving the clear impression that members of *Reach Out* are different from other people.

Nevertheless, Felicity objects to a view that sees people with learning disabilities as far too different. She tells of being told that people with learning disabilities did not need salvation like everyone else as they were seen as innocent. Felicity objects that this positions people with learning disabilities as less than fully human. However, she insists on the need to be 'realistic'. 'People with learning disabilities can achieve greater potential, of course, but it is not going to go away. They will always need a bit more understanding and support.' Her view is summed up in this comment 'for me it was the awareness that people can be different but they are still people'[field notes March 2005].

Lee, talked about an incident where her son was being treated as the same as other young adults and he was upset. He wanted to be treated as a child when it came to having the church sing 'Happy Birthday' to him. Lee says that they (at another church) knew it was his birthday but missed him out, probably because they thought he was too old.

Different from others in positive ways

However, difference is also seen in more inclusive and affirming ways. Lee, tells me about her son's girlfriend. '...a lovely lady in a wheelchair and he doesn't seem to notice it. They are so accepting that they just see the person.' In the focus group, Wanda (from the Diocese) who has much experience of working and living with people with Downs Syndrome, makes the same point. She says,

This is one of the wonderful things that I keep learning from Downs Syndrome youngsters. They genuinely see everyone as equal and it isn't pretence and they don't have to keep reminding themselves. It doesn't matter what they look like, how old they are or what their status in society is. Everyone is equal [field notes Nov.2006].

What these slices of data illustrate is the complexity and overlap that occurs in practice, where issues of difference are key parts of social interaction. Furthermore, there is also some overlap where sameness is concerned. A key finding here is Lee's

observation supported by Wanda about Down Syndrome people seeing beyond the surface and accepting one another.

5.12 Inclusion

I now move into the final area of inclusion. Although the principal concern in my research was the issue of inclusion for people with learning disabilities and disabled people in general, I wanted to discover how inclusion was worked out more broadly. Thus at *Riverside* I noted inclusive practice in other dimensions of difference as indicative of an ethos of inclusion. Before moving to report the data on people with learning disabilities, I provide two vignettes to show what social inclusion looks like for the Deaf Community and Chinese believers at Riverside Church as examples of inclusive practice.

Deaf Community

Apart from some minor provision for wheelchair users, most acts of inclusion were directed towards the Deaf Community. There was a small group of signers (signing is labour-intensive work) and they signed for a group of people who sat in a specific block at the front of the church. On one occasion one of the elders stands with the Deaf group and during the worship he is doing some sort of signing and checking with the signer and joining in where he can. The pastor once enquired of a signer how to sign 'more than'. He then takes it up and uses it in his sermon.

Although the provision of signing is a positive and inclusive act, there are some disadvantages that I note. First of all, I note that the signers tend to lock gaze on one particular person and I wonder if that is an occupational hazard of signing. However, two of the signers are related to each other and to a third person who is in the Deaf block. Signing is vulnerable to people obscuring the view of the signer. On one occasion a woman got up and left the auditorium, then returned and then left again and each time she walked between the signer and the Deaf Community thus 'silencing' the signer who raised her eyebrows in exasperation the final time. The congregation need to have their awareness of this issue raised. One final drawback with the provision of signing was that although it appeared to be a weekly provision, one week there was no-one there to sign and I was not aware that there had been any prior notice of this. Since this ministry was largely performed by one family a family crisis could knock this ministry on the head quite easily. I wondered if anyone else had come expecting to have signing available [field notes Jan.2006].

'Race'

This church has a large number of Chinese students and some of the members have an interest in China. The Chinese students have their own interpreter in the same way that the Deaf Community does. On one occasion the Chinese group lead the worship time. There are several testimonies and then they sing in Mandarin and the words go on the overhead in both languages. However, when it is just in Mandarin it excludes the Deaf believers as they can neither hear the singing nor read the Chinese script so they sign among themselves for a while [field notes Jan. 2006].

People with learning disabilities

Moving on to look at inclusion of people with learning disabilities I will set out my data from the main meeting (*Riverside*) first and then look at the afternoon group (*Reach Out*).

At Riverside

In this section I look at people with learning disabilities in the congregation and to detail any strategies and practices of inclusion that I observed. One young woman who goes to *Reach Out* regularly sits in the heart of the congregation with other church members. She plays in the music group and has a job in a shop on the High Street, so is well integrated in both the church and the society at large. A young man I have got to know, who is not integrated in the society in the way that the woman is, is more often sitting on his own, like an island, and dozes off frequently. Sometimes others come over to speak to him. While this is a short section I believe it is useful to document my observations that little direct or overt practices of inclusion were evident in the church setting.

At Reach Out

However, the situation was different at Reach Out. From my observations, I charted a number of inclusive practices, for example, the meetings always start with a time of worship and a box of musical instruments is handed out so that each person can choose something like a tambourine or the maracas to shake. They are also encouraged to do the actions with songs. On one occasion, a young man with autism is invited to come to the front and do the actions with a leader. A woman from the Tuesday group (house-group for people with learning disabilities) always makes the

tea in the kitchen, which is quite a big operation with cups of tea for as many as 70. On one occasion, one of the women in the Tuesday group leads the worship from the front with two of the leaders. At the Garden Party there is also a woman with Downs Syndrome, who I have not seen before (absent for a while), who is leading the actions to the songs outside. This suggests that when this woman was a regular attender at *Reach Out* there may have been greater inclusivity. A very sociable woman with Downs Syndrome is always on the welcome desk when people arrive, ticking off names. On one occasion she is asked to present a bouquet of flowers to a helper who is leaving.

In the meetings there are often little sketches that are enacted, which people are asked to join in. One day, they do a drama about Jesus calling the disciples and 12 of the group who volunteer get names put round their necks. The man who is severely autistic is included as is a wheelchair user who makes little distressed cries intermittently. Craft activities are always an option where people can make a collage or make marzipan figures, or cardboard fish to write prayers on.

Prayer is always evident. Sometimes a brave volunteer is requested to pray for everyone. The group make requests. One man says he wants to thank God for making him happy, a woman mentions her mother who has broken her arm. One man gets up to speak and goes completely off task. It did not seem to bother anyone but it was not opened up to the floor. There were other examples of people speaking off task. One man chose a fish card and discovered that it was the one he had written a prayer on the previous week. He started to try and read his prayer out again and faltered and one of the leaders started to tell him what to say. She then backed off and let him speak – he seemed happy to have been able to speak even if he had gone off task. One man with Downs Syndrome comes to the microphone to pray and sings ‘Edelweiss’. A leader tries to refocus him, he makes some grunts into the mike and the leader makes some affirming noises and thanks him and he sits down [field notes Sept.2006].

The worship time consists mostly of prayer times, singing, playing instruments and dancing. Sometimes during prayer requests, people are directed towards giving thanks or praying for people who are unwell. During the worship they are sometimes

asked to walk round and greet one another and there is sensitivity to those who cannot walk, who are told to stay where they are as others will come to them. Some of the group also like to dance. A dance is developed as part of the theme one week and they practice the dance several times before doing it for the rest of the group. They also do Jewish folk dancing sometimes.

Felicity records a more nuanced perspective on the complexities of inclusion in her interview: 'there is always a tension between being inclusive and anyone can come.' One afternoon I have a long talk with James who seems to be sensitive to the fact that I am interested in inclusion, and seeks to explain why, in his view, it does not work. In interview he explains that segregation is a necessary stepping stone towards inclusion. In the focus group he elaborates his thinking.

My thinking was that you don't set up special groups but involve them in the regular ones. But then I began to realise that there were some capacities that were not going to change. So they needed their own aspect of specialism in the church. So these groups became a safe place where they could dip into the church's life and experiment and if it didn't work come back to the base group, like a strong family. That was something of the philosophy.

Patrick (from the Diocese) in the focus group seems to echo this view. He says

I think it (inclusion) is a really difficult issue. Because I am sure we all want to include people – that is our starting point really – I'm sure we all want to include people in the life and ministry and their ability to serve in different ways, that on the one hand, and on the other, the needs people have and the value of a dedicated group for certain things and how these things relate together is quite hard. To go all overboard on total integration one might find, I don't know, that needs are not properly met.

Thus, although inclusion may be the intention, Patrick and James claim that separation may be required for a while.

Over the months it seemed to me that the afternoon group became more inclusive. However, in my field notes, I noted that the type of participation was sometimes quite limited. Thus, I formulated a notion of open and closed participation – rather like open and closed questions. An open question permits the respondent to go where they want with the question and say what they want (for example, What changes do you notice in Autumn?) whereas a closed question is highly structured and controlled giving a proposition that the respondent has to agree or disagree with. (For example

what colour are the leaves on the trees in autumn? Or, more closed, a yes/no question such as, ‘have you noticed the leaves change colour in autumn?’) This approach was especially noticeable in the prayer times where prayer was often structured along the lines of ‘thanks’, ‘sorry’ or ‘please’.

One incident at the afternoon group illustrates this complexity in practice. Preceding the prayer time, a woman in a wheelchair mentioned her father. The person leading told the group that her father had died about two years previously. The leader then said that they could give thanks for this woman’s father. Later in the afternoon I happened to be standing next to this woman, who was in a wheelchair, and she took my hand. I held her hand for a while not thinking much about it. Then a woman she knew better came closer to her and she managed to nestle her face in the woman’s side, thus giving strong signals that she was in need of comfort. Thinking back later, I suspected that her comment, ‘My father,’ was an indication that she was suffering on account of the loss of her father. Many people with learning disabilities are forced to go into institutional homes when their parents die and if this had been the case, this could have led to a radical lifestyle change for her. Thus, she may have been missing her father and her family home and many other associated things. On reflection it seemed to me that her needs had probably not been met and that thanking God for her father had quite likely missed the mark. Overall, one of the most striking aspects of this ministry was the lack of open participation and a general tendency to treat the members as children, or simply as people who cannot be expected to know their own minds.

To conclude, as I have detailed more fully in my methodology and methods chapter, I spent some time in both settings. I endeavoured to build relations with the key workers, other helpers and the leaders of the groups. I also attended many of the services provided by both Churches in order to become familiar with the settings, the congregation and all the members of both groups. In all, I spent one year undertaking data collection in each setting. Not surprisingly, I collected a great deal of data, in particular, my observational field notes were extensive and covered many different ‘events’ – from parties, formal and informal prayer meetings, tea and social occasions etc. My focus was on documenting the experiences of and provisions being made for these two groups of people with various impairments.

In this chapter, I have drawn significantly on my observations, and to a lesser degree, on my small number of interviews with some of the key workers (see tables 1 & 2). Thus my field notes provide the basis for the bulk of what is included in this chapter. As stated in the methodology and methods chapter (Van Maanen 1988) insists that field notes have their own difficulties.

I explained at the start of this chapter that here I would be detailing and describing the data that I collected. In the next chapter, I move towards a discussion and analysis of these ‘events, observations and conversations that took place in the field.’

5.13 Summary

With the first three themes there is more commonality than divergence: in relation to the models of disability, both sites appear to have outgrown the medical model although the medical model language of deficit is still in evidence at both sites with varying degrees of discomfort in using it. In relation to category 2, personhood, there is some similarity in the way in which a high regard for the person is evidenced both in the special groups at the main church services. The findings are very nuanced so with a considerable degree of similarity there is some notable difference with regard to the way in which participation in church is conceived, marked more by mutuality at *CGS* than at *Riverside*. A difference in the underlying doctrine of humanity at both sites could be the reason for this impact on personhood. *Kingsway* leaders and helpers see people in a more ‘Catholic’ way as made in the image of God and having incomparable worth, while *Reach Out* leaders and helpers take a more conservative Evangelical view of man as depraved and corrupted by the Fall, shattering the image of God. Regarding the third theme: theology there is considerable accord, the main difference being in relation to a theology of diversity and that largely seen at the level of practice: *CGS* having such a wide variety of people participating in their services. Regarding no 4: modes of engagement, at *Kingsway* people with learning disabilities are consistently treated in an adult to adult mode with active awareness of the dangers of lapsing into an adult to child mode of engagement. However, *At Reach Out* much of the interaction is more suited to children and there is perhaps

insufficient awareness of the adult feelings of some of the members.⁷⁴ The most clinching factor under this category is the way in which the helpers at *Reach Out* see a background in teaching children as a suitable training for working with adults with learning disabilities, while helpers at *Kingsway* see the same background as a likely hindrance, tempting them into relating to adults with learning disabilities as if they were minors. Regarding no 5: seen as same and different in both positive and negative ways, there are no examples of same as negative at *Kingsway* yet many examples of same as positive. In contrast, at *Reach Out* there are many examples of different as negative. The difference here then centres around the variable of negative/positive rather than same or different: *Kingsway* highlighting more positive factors and *Reach Out* perceiving more negative ones. Finally with regard to theme 6: inclusion, the difference between sites is across the board as inclusive practice is evident in the main church service at *CGS* yet not significantly at *Riverside*, and the difference in the special groups lies predominantly in the way in which participation is conceived, At *Kingsway* there is a more open form of participation whereas at *Reach Out* it is more structured and therefore, a constrained form of participation.

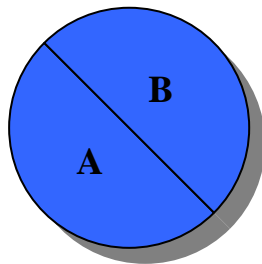
⁷⁴ On one occasion a three-week old baby was passed round and I wondered if any of the older women had ever had to give up a baby as was the practice with girls who fell pregnant in earlier times. The disability literature is full of such instances.

6. DISCUSSION OF RESULTS

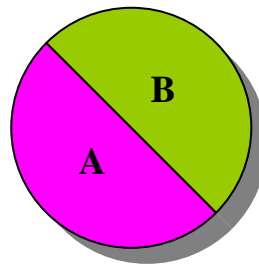
A conceptual diagram gives an overview of the general level of similarity and dissimilarity between sites. This is not an exact statistic (as the work is not quantitative) but by splitting the circle in two according to the two sites it is possible to depict through colour coding the general inclination towards similarity or difference on each of the six factors examined.

Conceptual Diagram

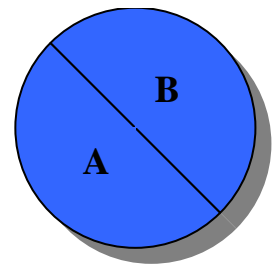
1. models of disability



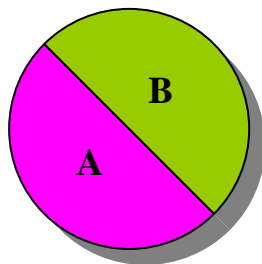
2. personhood



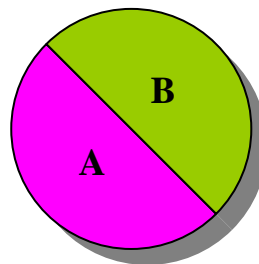
3. theology



4. modes of engagement



5. same and different



6. inclusion

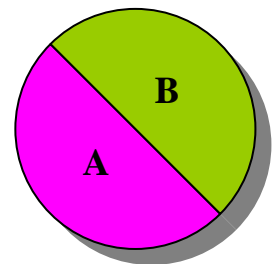


Diagram of 6 discs. A & B denote the research sites and where both sites are blue this denotes similarity and where the two halves are pink and green this denotes dissimilarity but does not indicate the degree of dissimilarity.

In the last chapter I set out my findings under six main themes. As I move towards analysis and critical discussion of these findings in this chapter, I will continue to use the same main headings: models of disability, personhood, theology, modes of engagement, issues of sameness and difference with either a positive or negative stance, and finally, inclusion. Since my research was a comparative case study I pay

some attention in my analysis to the two sites, (*Riverside Church* and *Church of the Good Shepherd*) in contrast.

6.1 Models of disability

Leaders and helpers at *Kingsway* and *Reach Out* used a language of disability which foregrounds deficiency yet, in both places, the leaders, Greg and Lisa and James and Felicity registered discomfort in using these old terms and expressed a desire to distance themselves from such ‘outmoded’ terminology. However, leaders and helpers at *Reach Out* used many more deficit terms using words like ‘help’, ‘care for’ and ‘lacking’ etc. One leader at *Reach Out*, James, expressed the view that reality rather than language was what mattered. While language *may* be indicative of attitude, I will look more to the practices than language to gauge this view. Only one person, Angie, at *Reach Out*, specifically said she could learn from people with learning disabilities. Her response reveals more of a minority culture or relational view of disability (as explained in models of disability chapter 2). Doreen, at *Kingsway* also comes near to expressing this approach when she says that she has learnt from the group how complex people are and how much they can understand. She now realises that God can use all of us. As a teacher of people with learning disabilities she says that she is aware that people with intellectual impairments can also be her teacher.⁷⁵

Regarding the four propositions about disability⁷⁶ on the ‘disability is’ cards, (see methodology, chapter 4, page 103) everyone at both sites rejected the view that disability is the result of personal sin, although one leader at *Reach Out* made one caveat that the Fall has led to the whole creation being less than perfect. At both sites there seemed to be a high level of acceptance of the proposition that disability is a deficiency and even where the leaders and helpers rejected this view, some of them displayed a lack of commitment to this position through the deficit language that they

⁷⁵ Dorothy Soelle in *Strength of the Weak* (1984) points out the need to learn from those we may be teaching.

⁷⁶ The four propositions loosely embody some of the main theories of disability. No1 reflects a minority culture view which refuses to see disability in negative terms; no 2 is in line with the social model of disability; no3 reflects the medical model of disability and no 4 expresses the universal folkloric view of disability sometimes misguidedly associated with Judeo-Christian thinking, as argued by many in the Disability Movement.

continued to use regarding disability. However, at *Kingsway* both Greg and Lisa insisted that people were *different* rather than *deficient* and two people at *Kingsway*, Lisa and Doreen, stated that ‘people aren’t *dis* anything really’ The proposition that disability is a sign of God’s goodness and blessing (no 1) and the notion that disability is a social construct (no 2) gave rise to confusion in leaders and helpers at both sites and they tried to redefine the concepts to accommodate them (as outlined in the findings p127) Lisa and Doreen at *Kingsway* and Angie at *Reach Out* were the only ones to express the view that they can learn from people with learning disabilities.

While I have noted some minor differences between the two sites, in terms of the degree to which deficit language was employed when speaking about disability, there was more similarity than dissimilarity between sites. This was both with regard to their perspective on models of disability and their Christian integrity and pastoral concerns which led them to reach for a more life-affirming view of disability. Nevertheless, in the absence of an alternative theoretical framework they seem locked into the language of deficit and the assumption (especially at *Riverside/Reach Out*) that people with learning disabilities are recipients rather than conduits of God’s Spirit and charisms.

One of the critical research tensions that emerges in relation to my consideration of ‘models of disability’ that may or may not underpin or simply influence behaviour and practices is that of working with interview data and observations. Much of the language and lexical choice displayed in interviews comes from an older model of disability which may merely reflect a lack of awareness of shifts in the field rather than a perspective that sees people with disabilities primarily as ‘lacking’ or being ‘deficient’. My observations of the day to day interactions, events and practices assert a more positive and affirming approach that contradicts some of the language deployed in the interviews; and this is more the case at *Kingsway* where members have significant ministerial roles in the main church at *CGS*. At *Reach Out* and the main church of *Riverside*, the practices are more congruent with the deficit language employed. For example, people with learning disabilities are not deemed suited to being members of house-groups on account of their ‘lack’.

6.2 Personhood

Turning to my second major analytical theme of personhood, both sites revealed a strong sense of the person reflected in the main church services and in the groups: *Kingsway* and *Reach Out*. Personal acts included an emphasis on photographs, the observing of birthdays and the giving of flowers.

One of the most notable differences between sites lay in the way that people with learning disabilities were perceived to be part of the Body of Christ. At both sites, a connected view of people with learning disabilities to the Christian church was revealed yet with significantly different concepts of the likely outworking of that connectedness. For example, leaders and helpers at *Reach Out* placed an emphasis on the notion of ‘help’ and ‘care’ and ‘acceptance’ as if being connected to the Body of Christ only entailed being passive recipients of the grace of the rest of the congregation. James said ‘it is what is within us that makes the real life [field notes March 2005] in the context showing that he wanted to minimize externals, such a markers of status in society, and Felicity was emphatic that ‘we are *all* the Body of Christ’ [field notes Nov 2006] which she saw as being pivotal to inclusion. Nevertheless, James and Felicity did not seem to be seeing the Body of Christ as a reciprocal relationship with each having something to give as well as receive. Nevertheless, this may not reflect their own view but may be indicative of working under constraints in their congregation. As previously reported, Angie, at *Reach Out* was the sole person at either site to state that she had learnt something from people with intellectual impairments rather than just helping them [field notes Oct 2006].

CGS and *Kingsway* people revealed a more rounded view of persons. Not simply because there was a reciprocal relationship with the rest of the congregation, but because people with learning disabilities held public ministries at *CGS*. This was perhaps, best demonstrated by people with Down Syndrome being servers at Communion. In this context they were the agents and the congregation the recipients. Furthermore, Greg underlined a Trinitarian view of personhood suggesting that he regarded people with learning disabilities to be at their best, the same as all people, when outer-focused and not introspective. He says ‘so much of their life is about their own basic needs. People with learning disabilities, and probably everybody, are

at their best when thinking about others.’ [Field notes Oct 2006]. Greg was expressing a balanced view of people with learning disabilities as having something to give to others, irrespective of what their needs may be.

Under personhood we are perhaps seeing a different doctrine of humanity coming into play. Patrick (from the Diocese) raised this issue in the Focus group where he reflected on his own former work as Chief Executive of a Christian charity for people with learning disabilities. He explained how they often discussed why they wanted to support people in the community with learning disabilities and he said they were clear that it was because all people are made in the image of God and therefore have infinite value. However, this perspective was not in the charity’s statement of faith so they rectified it. Patrick contrasted an Evangelical doctrine of humanity which he saw as negative, being all about the Fall and needing grace, with a more Catholic view, which he expressed as ‘ the amazing value they place on every individual made in the image of God’ and he saw this as ‘a corrective emphasis’ from some non-Evangelical backgrounds which he believed Evangelicals could learn from.

I note here that a deficit model of disability can cohere with a deficit doctrine of humanity that Evangelicals incline to, with negative consequences. Greg at CGS told me that he had rejected this ‘low view’. Conversely, a minority culture or relational view of disability can cohere with a doctrine of humanity from the ‘higher’ traditions of the church: *Imago Dei* with positive effects.

6.3 Theology

My third analytical category is theology under which I noted three aspects: tough theology, a theology of weakness and a theology of diversity. While both churches revealed an awareness of ‘tough theology, as evidenced in some of the comments noted in sermons, I collected far more of this material from CGS, partly because I attended the main services for a much longer time than at *Riverside Church*.

However, the material gathered was equally challenging⁷⁷ to the congregation at both sites. Moreover, there is less evidence of tough theology in the special groups for people with learning disabilities, although occasional challenging remarks were noted.

I also noted a more prominent ‘theology of diversity’ in *CGS* accentuated most by their practice rather than through mere rhetoric. The variety of people involved in the services; men, women, white people and those of a minority ethnic heritage, adults and children and people with learning disabilities. Children were not merely included but allowed to be distinct and not expected to be little adults: they were welcomed in their diversity.

The notable differences in both ‘tough theology’ and a ‘theology of diversity’ may both arise from a dissimilar stance towards the *status quo* as it could be expected that a congregation that is prepared to challenge the *status quo* would be willing to embrace and fully include persons not highly regarded in the society at large and that there may also be more of an appetite for the preachers to truly preach the Gospel of Jesus Christ, urging the congregation to go beyond their comfort zones. Journalist and popular speaker, Philip Yancey (1997) notes that the Christian Church is often beset by ‘a culture of respectability’ and this renders the church ineffective in the dominant culture.

Nevertheless, a ‘theology of weakness’ was discernible in both the special groups for people with learning disabilities, and also at both sites in the main church services. This latter context is significant as the regular members of the congregations comprised many of whom would be counted among the strong in the society at large. This suggests that there must be some counter-cultural thinking going on even if not a wholesale desire to subvert the *status quo*, for which there was more evidence at *CGS* and its *Kingsway* group.

In addition, as I have reported in the previous section on personhood, there were differences in ‘high’ and ‘low’ theology between the two settings. For example,

⁷⁷ By challenging I mean concepts which challenge the ‘*status quo*’ thus urging believers to live beyond their comfort zones.

‘high theology’ was in evidence at *Kingsway* while a more ‘low theology’ was held to at *Reach Out* where a doctrine of humanity was concerned.

6.4 Modes of Engagement

Thus far I have observed that the two sites were marked marginally more by similarity than dissimilarity. However, in this fourth theme, (and the two that follow) I begin to move towards some areas of notable difference.

Turning to my fourth analytical category of modes of engagement, the discussion in this section will be based almost exclusively around the afternoon meetings at both sites. As I have already reported (in the findings chapter) the mode of interaction at *Reach Out* was frequently more suited to children than adults. However, the house-group meeting that I attended once at *Riverside* shared more similarity with *Kingsway* in terms of being marked by a preponderance of activities throughout the year suited to their age. At *Kingsway* there was evidence of people with learning disabilities being discouraged from behaving like children, whereas I found no such examples at *Reach Out*.

One significant difference regarding the way in which adults with learning disabilities were viewed at each of the sites was foregrounded in contrasting answers to two of my questions addressed to helpers in my interviews. See findings p152.

Two people at *Reach Out*, Angie and Carol, saw their work with children in special needs education as an asset whereas two people at *Kingsway* saw precisely that type of background (‘special needs’ education) as a potential hindrance to this ministry with adults. Thus, the issue of treating adults with learning disabilities, as children (at least as a temptation rather than necessarily a fact) comes to the fore: the helpers at *Kingsway* seeing such an outcome as thoroughly inappropriate, with the helpers at *Reach Out* not appearing to make that link.

Furthermore, at *Kingsway*, Lisa and Doreen expressed concerns about some skills associated with a teaching background. Lisa told me that she refuses to use one

person for catering who used to teach children with learning disabilities as this woman tends to treat them inappropriately, as children, and exercise portion control. Doreen said in response to the 'hindrance' question the fact that she regards herself as an old-fashioned type of teacher, inclined to do too much talking. Dalpra (see chapter 3) points out another point of inappropriate connection that people make between working with children and adults with learning disabilities and says

While I approach comparisons of learning disabled and children with caution (I was told to be very wary of Sunday School teachers who think they automatically qualify as teachers of learning disabled adults as the skills needed are hugely different) (Dalpra 2009:24)

So at *Reach Out* two people offer their experience of teaching as an advantage and a possible preparation, whilst at *Kingsway* two people identify this sort of experience as a likely hindrance. Nevertheless, At *Reach Out* there is a young woman who is about to start as a helper and she is concerned that she has not had any special needs training. This is an indication that new recruits are not necessarily expected to have this experience, which suggests that *Reach Out* is not consciously forging a link between special needs education and working with adults with learning disabilities.

In conclusion, *Kingsway* routinely resist treating adults with intellectual impairments as children and actively engage with them in an adult to adult mode whereas, *Reach Out* was characterised by a tendency to infantilise its members with some worrying consequences for their feelings when operating in an adult to adult mode. The difference evident in practices may be an oblique effect/a trickle down effect, of the underlying models of disability at work. As I have noted previously, leaders at *Reach Out* utilised a discourse of deficiency when talking about disability, and this might well incline them to infantilise their members. Conversely, *Kingsway* leaders expressed resistance to deficit language which they sometimes used but with manifest discomfort, as no longer being appropriate. This underlying resistance to a model of disability that see people with learning disabilities as lacking and this together with an empowering view of personhood may well be the reason why leaders at *Kingsway* consciously employed an adult to adult mode of practice.

6.5 Members seen as ‘same’ or ‘different from others’

Moving on to my fifth analytical category, I note, as indicated before, that the sites are now becoming more dissimilar from each other. Thus, with regard to whether the members are seen as ‘same’ or ‘different from others’, the two settings are marked more by difference from than similarity to each other. While both sites see people with intellectual impairments as both ‘same’ and ‘different from others’ in *positive* ways, the principal difference is with regards to the variable of *negative*. Interestingly, Kingsway has *no* examples of same as negative and overwhelmingly more examples of same as positive. *Reach Out*, in contrast, has significantly more examples of different as negative and *no* examples of different as positive. On balance then, the difference between sites is not marked within sameness and difference but with regard to the variable of positive and negative.

In sum, my data suggests that *Kingsway* leaders and helpers see people with learning disabilities in a more positive light while *Reach Out* leaders and helpers tend to perceive a more negative aspect. Again, in order to explore the underlying reason for this difference in slant, I return to the issue of the underlying models of disability: importantly, a medical model posits that people **with** intellectual impairments may be ‘lacking’ but not people **without** intellectual impairments. At *Kingsway* (and also with Peter and Wanda, from the Diocese, in the Focus group) there is a more counter-cultural worldview granting the freedom to acknowledge that sometimes people who are not regarded as impaired: that is, those within the mainstream culture, may actually be the ones who are ‘lacking’ and in need of learning from people with intellectual impairments as those marginalised rather than acculturated by mainstream culture. This in part can be attributed to a worldview which, in Christian circles, is sometimes referred to as, ‘the upside down Kingdom of Jesus’, which upturns the values of the *status quo*, thus rendering those who are deemed ‘rich’ to be lacking rather than those deemed ‘poor’ who are on the upside, or in Biblical terms those who ‘will inherit the Kingdom of heaven’ (Matthew 5:5).

6.6 Inclusion

My final category for analysis highlights some contrastive differences in approach. The main church at *CGS* was thoroughly inclusive across categories of race, gender and age. In addition, its special group *Kingsway* is wholly owned by the congregation, as an integral part of the ministry of the church. I noted in the findings chapter that church wardens and others take an active interest in what goes on at *Kingsway*, disseminating information to other interested parties, including the P.C.C.⁷⁸ At *Riverside* there are only a few members of *Reach Out* present in the congregation and these are a largely unacknowledged presence, especially one man who regularly sits alone and falls asleep during the service.

The special groups were dissimilar in that there was more initiative taking at *Kingsway* and prayer times were marked more by an open form of participation. Some members helped in the setting up. Quite possibly this was more straightforward as *Kingsway* was much smaller than *Reach Out*. Also, *Reach Out* drew from the institutional homes and did not assume that all members were believers. *Kingsway* served a number of local churches. *Reach Out* could be said to be more of an outreach event although *Kingsway* had an element of that too as Greg had explained in interview.

This issue of presence is important, as Felicity at *Reach Out* who in her interview says about inclusion, ‘there is always a tension between being inclusive and anyone can come.’ Also she says, ‘part of the love of God is to be there for everyone.’ This suggests a view of inclusion that is based more on presence than on active participation or just simply giving and receiving.⁷⁹

At *CGS* people with learning disabilities were not only fully included in an active way, servers at communion, the carol service etc but were actively known and

⁷⁸ P.C.C. is parochial church council.

⁷⁹ An example of giving and receiving could be taken from something Patrick said in the focus group discussion when he mentioned a visit to the place which I attended once. He said that the group from the charity for supporting people with learning disabilities that he had worked for, was leading the whole worship. ‘They led a lot of the music side and went round singing to one another ‘The Father himself loves you.’ They went round the congregation singing it. That spirituality was Godward and with each other and it was very moving and they were ministering to one another.’

welcomed, as witnessed in between services where church members greeted *Kingsway* members by name and welcomed them affectionately. Thus they were valued for their presence whether or not they had a role to play in the proceedings.

This desire for full inclusion in the Christian church, most powerfully demonstrated at *CGS* and *Kingsway*, is in accord with what we documented of the historical Jesus (pp28-32) who showed a remarkable concern for inclusivism that is reflected in the ideals, though by no means always the practices, of the Christian church. The Kingdom of God is an inclusive community: God's love and grace breaks all boundaries: national, cultural, gender, disability etc as Paul strikingly writes 'In Christ there is neither Jew nor Gentile, neither slave nor free, nor is there male and female, for you are all one in Christ Jesus. (Gal 3:28).

6.7 Summary of discussion of six themes

Analysis of the two sites in relation to my six analytical categories reveals that, on balance, the two sites are marked more by dissimilarity than similarity. The ministry to people with learning disabilities was thoroughly owned by the congregation at *CGS* while conspicuously not so at *Riverside Church*. It can be seen that the work with people with learning disabilities is integrated across the board at *CGS*, whereas disability seems to be an issue that the leadership at *Riverside Church* is trying to accommodate while the majority of the congregation seem much less aware. It seems a disconnected ministry and people with learning disabilities are not yet seen as the Body of Christ, as Felicity so clearly expresses it in the focus group 'this is something that we need if anything in the church, that *we* are the Body of Christ.' – presumably in the context in which she speaks including people with intellectual impairments as the Body of Christ.

Only at *CGS* had the whole congregation really owned this ministry while the leaders at *Riverside Church* showed repeated efforts to raise consciousness of disability issues, the congregation appeared to be uninvolved, in the main. Frustration about this matter was expressed by one of the helpers at *Reach Out*. A final finding is the consistently inclusive nature of the ministry at *CGS* and *Kingsway*.

6.8 Critical discussion of cultural issues at both settings

I approached my research, drawing on some fundamental analytical categories that have remained as central organising themes in my literature review, data collection and analysis. However, from the coding and analysis of my in-depth interviews, my field notes and observations, it was evident that other issues, beyond my analytical categories, were in play in both settings. Here I want to start to critically unpack two aspects related to the culture that was evident in both settings. These are 1) things that challenge the way non-disabled people think and how they 'do church' and 2) evidence of a different culture and perception among people with learning disabilities which those who are not intellectually impaired could learn from.

Challenging the way non-disabled people think and 'do church'.

At *CGS*, I saw how widening participation leads to inclusion and not the other way around as I would have imagined. Allowing people with learning disabilities to participate in church and also in outside social events, such as holidays, valentine's dicso etc., is part of normalisation and makes them less 'othered'. Where people are less 'othered' they are more likely to be included because they are 'one of us' and not 'one of them'. Those who had ministries at *GCS* e.g. the men with Downs Syndrome who served communion, were more an integrated part of the congregation than were some others.

At *Reach Out* I saw through doing the dance at the afternoon group four times that to accommodate people with learning disabilities, the general congregation would have to become much more patient encouraging development of the fruits of the Holy Spirit.

At both sites helpers observed that because it was the group for people with learning disabilities they were not overly concerned for everything to be 100% right or if leaders had some problems themselves (e.g. poor eyesight). Thus perfectionism went to the wind. Working in this ministry opened leaders and helpers to a more *laissez faire* value system than they were used to in church where excellence in performance was striven for. James said in the focus group 'if these people prayed as

they wished, it would not be found acceptable – the doctrine – the manner of expression, in most church set ups. People wouldn't find it easy,' thus confirming what is normative in most churches.

I also found from my immersion in the context of *Reach Out* that people with learning disabilities *en masse* can be rather overwhelming. Even theologian, Frances Young who has an intellectually disabled son found people with intellectual impairments quite threatening (psychologically) *en masse*. At *Kingsway* I experienced how much less threatening people with learning disabilities felt to me in smaller numbers and also that it was easier to get to know them as individuals when numbers were fewer and this in turn reduced my sense of unease. This could be a reason why the church was more involved at *CGS* and not involved at *Riverside Church*.

I observed at *Reach Out* in order for prayer needs to be met adequately there needed to be a level of freedom in the prayer requests and sensitivity to what people might be asking for. Perhaps encouraging those with suitable gifts of the Holy Spirit to pray for one another would facilitate this happening as might occur at *Kingsway*.

Finally through both sites I observed that a genuine love of people and a Trinitarian understanding of the *Imago Dei* was more crucial than special needs training.⁸⁰ For 'Special needs' teacher training could sometimes lead to the members being 'othered', whereas a deep love for people was more likely to lead to more inclusive and affirming behaviour. In my view, it was this that created the ethos in which people with intellectual impairments were enabled to flourish.

Evidence of a different culture and perception among people with learning disabilities

At both sites I observed how uncompetitive the members were, evidence, it would seem of a different value system at work. It could be argued that because people with

⁸⁰ This is not to suggest that 'special needs' training has no value.

intellectual impairment are not 'productive' in the ways in which people are expected to be in society, they are 'out of the loop' as far as competition is concerned. Grey (1989:31) claims that the relational strength of women is the result of being left out of 'the competitive/aggressive/dominance ethic which controls the public arena.' It could be argued that the same might be the case for people with learning disabilities, as the issue is power, and this reversal is a strength that the church needs to recognise and emulate. At *Kingsway*, the evening that I took a video recording of the carol service to share was notable: the group were at pains to affirm one another. One young woman did not want to see the video as she thought she had looked foolish so the members made a big fuss of her when her turn was shown in order to build up her confidence. Also at *Reach Out* a volunteer was requested and one woman hesitated and lots of people started to say to her 'oh go on, you know you are really good at this.' In both instances, the focus was reminiscent of St Paul's injunction in Philippians 2:3 'in humility value others above yourselves.'

At *Kingsway* Lisa told of a woman with learning disabilities who noticed that her (Lisa's) grieving friend had not been at church for several weeks. No-one else in the congregation seemed to have noticed her absence. I puzzled over why this should be and came to the conclusion that some people with intellectual impairments may be less likely to have their vision filled with their own importance leaving them freer to notice others. This example illustrates a form of counter-cultural behaviour because people who are successful in worldly terms may be encouraged to see themselves as important (a point James alludes to with objection) and it may be that this self-aggrandisement can obscure their vision of others.

In consequence, it seems that everyone in the church can learn from people with learning disabilities as their value system (through exclusion from main stream society's values) may well be the reverse of society's in general and, as such, is fact closer to the values of the 'Upside down Kingdom of Jesus' which the church should be aiming for. This is not to argue for some essentialist difference⁸¹ between people with intellectual impairments and others but for the result of social conditioning (eg being in or out of the 'aggressive/dominance/ competitive/ ethic' which Grey notes

⁸¹ In this thesis diversity is celebrated as part of God's rich tapestry, therefore, difference is not automatically glossed as deficit here.

(see previous page). Leading on from these differences engendered by social conditioning, we need what Yong (2007) calls a ‘pneumatological imagination’ (further expounded in chapter 7) to be able to hear what the Spirit is saying. Until we see the need to challenge the *status quo* and see *ourselves* as ‘the lesser brethren’(Matthew 25:40), rather than people with learning disabilities we are inclined to think if the Holy Spirit is at work, people with intellectual impairments will behave more ‘like us’ and not the reverse.

Furthermore, people with learning disabilities sometimes appear to be more straightforward and therefore might be more honest. As Doreen, says she loves the Kingsway group because it is ‘very basic and simple and lovely – how people are – straight.’ For example at *Kingsway* a man is asked if the person next to him is his brother to which he replies bluntly ‘no, he bloody isn’t.’ Social conventions dictate that even if that is what one may be thinking it should be communicated in a far less than truthful way. Societies vary in their conventions according to regions but politeness theory reveals that there are conventions for behaviour that protect face and while such bluntness may not be socially desirable there is something refreshing about people not being practised in the two-facedness that ‘polite’ societies are steeped in. This is not intended to be patronising for I am arguing here for a level of difference being the result of the social conditioning that issues from being ‘outside the loop’ and this is regarded here as something positive, a mark of integrity and integrity is a value to be emulated in the Christian church.

Finally, it should be noted that while there was very little awareness at either site of the Disability Movement and its concerns, any accusation of Judaeo-Christian thinking being at the root of disability being negatively constructed, does not stand up to close inspection. None of the people interviewed at either site gave any credence to the popular view that disability is the result of personal sin and there was no evidence of any belief in this view in the practices I observed. Where *Reach Out* revealed less of an expectation of mutuality in engaging with people with intellectual impairments, this could be said to be somewhat oppressive for disabled people. Nevertheless, there is a community of practice in both churches revealing love and respect for people with learning disabilities as made in the image of a relational God. So Judaeo-Christian thinking was found to be at the root of this good practice. Next,

I will draw out the underlying theological reflexes at work inviting full inclusion of disabled people, in order to posit an explicit theological rationale to make sense of the degree of good practice uncovered in the data. It is to the task of formulating a constructive theology of disability that I now turn.

Part three

Towards a constructive theology of disability

Part Three consists of five chapters which begin to develop a constructive theology of disability. The first is a Christian exploration of suffering which argues for the universality of suffering in the human condition. Chapter 8 is then an exploration of what personhood means and the fact that it is also a universal ascription for all those made in the image of God. Chapter 9 looks at some tenets of an emancipatory church drawn from various liberation theologies and chapter 10 is the formulation of an emancipatory church that can be fully inclusive of people with intellectual impairments along with all other persons. The final chapter outlines the conclusions and recommendations of the thesis.

7. THE THEOLOGY OF SUFFERING

This chapter seeks to de-stigmatise suffering, arguing for its presence in the lives of all people as part of the human condition. It sets out the Enlightenment conundrum of theodicy underlining the futility of that debate. Trinitarian Theism and incarnational Christianity are explored in contrast and issues of power and sovereignty are discussed in this light. The centrality of the cross for a true Christian theism is foregrounded and here the suffering of God Godself is introduced. Finally, the reason for inclusion of this topic in the thesis is set forth underlining the normativity of suffering in the interconnectedness of the human experience and the benefits that can accrue from the position of fellow-sufferer.

7.1 Suffering, evil and the Disability Movement

It must be acknowledged at the outset that the issue of suffering is a thorny topic with the Disability Movement as some resent disability being glossed as a form of suffering (as already noted in the section on language and disability). The Disability Movement has also been noted as being divided over the issue of impairment. Sally French and others (Wendell 1996) point out that some forms of impairment are not susceptible to social manipulation.

However, I have some sympathy with the dilemma and reflecting on some of my own tussles with gender I think I can understand the emotional charge, while seeing the root problem as being elsewhere. It would seem not to be so much a question of ‘impairment’ as what it argues for regarding inclusive practices. So I am hoping to take the heat out of including a section on suffering in a thesis on disability by pointing out that the issues that cause offence do not need to be part and parcel of the argument. Where our purpose is to include and qualify for participation we may be able to look at some unpopular matters without causing alienation.

Folkloric interpretations for the existence of disability and suffering in general abound (see appendix 4 for disability in cross-cultural context) yet we have seen from the church fieldwork that causative explanations are not countenanced and suffering is seen as an enigma and universal and therefore not related to personal sin.

Before venturing into any discussion of suffering it is necessary to comment on the common conflation of evil and suffering. While evil invariably involves suffering, suffering may occur (even to an extreme degree) without any intimation of evil. The best and most commonplace illustration of this latter fact must surely be in the reality of childbirth. Women may suffer even to the point of death yet childbirth is generally seen as a very positive event⁸².

Hauerwas defines suffering for us in *Suffering Presence* as 'a brute power that does violence to our best laid plans'(1986:165). Jesuit priest, Paul Crowley, offers us a not dissimilar definition in *Unwanted Wisdom*: 'suffering is first and foremost the involuntary loss of an intrinsic good'(2005:32). Clearly this would not ordinarily encompass the experience of childbirth, but where suffering more often crosses with evil and destructive forces then this is a useful definition.

Certainly in life there are experiences that come 'as a brute force' and 'do violence to our best laid plans' and disability is only one among many. As disabled feminist philosopher, Susan Wendell says, 'Every life has burdens, *some of them far worse than disability*' (my emphasis) (1996:154). In any difficult circumstance, bereavement, redundancy, natural disaster, etc, we are forced to grapple with how the world is and who God is in new ways and it could be argued that the worst of the suffering may be the violence it does to our best laid theology too! McGrath expresses this impact 'Suffering possesses a double cutting edge: the sheer pain and distress of the experience is driven by an unbearable intensity by what that suffering might imply' (2000:76).⁸³

We will examine now the attempt that philosophy makes to resolve the issue of an Almighty God with the existence of tribulation in the world.

⁸² Some psychologists believe that the pain of childbirth contributes to the bonding between mother and child.

⁸³ Frances Young (1990) speaks of this double impact when she says that Arthur (her mentally impaired son) was not the main problem but the sense of abandonment by God that she felt.

7.2 The Enlightenment conundrum created by philosophy and Classical theism

The word 'Theodicy' is a composite of two Greek stems; *theos*, meaning God and *dike*, meaning justice or righteousness. The term was coined by Leibniz as the title of his 1710 text which 'explains' how this world is the best of all possible worlds. In modern theodicy God not humanity is on trial and this is because of the problem which is foregrounded. Disablist theologian, Tom Reynolds, sums up the problem when he writes that 'the issue amounts to whether and how we can justify God's abiding love and sovereign purpose given the constancy and ubiquity of human suffering and brokenness (Reynolds 2008:29).

Tilley, commenting on the book of Job concludes

Job is not a book of answers, but a text of warning, even a text of terror....failure to listen to the voices in Job has led theodicy to this long search in the wrong direction. Although people may be redeemed suffering is irredeemable. (Tilley1991:109)

In recent times two camps have emerged: one which foregrounds the problem of pain and the other the issue of God's justice. The twentieth century has intensified the historic problem as massive disasters such as Hiroshima, the Holocaust and other genocides have been brought to our attention as well as natural disasters on a grand scale.

Some argue that the project of theodicy is itself an evil (Tilley 1991 arguing from a position of speech act theory) or futile and the very thing that we are warned against in the book of Job (Habel 1985; Tilley 1991; Reardon 2005). Henderson & Hein (2001:109) summarising the theodicy of Austin Farrer, caution against 'the prideful boasts of the homespun theologian'. Theodicies, according to Tilley are part of an Enlightenment obsession with reducing the murky and mixed to the distinct and transparent at the price of idealising the reality of evils. It tends to divide suffering neatly into human sin and natural suffering thus failing to name structural sins as evil. A further objection is that one becomes blinded to 'a practice which serves to marginalise all other discourses about God and evil' (Tilley 1991:2) silencing the voices of those who are suffering and oppressed by, theologically-speaking, writing them out of the script. In Tilley's terms this suppressing of the voices which curse

God, express lament and grief and seek to counteract evil practices creates a disjunction between academic theology and pastoral counsel (1991:3). Relating to this disjunction, Surin (1993) points out that there are both theoretical and practical theodicies, the latter declining to offer theoretical answers but more often offering specific examples that reveal a suffering God. Surin says that practical theodicians value 'the fundamentally moral rebellion against God displayed most typically by Dostoevsky's Ivan Karamazov' (1993:195). It is a praxis-oriented approach which seeks more to promote a view of God as not detached from suffering, than to hold out abstract answers.

Finally, from a disability perspective, Reynolds who sees that theodicy is the pivotal issue concerning the awkward relationship between disability and theology, warns

....theodicy questions, inevitable as they may be, can produce unintended but palpable mechanisms of exclusion that obviate the call to hospitality at the centre of Christian faith. Under the banner of love, the allegedly benign intention to understand ,accept, help and heal disabilities can ironically stymie the genuine welcome of disabled persons into our communities, signifying a deeper and perhaps more pernicious exclusion. Hence we must proceed with great caution and circumspection in the attempt to discern God's hand in human disability (Reynolds 2008:30).

The philosophical problem arises as the believer holds to a number of premises, which can be summarised as: God exists and has an ongoing interest in his creation; God is both good and omnipotent; and does not wish suffering on his creation. David Hume and John Stuart Mill both show that starting from these facts and in the absence of any other assumptions, it is not possible to arrive at the all-powerful and wholly good God of Christian theism.⁸⁴ (we can see here that what they call Christian Theism is in fact a classical overlay on the Christian God and a far cry from Trinitarian incarnational Christianity, a theme we shall return to).

A series of arguments are advanced to solve this dilemma. First, Thomas Aquinas believed the world was good and perfect because it was made by a good and perfect God.⁸⁵ He argues for a theocentric vantage point rather than an anthropocentric one. Natural evils, the argument runs, only appear evil when seen from our perspective.

⁸⁴ There is a view that since the concept of a loving God cannot be extrapolated from the data it must be a divine revelation and certainly C S Lewis, while an atheist, was perplexed at where the notion of a loving God could have come from.

⁸⁵ A similar rationale is advanced in Islam.

A second line of argument resides in the Free Will Defence which holds that in order for individuals to be free and exercise choice God allows evil and suffering to occur. This argument seeks to remove responsibility for evil from God by blaming humans for wilfully misusing their right to freedom of action. In some ways, Demonic power, which is a third line is an extension of this argument as it hinges on the view that Satan and his angels had free will and chose to fall from grace and thus the Earth is now under this evil influence. It also serves the function of deflecting blame both from God and human beings for the suffering in the world.

A fourth approach centres on the existence of natural evil in the world and this is said to be a result of the need for natural laws to operate in order to regulate the environment. The objection to this view is that the degree of suffering arising from natural forces is hard to justify and having witnessed the 2004 tsunami in the Far East who could disagree with that view?

Finally, others retreat into divine mystery insisting that God's ways are not our ways. However, this oft quoted sentiment from the book of Isaiah contextually is about forgiveness (Isaiah 55) thus demonstrating that God's ways are manifestly higher than our ways and not lower as would be the case in a context of gratuitous suffering. Roger Forster takes issue with the argument that God is beyond reason stating that the Logos (a name for God) comes from the same root as our word 'logical' and therefore this attempt to dismiss the problem is bogus. (2006)

In much more recent times there have been others, who have taken refuge in revisionist readings of God. Don Cupitt,⁸⁶ among others, dispenses with a traditional view of God.

While we stay within the classical framework we can make very little progress on this topic. Wendy Farley, departing from classical theology, offers a revisionist reading of God⁸⁷ which succeeds in making God loving and co-suffering without

⁸⁶ Sea of faith founded in 1984

⁸⁷ She states that tragic vision is theistic and repudiates the metaphors of a savage or malevolent cosmos. It is not gnostic but shares with classical Christian theology a belief that creation is good.(1990:31)

being impotent.⁸⁸ Farley insists on placing suffering rather than sin at the centre, not out of a desire to minimise sin but because she believes that suffering is a more important anomaly for Christian faith. (1990:12)

We now move towards a Trinitarian view of God, dispensing with Aristotle's Unmoved Mover, and embrace an incarnational God who suffers with us in order to see the world differently and encounter a much more complex universe.

7.3 Trinitarian Theism and Incarnational Christianity

Within this framework we have to reconsider two main issues: namely, God's omnipotence and the reality of suffering in God's world. In this section God's sovereignty and omnipotence and the related question of might and power will be explored. The complexity of the universe and the Creator who made it will be underscored together with a theology of connection which can unexpectedly give rise to suffering. God's purpose of drawing us deeper into a relationship of love and freedom is then expounded.

Perspectives from Process Theology and Open theism help us to see the complexity of the world. Process theology, previously popular with liberals, which argues that reality is characterised by becoming, change and event, has been largely superseded now by Open theism. Within this view God is both affected by the world as well as affecting it. In this respect it highlights the fact that God is self-limited by his creation. Fiddes says

Process theology has a distinctive contribution to make to theodicy, as it can extend the Free Will Defence of the existence of suffering and evil beyond what is usually called the 'moral evil' of human decisions (1993:474).

However, a common criticism is that while it removes responsibility from God for evil in the world it leaves him powerless to overcome it. Open theism, however, has gained some ground among Evangelicals as it claims to be a thorough-going Biblical rethink which parts company with classical theology because it is seen to be

⁸⁸ Farley's theodicy will be explored further in this chapter.

unbiblical in its powerful overlay of Greek philosophy (Pinnock et al 1994). Some open theists like Roger Forster, take a limited view of the 'openness' of God, and while agreeing that God does not move every pawn on the board, as this would violate the freewill at work in the universe, nevertheless, takes the view that God being like a Master Chess player, can still determine the final outcome without restricting the free decisions of other key players (2002:6). Forster's view enables us to hold to the 'sovereignty of God'⁸⁹ within a complex framework of the universe. God's own answer to Job involves an insistence on the complexity of human existence (Job 38). We will unpack further the misconceptions that arise from a classical overlay regarding the sovereignty of God.

Much of our thinking on God's sovereignty is conditioned by Calvinism which sees absolutely everything that happens in history as being expressly God's will. Some illumination on this issue is brought by Costas Karras in his appraisal of the doctrine of the Trinity in relation to political thought and action. The matter hinges on our understanding of God's power. He writes

Once the distinction between the human way of comprehending power and God's way of exercising power is understood, we can be freed of the delusion that the broad currents of history must be God's work. Certainly God may and does act in history, but on the one hand his action is subject to no necessity while on the other he has granted autonomy to his creation of which man is the crown. Certainly there must have been currents of history pleasing to him, but to assume that whatever occurs is his will suggests either fatalism or else the choice of a comfortable but self-serving idolatry of our age (Karras 1991:170).

Farley (1990) and Blumenthal (1993) take a similar view seeing the need for God to limit God's own power for the sake of the integrity of the creation. Since God has created a being capable of moral judgement God has to limit God's own power in order to empower the being God created. Blumenthal says (1993:16) 'power is dialectical. It is the intertextuality of God's and human kind's expectations. Vardy (1992) also sees God's power as being self-limited. This is consistent with a New Testament view where the stress is on the promise that God will be with us whatever the circumstances. The promise of Romans 8:28 surely underscores that life is not

⁸⁹ Forster rejects a particular type of belief in 'the sovereignty of God' which is popular and fatalistic (2001:6).

being delivered to us as exactly what the creator ordered!⁹⁰ There is nothing deterministic about this view as the onus is on us to respond well and co-operate in order for good to result in some way. The issue of prayer is a practice which becomes problematic in this debate, as acknowledged by Philip Yancey (Yancey 2006). According to Matthew 5:45 'even the hairs on our heads are numbered' but this need tell us no more than that God is omniscient and not that God is occupied with bringing about when each hair will fall out. Vardy positively rails against this kind of false conclusion laying bare its negative implications which those in anguish will readily detect.

To hold that God plans each thread of our lives with care makes him into an obscene God, not a loving God. God does not want suffering, he does not will evil, he does not use suffering as a means to some wider end. Jesus fought against evils, he cried when Lazarus died. Compassion and God's tender care was central to his message (1992:119).

Forster points to some consequences of this type of thinking which every evangelist and pastor should surely heed. He claims that Christianity went into decline in this country after two horrific world wars in which young men returned home deeply traumatised by what they had witnessed and, no doubt, participated in, only to be informed that this was the will of God (2006:9).

We also need to consider what the Christian God's power looks like. William Placher (1994) taking a Christological view argues that God's power is shown in weakness and vulnerability. Jesus on the cross embodies this truth as many onlookers taunted him assuming that if he was powerful he would come down from the cross (Matt 27:40). We might say that his power was best expressed in sacrificial love, unconditional forgiveness, and by fully entering into the human predicament.

The book of Daniel (chapter 10) reveals some of the complexity of the spiritual realm where we are told that the Archangel Michael was resisted for 21 days when trying to respond to Daniel's prayer (Dan 10:13).

Vardy states 'to claim to understand the ways of God would be presumptive folly' (1992:90). It is precisely this 'presumptive folly' that motivates Job's comforters and some in the church today.

⁹⁰ Roger Forster points out that the Greek . σύνεργει literally means God 'in-works' all things (2002:6)

Some philosophers, including Thomas Aquinas, try to solve the problem from a disengaged position, while others try to work things out from an acutely engaged position, as did C.S.Lewis after the death of his wife. This may prove to be too subjective leading less to thinking than to knee-jerk reactions, as Lewis admitted in *A Grief Observed* (1961:29).⁹¹ On balance it could be argued that an insider position is better as it is likely to engender insight which total detachment is not. Paul Crowley wrote *Unwanted Wisdom* (2005) after the traumatic loss of two of his siblings in which he reveals the unwelcome truth that wisdom and insight can come from an acutely engaged, insider position. Crowley cautions against an over-individualistic interpretation of suffering for he sees that we live in a connected world. He simply puts it 'very little that happens to us is so private, so much my own problem, that it does not have ripple effects (2005:38). Moreover, Crowley cautions that suffering is irreducibly personal as it is people who suffer and not just populations, classes and groups (2005:27). Farrer marginalises suffering when he says 'we are concerned with the practical problem only. If what we say is neither comforting nor tactful, *we need not mind.*(my emphasis) Our business is to say, if we can, what is true' (1962:7) Liberation theologians object to this view and Gutiérrez says 'Job's words are a criticism of every theology that lacks compassion and contact with reality (1987:30). Disabled Professor, Stewart Govig (1989:13) complains that some preachers believe that 'tough times don't last, but that tough people do.' He insists 'tough times last. To pretend otherwise is a romantic falsifying of truth. It only intensifies the non-sense of disease and disability. Yet healing and hope are also realities.

In incarnational theology we are confronted by the centrality of the cross and therefore of suffering. The cross also instructs us of the fact that the power of the Christian God resides in weakness and not a show of might, as those who taunted if you are the son of God come down from the cross believed. (Matt 27:40). In Trinitarian theology we are reminded of the connectedness of all things. An over-individualistic worldview can assume that every small thing that happens is for our own good but if we take a connected stance then there must be times when what happens to us is simply part of a domino effect.

⁹¹ Lewis's own work provides an interesting contrast on this point as I suspect that he would not have turned to his own work 'the problem of pain' when his wife was dying of cancer, and the work which emerged from this harrowing experience (*A grief observed*) is a very different text!

Wendy Farley in her ground-breaking book *Tragic vision and Divine Compassion* posits what she calls a contemporary theodicy which in my view avoids these pitfalls. For Farley tragic vision locates the possibility of suffering in the conditions of existence and in the fragility of human freedom.

The very structures that make human existence possible make us subject to the destructive power of suffering. Since guilt is not the primary problem, atonement and forgiveness cannot help transcend tragedy. Tragic suffering cannot be atoned for; it must be defied. Compassion is that power which survives to resist tragic suffering. (1990:29)⁹²

Furthermore, towards the end of his career, Kahl Rahner gave a short address entitled 'Christian pessimism' in which he speaks of the 'radical perplexity' of human life. Taking 2 Cor 4:8-10 'We are perplexed but not driven to despair,' as his text, Rahner claimed that perplexity was an integral part of human existence.

Gerald May in the introduction to his book *The dark night of the soul* brings this professional judgement which seems in concert with Farley's perceptions.

But John of the Cross's insights have helped me understand that suffering does not result from some divine purgation designed for a spiritual elite. Instead, suffering arises from the simple circumstances of life itself. Sometimes human suffering is dramatic and horrifying. More often it is ordinary, humble, and quiet. But neither way is it 'God's will'. The divine presence doesn't intend us to suffer, but is instead *with* us in all the experiences of life, in both suffering and joy. And that presence is always inviting us towards greater freedom and love. (2004:9)

McGrath, who abhors detached theologising on suffering says 'The real issue is not about defending God's honour or integrity, but about making sense of our experience' (2000:9).

Finally Forster (2006), and Ward (1982) affirm that the purpose of human life is to be in a love relationship with God and others: the highest good in view is not pleasure but a love relationship with the Creator (Ward 1982). Added to this John of the Cross and Teresa Avila insist that God is always calling us into new realms of freedom. That is perhaps the best lens through which to view all that happens in this

⁹² Farley sees this 'divine compassion' not as an emotion but as an efficacy, a driving force that brings relief and which is constantly drawn into situations of distress. She states Redemption requires not only solidarity with suffering but opposition to its destructive effects. (1990:112)

world. One might question just how suffering is going to enhance this love relationship, although, strangely, that may be the case. In this vein, Farrer offers us this insight.

God does not give us explanations; we do not comprehend the world, and we are not going to. It is, and it remains for us, a confused mystery of bright and dark. God does not give us explanations; he gives us a Son....A Son is better than an explanation (1960:27).

The quest for answers is fuelled by the intensity of inner pain and yet answers do not relieve the pain overmuch but an encounter with the Son certainly can.⁹³ Crowley, who is influenced by Karl Rahner, talks about ‘a theological reflection that takes seriously the concreteness of the human experience of suffering as a place where the holiness of God can be encountered’ (2005:19).

7.4 The centrality of the cross and the suffering of God

Having moved away from classical Theism into incarnational Christianity we must be mindful that the cross is the central motif which alone makes sense of God’s loving involvement with his creation. We will begin by exploring the issue of Holy Saturday and then by discussing the suffering of God, followed by a consideration of the question of redemptive suffering and the indications that suffering can produce some creative outcomes.

Alan Lewis in his book *Between Cross and Resurrection* (2001)⁹⁴ explores the meaning of Holy Saturday in the Easter narrative. It is necessary here to offer a definition of the concept of Holy Saturday. It is the second day of the Easter drama and, as such, it is characterised by a sense of total desolation and godforsakenness as Jesus lies dead in the tomb. It is a day of deep darkness where everything is defeat. Admittedly it is the eve of Easter Sunday but that is not known from the vantage point of Saturday, therefore it is a day of deep gloom and hopelessness.

It is a day of waiting, a hiatus and a barrier which prevents a knowing, onward rush to victory and joy by interjecting a painful pause, empty of hope

⁹³ In point of fact, this is circular - arguments do not relieve the pain in the heart yet it requires some progress there in order for those in pain to feel encouraged to move towards the Son.

⁹⁴ Alan Lewis was a promising young theologian who battled with cancer during the writing of this book and later died at a very young age.

and filled instead with death and grief, with memories of failure and betrayal, of abandonment and anguish (2001:412).

Suffice it to say, there is nothing triumphalistic about Holy Saturday. Importantly, Lewis concludes that Holy Saturday identity defines not what it is to be a Christian but what it is to be human. Perhaps in this issue of suffering and evil we need to self-identify first, as human and only after as Christian for the answer to our plight lies more in regard to the universal human condition from which we as believers are not exempt. Moreover, to identify as Christians at all, is to worsen the problem as the New Testament makes clear for we are in a battle. The life of Paul is a startling example as there can be no doubt that much of the grief that he experienced could have been avoided had he not become a follower of Jesus with missionary zeal.

To those who suffer without knowing why, it is helpful to understand the degree to which Jesus suffered. Alan Lewis, who at the time of writing was a relatively young man dying of cancer, says 'How can we do otherwise than speak to our suffering world of a suffering God?' (2001:164) Lewis is concerned that we have a habit of rushing on to the end of the Easter story in order to make it all alright. Human beings have a tendency to want to push life stories into a schema of 'they all lived happily ever after'. However, Lewis is clear that the joy of Easter Sunday does not remove the desolation of Holy Saturday. And so it is with us, we have to face our Holy Saturdays head on in all their starkness, with the hope of Easter Sunday ahead of us which gives us hope but does not diminish the pain. Alan Lewis writes...'and the confusion of emotion lies...in the additional bitterness of knowing that the final scene of joy cannot be reached without the enduring of heartbreak first (2001:77).

Lewis offers no soft soap comfort, but there is something so real here that it galvanises. Continuing from the above quotation, he says

But any relief that the first day is not the end must compete with the horror that the final outcome will only be arrived at through the darkness and distress of the penultimate. And that means having to understand how it is that death and darkness *can* turn into life and light, and harder still - why this life and light are only of a special sort, born out of, and determined by, the death of all things, *maybe even God*_(my emphasis)(2001:77).

We come now to look at the question of God's place in all this misery. There is an ambiguity in the concept of a triune God here. For while one can speak meaningfully

of the Son and the Father as distinct persons in the event of the cross, if Jesus is fully God, as Christians affirm, then is it possible for Jesus to die without the living God being put to death? (Jungel and Moltmann's positions) Rev D G Atfield in discussing this issue makes this point,

Following Luther, Moltmann assumes that the divine nature of the Son constitutes the logical subject of Jesus. Therefore all the predicates ascribed to Christ must apply realistically and not just verbally to God. So the problem of divine suffering emerges (1977:47).

Alan Lewis confronts us with some very unpalatable ideas about the suffering of God and even the godforsakenness of God but limiting himself to the crucifixion narratives.

We are close here to the unthinkable; and we can perhaps begin to see why all of us, not least those otherwise inclined to take all the Bible says at face value, prefer not to treat too seriously Christ's dying cry of dereliction on the verge of hell.(2001:55)⁹⁵

Lewis insists that once we rightly hear the Gospel story of the cross and grave, with its exposure of the failure, supremely, of God himself in forsaking the Son and abandoning the world, then we will perceive this Saturday as 'a day of atheism' (2001:56) This is not to say, as Lewis makes explicit, that God is not vindicated on Easter Sunday, but we must not let that hoodwink us to the reality of Holy Saturday as experienced in real time. Moltmann , in *The Crucified God*, says:

With the Christian message of the cross of Christ, something new and strange has entered the metaphysical world. For this faith must understand the deity of God from the event of the suffering and death of the Son of God and thus bring about a fundamental change in the orders of being of metaphysical thought.... It must think of the suffering of Christ as God's potentiality God suffered in the suffering of Jesus, God died on the cross of Christ, says Christian faith. (Moltmann 1973:215/6)

There can be no question that Jesus suffers horribly and unbearably on the cross. The current writer finds it quite sufficient that Jesus suffered his own agonies in his life and death without wanting to assert, as some do, that God is the victim of universal suffering: that God suffers in Auschwitz, in Chernobyl, in Bosnia, the cancer ward etc etc. Dorothy Soelle takes a poem about Dagebert Biermann who died in Auschwitz and reads into it the death of Christ 'who was murdered in Auschwitz and in Vietnam and in all the continuations of Auschwitz' (Soelle 1984:74) Surely Jesus

⁹⁵ For a fuller understanding of his view, see the rest of Lewis 2001:55.

Christ has his own particularity and therefore lived his own particular life which must be distinct from the lives that others live and die? There arises the question of whether there is a significant difference between the Son's incarnate life as Jesus Christ and his discarnate role within the Trinity. It may be on just such a point that the issue hangs as to whether it can be realistically stated that God dies in every global catastrophe as Dorothy Soelle and others assert. Of course, the risen Christ comes to us in the stranger so there is a sense in which he appears in the guise of others.⁹⁶ Nevertheless, for God to be the victim of all suffering seems not only unjust but would imply that the God of creation is more than a cosmic sadist (an idea that C.S.Lewis toyed with) but rather a cosmic masochist⁹⁷ as he would have determined at the foundation of the world that it should be so. Karl Rahner objected to a theology of divine suffering as he felt it eclipsed the fact that some suffering is alone endured by human beings⁹⁸ and he also struggled against a view of God that made God so embroiled in the finite and contingent that misery would eclipse his glory. Crowley feels that Rahner has the key to understanding Suffering and a God of love. He writes '...Rahner offers a breakthrough by linking the mystery of suffering with the mystery of God but in such a way that the divine empathy for those who suffer does not slip from sight'(2005:15).

Images of the holy easily become images - sacrosanct. Our idea of God is not a divine idea. It has to be shattered time after time. C.S.Lewis insists

He shatters it himself...(Lewis 1961:55)... Could we not almost say that this shattering is one of the marks of his presence? The incarnation is the supreme example; it leaves all previous ideas of the Messiah in ruins. And most are 'offended' by the iconoclasm; and blessed are those who are not (Lewis 1961:56).

The idea that God suffers with his creation has become prominent in modern Christian thought, challenging the Mediaeval and patristic concept of an impassable

⁹⁶ As mentioned previously, Attfield makes an important point here in discussing the notion that God is crucified. He explains 'Following Luther, Moltmann assumes that the divine nature of the Son constitutes the logical subject of Jesus. Therefore all the predicates ascribed to Christ must apply realistically and not just verbally to God. So the problem of divine suffering emerges. (1977:47) Soelle seems to make this same connection.

⁹⁷ Fiddes (1988:61) addresses the issue of choosing to suffer and masochism.'It is not masochism for Christian people also [as well as God] to choose suffering, if the suffering is inflicted upon them by others who do not have to inflict it.' Also he argues that God chooses to suffer out of love.

⁹⁸ Metz (1998:126) sees this refusal as being grounded in Rahners' respect for the history of suffering humanity.

God. Fiddes (1988) identifies four reasons for this. The first is found in a psychological view of the nature of love which is seen as participative and sympathetic. The second is drawn from a Christological view and a theology of the cross. The third is part of the defence against God for creating this world as he must share in the consequences of the risks accrued from freedom. Finally, as stressed by process theology, the world is seen as a living organism and thus God too must grow and suffer with his world. Fiddes (1988) argues that the participation of God in suffering as in the atonement, has a transforming effect upon human personalities,⁹⁹

The psychological effect upon a sufferer of being aware of a suffering God who understands his [sic] predicament may be below the level of theological argument, but it may in the end soar on wings far higher than any formal theodicy can (Fiddes1988:31).

On the psychological level, it could also be argued that it panders to our baser need for revenge too. This can, perhaps, be seen in C.S. Lewis's outburst: 'Sometimes it is hard not to say 'God forgive God'. Sometimes it is hard not to say so much. But if our faith is true, He didn't. He crucified Him' (1961:25). Whatever psychological and emotional value there may be we must take a theological look at this question for the debate centres around just how far we think we should push the suffering of God.

Finally, we come to the contentious question which the context of the cross also raises: to what extent, if at all, is suffering redemptive? Henderson and Hein quote Farrer as saying 'The event of the cross clearly indicates that God takes suffering to be the pathway to redemption' (2004:109).

Certainly it tells us that the suffering of Jesus is central to our redemption, but to what degree we can extrapolate from that that our suffering is redemptive is highly questionable. It might be objected that if all suffering is purely and simply redemptive why did Jesus spend so much of his ministry interfering with this therapeutic effect of suffering? John says that Jesus came to destroy the works of the

⁹⁹ It must be noted that feminist theology is ambivalent on this point . Brown & Parker (1989:19) object 'the suffering God theologies continue in a new form the traditional piety that sanctions suffering as imitation of the holy one. Because God suffers and God is good, we are good if we suffer. If we are not suffering we are not good. To be like God is to take on the pain of all.' However, the notion of a co-suffering God continues to be particularly significant to womanist, mujerista and minjung theologians (Slee 2003:68).

evil one (1 John 3:8) and that brief seems to have led him to remove a lot of earthly sorrow and pain.

A further objection to the view that suffering is redemptive is articulated in liberation theology which takes issue with this view for the effect that it has upon the project of social justice and the fight to remove all sources of oppression. If suffering is for our redemption then we would hesitate to offer relief to anyone in difficulty. However, as we saw earlier in this thesis, Alister McGrath expresses the reverse view stating 'By working to lessen the suffering of God's world and God's people, we are easing his heartache over their pain' (2000:103).

John Hicks (1966) argued in *Evil and a God of Love* that this world is 'a vale of soul making' and therefore suffering and evil are essential to the project of developing individual souls. This view can be said to question the hedonistic view that this world exists for our pleasure. We will return to this theme but it may well be that what the suffering does to our view of God is not incidental but critical to the project of our spiritual growth.

There are such diverse views about suffering for some are so relentlessly upbeat that it is tempting to think that suffering could be defined in lesser terms than those who take a more sober view. However, it could be that the spectrum is so widely ranged because some have an eye on the experience of suffering while others are likely to have more of an eye to God's nature and purposes. Kathryn Tanner seems to tend more towards the latter position and may well be embracing a Thomist position predicated on the unfailing goodness of God when she asserts:

The world is perfected by being brought into closer relations with the God who perfects it. In union with God, in being brought near to God, all the trials and sorrows of life - suffering, loss, moral failing, the oppressive stunting of opportunities and vitality, grief, worry, tribulation and strife - are purified, remedied and reworked through the gifts of God's grace (2001:2).¹⁰⁰

Crowley grounds his writing in his own desperate experience and makes use of a graphic quotation from Karl Rahner about the suffering of bereavement 'and thus, as

¹⁰⁰ Elsewhere she gives a definition of suffering that restricts suffering to the ungodly opposition to God's purposes and therefore states that this cannot be said to be good or from God. (2001:76)

death has trodden roughly through my life, everyone of the departed has taken a piece of my heart with him and often enough my whole heart'(1960:54). Towards the end of his career, Kahl Rahner gave a short address entitled 'Christian pessimism' in which he speaks of the 'radical perplexity' of human life. Taking 2 Cor 4:8-10 'We are perplexed but not driven to despair,' as his text, Rahner claimed that perplexity was an integral part of human existence.

Rabbi Blumenthal in his exploration of the experiences of holocaust victims and victims of child abuse also takes a less upbeat position than Tanner. Wendy Farley, who also seems to have an eye on the lived experiences of suffering humanity, sees 'certain kinds of suffering as irredeemably unjust' (1990:22). However there is a very helpful creative tension in Farley's paradigm for while she is insistent that suffering is not redeemable and even all God's compassionate love poured out into the world cannot put right or undo all the horror that tragic vision has occasioned, neither is the hope of a painfree future sufficient consolation; nevertheless she sees suffering as the soil from which divine compassion is harvested in our own lives for compassion as an enduring disposition presupposes knowledge of suffering (1990:75). Therefore there is a sense in which suffering is both the problem and must play a part in the 'solution' Her vision of redemption is greater and more credible than merely attempting to make the horror of suffering redemptive. She writes,

Tragedy presses upon us a dark vision of reality, but it is in turn transcended by the apprehension of ultimate goodness. Its appeal to justice and its evocation of compassion are traces of an ethical order that is frustrated but not destroyed by unjust suffering (1990:29).

There is however, a third position which is harder still to prove but which does face the horror of the lived experiences of some believers and manage to maintain a firm footing on a belief in both the goodness and the providence of Almighty God. This view is commonly known as 'the dark night of the soul' as explicated by the sixteenth century Spanish Carmelite monk, St John of the cross. His view (and that of Teresa of Avila, his mentor) is that there are times of great difficulty and suffering in the lives of believers but that during those dark times God is doing some deep but hidden work that will bring the believer to greater union with his or her Lord. It does not minimise the distress of suffering but rather is predicated on an uncannily profound understanding of the complexity of human beings (four centuries before Freud). It

argues that the dark night is designed to bypass our defence mechanisms and dismantle things while we are unaware as otherwise we would obstruct this work – all of this bringing us to greater freedom from attachments and compulsions. Crowley testifies that there are times when the suffering that accompanies tragic reversal, forces upon us a wisdom that is not sought nor even desired yet, wonderfully, this same wisdom can become the key to a joyous freedom ‘where one discovers, all of a sudden, as if awakened from a long trance, that what once seemed very important simply no longer has any power over us’ (2005:147).

However, there is a view which considers that while God does not intend suffering for us that where suffering occurs God most certainly aims to use it for the good of ourselves and others. Many popular Christian writers express the view that God uses affliction to form us and perfect us (Derek Prince; C S Lewis; Selwyn Hughes; McGrath; Edith Schaeffer) although it may not always be clear if they think that means God intends it or allows it and transforms it. Certainly Prince believes that it is intentional as he speaks of God knowing exactly how high to heat the furnace of affliction to cause the dross to come to the surface.(1983). Theologian, Mary Grey objects to this popular notion of what she calls ‘God the pedagogue’.

Biggar (1998) and Bretherton (2006) argue that there is a weak and a strong type of redemptive suffering, a strong form being found in situations of unjust suffering where the believer is identified with Christ and submits to the Father's will. A weaker form would be, in not specifically making up the sufferings of Christ, but having value, nonetheless, and not being pointless or meaningless.

We are accustomed to thinking that if a view of God is ‘right’ then the tighter we hold that view brooking no dissension the stronger we are as believers. However, Gerald May, a Christian psychiatrist, building his thesis on an exploration of the work of St John of the Cross and his spiritual mentor Teresa of Avila, (16th century Spain) argues that this is not the case. ‘No matter what specific form they take, all such rigidly held feelings about God restrict our openness to the incomprehensible divine reality’ (2004:92). He points out that such an experience feels as if the very foundations of one’s faith are being violently shaken. This is surely what happened to Job.

If we turn to the New Testament we see that God refused to remove Paul's affliction as he could use it. Paul is expected to become stronger as a result of his weakness. (2 Cor:12:9) Paul also, underlining our connectedness in the Body of Christ, teaches that God ... 'comforts us in all our troubles, so that we can comfort those in any trouble with the comfort we ourselves receive from God' (2 Cor 1:4).

While it must be objected that God is not the author of suffering as 'he has compassion on all that he has made' (Psalm 145) there is biblical evidence (not to mention a host of anecdotal evidence too) that God does not waste our suffering and uses it productively provided that we co-operate with him. McGrath in his book *Why does God allow suffering*, argues that because Jesus went to the cross and we are called to follow him that believers should not expect to avoid suffering in their lives and that it can lead to good (McGrath 2000:9).

Added to, this Alan Lewis and Letty Russell both show that it is not always possible to know what is good and what is bad. Russell loses the sight in one eye and through it grows in courage: becoming at one and the same time both stronger and weaker (1993:103).¹⁰¹

Edith Schaeffer in her book *Affliction* (1978)(and elsewhere) gives another angle which is helpful, as it moves way beyond a desire to 'fix' things and yields to a trusting relationship with a loving Creator.¹⁰² She uses a number of different images to express the same concept and I will work with her image of the museum. She imagines that in heaven there is a museum with two large halls in it. Each believer's life is in the halls. In some parts of each life there was the type of overcoming victory that was characterised by a change in circumstances and those are recorded in hall A. However, each one also has life experiences where circumstances did not change and the challenge to the believer was to 'overcome' in the teeth of the adverse circumstances. Her idea is based on the book of Job where we see a royal battle in the heavenly realm where Satan tempts Job to curse God because of all the adversity

¹⁰¹ Elsewhere we have noted the case of Mary Semple who believed that her facial deformities were used by God to free her from an abusive marriage.

¹⁰² Michael Howard in *God in the depths* (1999) challenges an assumption that in times of crisis the God of the Bible is about bringing superficial control rather than working deeply to bring about spiritual maturity.

that has befallen him and also Hebrews 11 which gives a catalogue of those who overcame by the blood of the lamb - the first set in positive events and the second in persevering despite such things as 'being sawn in two'! She urges us to see in our suffering an opportunity to honour God and not withdraw our love and trust as a powerful sacrifice of worship and as a lethal blow against Satan, God's enemy (1978:76).¹⁰³ This understanding can give us something constructive to offer a person in distress, in fact, she claims to have had this insight while comforting a dying friend who felt he could no longer do anything worthwhile.¹⁰⁴ Nigel Biggar brings a similar insight about suffering even in the context of dying:

A life is valuable not only for what it builds, but also for what it says. So in the faithful, hopeful, charitable manner of my suffering I may be able to demonstrate salvific truths about, for example, the contingent value of the human individual, the gracious goodness of God and the humanising prospect of eternal life (1998:40).

Suffering threatens us as it confronts us with our utter powerlessness to control the world in which we live. Farley points this out in graphic detail leaving us no place to hide.

Once human suffering is possible, nothing restricts its range so that the kindest, or the weakest, or the most admirable people will be magically protected from it. Nothing limits suffering in its intensity, from driving people to despair through grief, pain or cruelty. Once suffering is posited as an essential component of human existence, radical suffering threatens every person.¹⁰⁵ No one is protected from suffering that is so terrible that it breaks the spirit...Suffering is a natural component of embodied, historical experience. (1990:34)

However, there is a positive side here as it rightly aligns us with our creaturehood; for as human beings we are limited. We see that this experience of suffering indicates not necessarily that something has gone badly awry but conceivably that we are in the flow of God's purposes. McGrath states 'The Christian Church is an extension of

¹⁰³ Prisca Sandri (eldest daughter of the Schaeffers) also expressed a similar view in an interview I did with her in 2005 in Switzerland.

¹⁰⁴ This is of course, provided that the sufferer is still allowed to express grief and lament and is not driven into denial as proposed by some sentimental Christian lyrics/ditties.

¹⁰⁵ This nicely repudiates a sentimental view which circulates among some Christians that we are never required to bear more than we can. The effect of this assertion is to trivialise other people's distress. Some feminist writers believe it has been used to minimise much of women's suffering. It appears to be a corruption of a promise in (1 Cor 10:13) that we will not be tempted more than we can bear and the reason given is that there is always a way of escape. Yes, you can always escape from temptation but there is no acceptable Christian exit route from intolerable suffering.

the passion of Christ. We are called to be members of the suffering people of God.'
(2000:33)

McGrath argues that suffering produces maturity (2000:56) thus we could say the demand for the Christian life to be free of pain is an insistence on a superficial and immature faith. In addition, 'suffering often brings out the full potential in human beings, unleashing a creativity which is too easily stifled by smugness and security.'
(McGrath 2000:56)

Amy Carmichael (Irish missionary to India for 55 years) is but one of many Godly people in whose service for Christ much suffering was endured. Her poem, sometimes used as a hymn, brings a fresh perspective to this common fact among the saints.

NO SCAR

Hast thou no scar?
No hidden scar on foot, or side, or hand?
I hear thee sung as mighty in the land;
I hear them hail thy bright ascendant star.
Hast thou no scar?

Hast thou no wound?
Yet I was wounded by the archers; spent
Leaned me against a tree to die; and rent
By ravening beasts that compassed Me, I swooned.
Hast thou no wound?

No wound? No scar?
Yet, as the Master shall the servant be,
And pierced are the feet that follow Me.
But thine are whole; can he have followed far
Who hast no wound or scar?

As we begin to see that suffering is normative in the Christian life (indeed, the human life) then we will be able to bring the only real comfort we can; namely, that of fellow sufferer which Govig sees may be a 'better sign of hope' for the world than are the schemes of those who promise paradise' (1989:115).

Sometimes we are fellow sufferers simply on account of what life has dealt us, at other times we can be fellow sufferers by choice – not grimly pursuing suffering and pain but perhaps refusing to take the softer option for the sake of the Gospel. ‘They overcame by the blood of the lamb as they loved not their lives unto death’ (Rev12:11). I would like to pay respect here to Sue and Andy Wheeler, former missionaries in Sudan, who I am privileged to know personally. In his book *Bombs, Ruins and Honey* Andy tells something of their story and the great struggle they had to interpret the suffering that encompassed them and the people around them in war-torn Sudan (2006). Sue nearly died in Sudan, in the early years of their marriage. Andy writes

For Sue this was a crucial time in which her faith and her understanding of life was dismantled and a process of reconstruction began. We had both grown up in a Conservative non-conformist tradition which did not find it easy to cope with unrelenting suffering. Faith and prayer were the gateways to God’s blessing and healing. These attitudes were often strengthened by the Charismatic renewal movement by which we, as well as other mission workers around us, had been influenced. Already on arriving in Sudan Sue found her faith challenged by the suffering around her to which there seemed no easy answer, or even any answer at all. To have the first three years of our marriage consumed by unrelenting sickness and weakness did not square with the framework of faith with which Sue and I had grown up (2006:38).

However, later they take advice to return to England and the local women weep as they do not expect to ever see Sue again as they know she is desperately ill. Once back in England, and Sue is still far from well, they decide to return to Sudan. The people are deeply touched by this act of love and commitment to them, being more accustomed to ex-patriots packing up and fleeing in tough circumstances. They read this bold act to mean that the Wheelers feel a sense of belonging to them and the relationships move onto a deeper level as a result.

We should not underestimate such an act to a people who probably felt bereft of God in their circumstances. Philip Yancey in *Where is God when it hurts* says that there are times when it is as if God cannot reveal his love but in such times we may be vehicles of that love to one another in the Body of Christ. Perhaps the Wheelers’ costly return put substance to the promise ‘I will never leave you or forsake you’ (Matt 6:25) when everything else may have communicated the reverse. If we take a

connected view of our humanity, as the Wheelers do, this act of solidarity may have been just what God could use.¹⁰⁶

7.5 Why include this in this thesis

In this final section we highlight the normativity of suffering in the human condition. A relationship between pain and grace is brought into view as is the value of compassion expressed through the role of fellow-sufferer.

Christian theology can gift to the secular Disability Movement the fact that it is ok to talk about suffering as it is universal and not ‘earned’ as the Hindu doctrine of karma insists. Of course it is not appropriate to assume that people with impairments are suffering in special ways unless they indicate that to be the case. We saw in the fieldwork how a Christian minister, who travelled with a theatre company which had 6 members with Downs Syndrome, decided to stop taking them to church as he was affronted by the way that they often prayed for ‘these young people who suffer so’ despite the fact that they had been performing with the Royal Shakespeare Company! Suffering can be seen to be a great leveller, for all humans suffer regardless of wealth, media adoration or any other source of prestige. As some of the testimonies that follow show, a loving creator identifying with the pain of his people is a very powerful grace and effect of the cross of Christ. These testimonies are drawn from the disability literature as that is our focus, even though disability has no particular place in the topic of suffering.

It is not easy to keep our hearts open when we feel so full of pain and distress. To close our hearts is to protect against further pain but equally it is to lock inside the woundedness and to lock out the possibility of God's healing. Many people may have been offended by the Bible and the Church yet an important challenge is to resist the temptation to take offence.

¹⁰⁶ Interestingly Sue’s church could only surmise that she had been sent to Sudan to meet her husband, (2006:38) not a priority of discipleship ever taught or indeed modelled by Jesus.

In a booklet called *The Bible in transmission* (2004) on disability in three separate articles it was evident that there is a clear relationship between a real epiphany and an openness of heart. Professor John Hull writes about the way in which Jesus uses blindness as an insult and speaks through typical ways that sighted people speak to sighted others. He quotes Jesus saying 'Blessed is he [sic] who does not take offence' (Matthew 11:6). He questions how it is possible not to take offence when his experience of life is not acknowledged or validated. Nevertheless, one senses the resistance in him to letting this understandable offence take root in his heart although he rejects the sighted assumptions that Jesus demonstrates in common with the culture of his day.

Later he tells of how touched he was by a revelation of Jesus as his 'blind brother' when Jesus was blindfolded before the crucifixion and provoked when he could not see his tormentors and also of a sense that Jesus may have experienced blindness again when the sky darkened while he was on the cross and he cried out in godforsakenness. Having challenged the sighted assumption that the blind cannot lead the blind, he goes on to celebrate the fact that he now follows Jesus his 'blind brother' who knows the way and so he gently touches his elbow to follow and that they have not got into difficulty yet. For Hull this revelation of Jesus as his 'blind brother' has brought him into a closer communion with his Lord.

Two other testimonies in this booklet underline the sense that if we can keep our hearts open, despite the absence of easy answers, that the Lord can eventually bring comfort. Nancy Eiesland, author of *The Disabled God* and wheelchair user talks of her own special epiphany when she saw God in a sip puff (breath powered wheelchair) and felt God's identification with her as a person with an impairment. Faith Bowers whose, now adult, son has Downs Syndrome, speaks of the pain she bore every day of his first 25 years until one day she attended a passion play in which Jesus was played by a man with Downs. When she saw the Downs features contorted in pain on the cross she saw Christ as a person with Downs and she says that from that moment the pain went.

Ambiguity is at the very heart of Christianity as we worship a God who is fully human while being fully divine. Kierkegaard (alias Climacus) in *Philosophical*

Fragments, contrasts two possible responses to the paradoxical claim that Jesus is both God and man. The two possible responses are faith or offence. These same two responses are what are before us in the paradoxical case of suffering and the purposes of a loving God. We can either keep our hearts open in a trusting attitude of faith or close our hearts in wounded offence.

This discussion of suffering is important for this thesis as it highlights the connectedness of the human condition – that as the apostle Paul teaches when one member of the Body of Christ suffers all suffer (1 Cor 12:26). It also demonstrates that the onus is on the church is to facilitate people moving closer into love relationships (with God directly and with God through the Body of Christ) when in deep pain, rather than being further alienated through half-baked theologies of guilt and blame. The role of fellow-suffer is a productive one and one that can only have potency if, in Farley’s terms we have been able to garner divine compassion from our own sufferings. Also an incarnational view of God enables us to revalorise vulnerability and brokenness. The Christian view of suffering bestows more dignity than a patronising response of ‘poor you’. While it has been argued that suffering is not redemptive *per se* as we have seen it can have redemptive potential.

Personal Account

Furthermore, I set out to do this work on inclusion of impaired believers not because I had any personal point of identification with ‘disability’ but because I had experienced exclusion based on embodiment (for being a woman) and was passionate for all people to be actively included in the church. However, strangely, as I continued on my journey (far longer than expected due to the disruption of two major bereavements¹⁰⁷) I became immersed in this reality through the prolonged illness of my son who was unable to attend school (nor study at home) for several years during the vital GCSE years on account of CFS/ME.

¹⁰⁷ After the sudden and premature death of my brother I immersed myself in literature on suffering as my former framework left me floundering and feeling deeply let down.

Sam became a shadow of his former self becoming withdrawn and unable to socialise as before. He had been a fun-loving happy and conscientious boy who was always on the go; full of ideas. I was shocked when one of the head teachers at his school with responsibility for children with special needs referred to my son's 'disability.'

Although the experience was heart-rending I tried not to resent it as I realised that it meant I was entering the pain of many of the people I had wanted to support. I genuinely felt that the experience was incarnational and one day in church I was singing a song that goes 'be glorified in me, be glorified in me' and the words came into my head very forcefully 'be crucified in me'. I did not change the words I was singing but I had the realisation that there was an element of Jesus being crucified in me in order to be glorified through this further suffering we were undergoing as a family.

Disabled, feminist writer and researcher, Jackie Leech-Scully, says that because disability is socially constructed it is not possible to know what an irreducible core of suffering exists with disability itself. (2002) Certainly I experienced the pain of being in a world that only values certain outcomes and with the prospect that this bright boy (our only child and the only grandchild on both sides of the family) might not even get any GCSE's! A mother of a Downs's son told me in interview from *Reach Out* that her son had had some physical problems and one time had to go into hospital for an operation. She was afraid that he might die and was deeply hurt when her own mother said that it might not be a bad thing if he didn't pull through. Although shocking it is perhaps not surprising that a grandmother can feel like that living as we do in a society that devalues all who cannot make a contribution to the market economy. In our case we had the advantage that the prognosis was good with the expectation of a full recovery, albeit a painfully slow and erratic recovery. Only one mother was interviewed in the research but her experience confirmed what I had read in the literature about people with disabled children.

7.6 Summary

In this chapter we have grappled with the issue of human suffering, first acknowledging that it is an unpopular topic for the Disability Movement on account of non-disabled persons wrongly insisting that suffering automatically accrues more to people with impairments. The common conflation of evil and suffering has been addressed and some definitions of suffering offered. The Enlightenment conundrum of theodicy has then been explored noting that the critical fact is that its theism (deism, in fact) is classical in character and thus not Christian at all. Being unable to make any progress with this framework we move on to a Trinitarian theism and incarnational Christianity where it is possible to bring some light to the topic. Key themes, such as the sovereignty of God and the nature of God's power are re-evaluated here with an insistence on the complexity of the universe including the connectedness of all humanity. The centrality of the cross in Christian theology is then foregrounded, and issues such as the suffering of God, Holy Saturday and the redemptive nature of suffering are discussed. Some creative outcomes of suffering are also noted. Finally, there is a section highlighting the significance of this chapter to the thesis as a whole closing with a personal account of both the researcher's journey of suffering throughout the writing of the work and the testimony of the pain of a mother whose own mother did not truly value the life of her Downs Syndrome grandson so that she deemed his possible death to be a favourable outcome.

8. A THEOLOGY OF PERSONHOOD

Having established that suffering is a central aspect of the Christian life - that the presence of trial and difficulty do not signal some particular sin or personal failing - we see that people with disabilities are not outside the orbit of all that makes for a 'normal' Christian life we move on to consider how disabled people also qualify for what makes a 'normal' human life. In this chapter we will explore what it means to be a person in contrast to an individual. The nature of persons is seen to derive from the nature of person first identified in the triune God. The relationship between the human self and disability is examined and feminist perspectives and that of Jungian psychologists which reject a separatist view of the Self are brought into the debate. Insights on personhood from theological anthropology are also included for their positive effects and contrasted with the social construction of the Self which has a marked dark side. Next, emphasis is placed on the church as the locus for personhood to be fully realised. Finally, there is a short explanation of the justification of an exploration of personhood for this thesis.

8.1 Who is fully human?

It has been said that any inquiry into what makes us human has an underlying agenda. Rieff (1964) claims that such concepts have polemical and institutional uses. This enquiry is no exception and in this section of a constructive theology of disability we are seeking to establish beyond reasonable doubt that those with disabilities (across the full range, including intellectual impairment) are by no means exempt from sharing full human status and more: sharing full personhood as those made in the divine image. In this respect our enquiry will serve polemical ends. Feminist writer, Naomi Scheman, drawing on her dual experience as lesbian Jew, gives us a timely warning. She argues

Twentieth century liberatory activism and theorising have lived with and on the tension between two visions. For one the goal is to secure for the marginalised and oppressed the relief from burdens and the access to benefits reserved for the privileged, including the benefits of being thought by others and oneself to be at the centre of one's society's views of what it is to be fully human. For the other the goal is to disrupt those views and the models of privileged selfhood that they underwrite - to claim not the right to be, in those

terms, fully human but, rather, the right to be free of a stigmatising, normalising, apparatus to which one would not choose to conform even if one were allowed or encouraged to do so (Scheman1997:124).¹⁰⁸

This present writer sees the danger of trying to co-opt marginalised people into a hegemonic notion of 'normality' and here the intention is to draw the boundaries wide and include all not in some privileged 'in-group' but to show how the whole of humanity can be embraced within the dignity of the ascription of person as intended by the Creator.

8.2 Individuals, Selves and Persons

In Western culture the Self is of central importance being at the intersection of, metaphysics, epistemology and ethics. According to Meyers 'at this juncture, questions of ontology, knowledge and value comingle magnifying the urgency and potency of philosophical doctrines of the self (1997:1).

Feminist writer, Catherine Keller raises a fundamental problem with the concept of the Self pointing out that both philosophy and psychology together with religion and myth have all centred Western civilisation on an assumption that selves are discreet beings, cleanly divided from our surroundings. She shows how language itself underscores this point. 'The Latin for self is se meaning 'on one's own', yields with parare 'to prepare' the verb to separate. For our culture it is separation which prepares the way to selfhood (Keller1986:1). Keller rejects this view¹⁰⁹ which Freudian psychology has strengthened: she finds more sympathy with a Jungian approach which is more integrationist.

Reintegration of the psyche on the basis of its own transpersonal scope requires the process Jung calls 'individuation'. Authentic individuality can be gained only when I experience myself as fundamentally connected to all of life; this is the wisdom of the Jungian outlook ' (1986:114).

¹⁰⁸ Letty Russell (1982:29) confirms this view seeing our view of reality as being like a pyramid with categories of sub and super-ordination and she detects behind this hierarchical ordering of life an assumed 'divine order'.

¹⁰⁹ However, we must note that she warns that a rejection of separate selfhood may lead to a fear of merger and self-dispersion which she sees being fuelled by a basic gynophobia. She fears 'any articulation of a feminist perspective, especially one unfurling a radical sense of interconnection, will be suspected of advocating female dominance and the defeat of the differentiated individual. To relax the severity of male ego-boundaries threatens to unleash a tidal wave of matriarchal collectivism. (1986:3)

It may be useful to clarify a number of terms that appear in the discussion of personhood.¹¹⁰ In some places person and personality are used interchangeably. I shall take personality to denote a psychological term which defines the specific characteristics and temperament of a given individual. Also to be a human being, a Self, an individual or a person are also often used synonymously. In this text the concept of being a person will be distinct from being either a Self or an individual or a human the latter three terms being construed as synonyms: 'self-conscious' beings. In addition, Christian psychologist, Paul Tournier (1982) differentiates between person and personage offering the concept of personage as being the mask of what we project with others when we first meet them. Nevertheless, 'Person' comes from the Latin for a mask and Jung talks of the persona as does Goffman: it is our interface with society. As such it does not denote anything ontological, coming, as it does, from the ancient theatre, persona was used to denote an 'appearance' as one actor may appear in several distinct and separate roles. On this basis a human being may be nothing more than a complex set of shifting facades. The Latin-speaking Church used the term persona, suggesting that the person is an 'agent'. However, the Greek-speaking Church spoke of a hypostasis (which literally means substance but could be usefully translated as 'subject') for this implies a reality underlying all that a person presents (O'Donovan 2002:52). This lack of ontological reality meant that the Fathers refused to use the Greek term (prosopon) for the persons of the Trinity as it would have rendered God as three masks with a true substance elsewhere. Tournier (1982) however, in his paired terms person and personage uses personage (the mask) in contrast to a person thus giving person some ontological reality.

Andrew Walker in an overview of the concept of a person in the social sciences (Walker 1991:139) argues that much of sociological personhood is in fact, individualism. Since we are working within a metaphysic of connection this will not be a direction in which to turn. However, Walker argues that theological anthropology can take us further in this discussion and, as we shall see, it can certainly provide us with a more connected sense of the self.

¹¹⁰ There may be some confusion arising from what follows. Although I argue that a person is qualitatively different from an individual or a self, it is still necessary to look at how the self /individual is constructed and conceived. Also in quoting the work of important others it is sometimes necessary to use terms like person in ways other than intended by the author of this thesis.

The Orthodox bishop, John Zizoulas makes a distinction between being an individual human and a true person. According to Zizoulas an effect of the Fall is that in the dislocation of the intimate relationship between humankind and God, humans cease to be full persons and become mere individuals. The wrenching of the image from the source causes damage that can only be healed if the union is restored in Christ through, in Zizoulas's view, the sacrament of baptism or in McFayden's terms through the call of Christ. So we become individuals by virtue of our human birth alone but only persons by participating in the divine personhood through the new birth.

Person, however, is here conceived as an ontological term that has the metaphysical claim of absolute being, built into it. It is a transcendent concept which derives from a relationship of communion, first with God and then with one another in community and especially within the community of the Ecclesia. Essentially it is an eschatological concept having 'its branches in the present and its roots in the future' (Zizoulas 1985:59).

Zizoulas clarifies the point:

Man's personhood should not be understood in terms of 'personality', i.e. of a complex of natural, psychological or moral qualities which are in some sense 'possessed' by or contained in the human *individuum*. On the contrary, being a person is basically different from being an individual or 'personality' in that the person cannot be conceived in itself as a static entity, but only as it *relates to*. Thus personhood implies...a movement towards communion which leads to a transcendence of the boundaries of the 'self' (Zizoulas 1975:408).

A number of theologians (Illingworth 1894; Zizoulas 1975,1985;Gunton 1991; Volf 1998; Fiddes 2000) argue that the concept of person only really came into clear focus when the nature of God was clarified. Mauss (1979:87) writing on sociology and psychology also supports the view that the notion of a person owes its metaphysical foundation to Christianity. Fiddes explains,

For Christian faith, it is the self-unveiling of God as Father, Son and Spirit which determines the use and meaning of the word 'person' in the first place.... Indeed, there is quite a strong case for maintaining that the notion of what it means to be a *human* 'person' received sustained attention for the first time in Western culture in the context of affirming persons in God (Fiddes 2000: 4).

Zizoulas expresses it firmly when he states ' the notion of Person is to be found *only* (my emphasis) in God and that human personhood is never satisfied with itself until it becomes in this respect an *imago Dei* (Zizoulas 1975:410).

Zizoulas' concept of a person fits well with a metaphysic of connection, for a person can only be such in communion with others. The famous work of Martin Buber, *I and Thou* also leads in this direction. Buber takes the view that we are persons because we can say *Thou* to another, and because our ego is broken open by encounter with the *Thou* of the other. In this way he believes we meet the transcendent *Thou* who is God. As Fiddes summarises it 'To be a person is to relate the between-ness that relates *Thous*' (Fiddes 2000:18). Buber also works within a metaphysic of connection noting that there are three spheres in which the world of relation arises: the world of nature, humanity and spiritual beings.¹¹¹ Building on these views of Buber and Zizoulas nicely accommodates a feminist concern to reject an individualistic and unitary conception of the self as rational chooser and actor which fails to emphasise the historical and social locatedness of the self (Meyers 1997). Women's experience articulates psychological, sociological, and philosophical insights which are broadly relational in character. For example, the social-psychologist, Nancy Chodorow argued that boys develop through separation, whereas girls develop through relationality and connection:

From the retention of the pre-oedipal attachments to their mother, growing girls come to define and experience themselves as continuous with others; their experience of self contains more flexible or permeable ego-boundaries and differentiation. The basic feminine self is connected to the world, the basic masculine sense is separate (1999:14).

Keller offers a new dyad to describe the different types of self that are experienced by men and women respectively. The self that is historically embodied by women she calls the 'soluble self' in contrast with the 'separative self'¹¹² of men which she alarmingly asserts acts upon the soluble self 'as a solvent.' (13) Building on

¹¹¹ It is unlikely however that he construes those categories in the same way as does Alfred North Whitehead who sees human, animal, botanical and geological matter as all being of the same status a uniting with all of them as leading to my own sense of self. We must assert that outside the Trinity there is nothing divine and that it is in God that we find our true selves and not in rocks!

¹¹² Keller's basic thesis is that patriarchy produces the separative self in men which is then identified with proper mature development in all humans. Theologically this is then linked to transcendence. Insightfully she suggests that the ethos of heroic egoism as epitomised in Greek mythology, may be the result of unrecognised self-doubt. She warns 'Descartes divided human reality into two independent substances...while meditating in solitude about whether he existed at all. (1986:11)

Chodorow's insights, the feminist, moral philosopher, Carol Gilligan (1982) underlines the relational nature of the self in moral decision-making.

Finally, Grey notes that the concept of 'existential estrangement' so beloved of Sartre and others, is crucially a problem of the 'disengaged I'. She asserts that 'the connected Self knows no existential estrangement' (1993:80).

8.3 The human self and disability

Regarding philosophy we must note the danger that 'moral and political philosophers often take the able-bodied, healthy adult as the paradigmatic person' (Tietjens Meyers 1997:6) MacIntyre (2000) (Cottingham 2008) also notes that philosophy has not paid attention to human vulnerability and disability as part of the human condition. This in part may be due to the charge that Brison brings that 'philosophers are trained to divert their gaze from the messy real world to the neater more controllable and more comprehensible realm of pure thought (1997:13). Susan Wendell (1996:69) also notes that our culture promotes the self-deception that we are not all profoundly dependent on one another; so we reject any concept of the 'independent' individual as being more fully human. In our attempt to consider what constitutes a person we extend the paradigm to embrace those who are other than 'able-bodied, adults'. Essentially all those who are 'made in the image of God' qualify to be considered as persons. Also this enquiry makes reference to real life observations (as seen in the fieldwork) and not just 'pure thought'.

Diane Tietjens Meyers identifies the root problem in moral philosophy as being the importation of 'the standpoint of those who have taken themselves to be self-sufficiently superior and of those who take the standards from those who take themselves to be self-sufficiently superior (1999:7). For the purpose of this thesis any such standpoint must be challenged.

Since we are primarily concerned with the subject of disability, we must consider the place of the body in the question of the self. McFayden says,

The body is an important element in the public recognition of personal identity: it is, indeed, our first and best tool in the identification of persons.

But it is not our only tool and that fact is crucially important; *important because it introduces resistance to the reduction of persons to the status of physical things.*¹¹³ (my emphasis) Whilst it is vital to take physical embodiment with the utmost seriousness, and to resist the artificial separation of the physical from the social, the reality of persons is, nonetheless, primarily social. Socio-personal life are founded upon embodiment in an interaction with the physical world, but individuals are constituted as persons through processes of social rather than physical, communications and exchange (1999:77).

Feminists have tended to take the matter of embodiment very seriously although some feminists caution that this has at times led to a romanticising of the body which sits ill with some of the realities of bodily impairment. Post-modern philosopher, Calvin Schrag argues that human subjectivity is also necessarily embodied . Unlike Enlightenment conceptions of the Self which rejected the notion of embodiment for its implication of fragility and likely dissolution; the decentred subject need not fear embodiment. Cunningham claims that this has implications for Christian ethics, specifically, calling us to 'practices of pluralising, in which embodied difference should be recognised and validated' (Cunningham1998:224).

For some Christianity and feminism are indeed strange 'bedfellows'. However, some feminist writers (who perhaps have a more nuanced understanding of both feminism and Christianity), notably, Nicola Slee (2003) and Serene Jones (2000), argue that while feminism can often provide a welcome critique of Christianity, especially with its embedded patriarchal values, it is also true that in some areas Christianity offers a worthwhile challenge to feminism. The first point is often more in evidence but here we have a good example of the latter. Seyla Benhabib censures a secular view of the self as being 'disembedded and disembodied' and drawing on a metaphor of what she refers to as 'in the beginning man was alone' (Benhabib 1992:155). A biblical view that 'in the beginning was God' which draws a relational and connected view of the Self as deriving from the Triune God, and takes the inter-relationship of persons within the Godhead as normative for human relations, mitigates against this error.¹¹⁴

¹¹³ Women and disabled people alike have noted the danger of being treated on the basis of their biology - appearances only.

¹¹⁴ However, Keller in *From a Broken Web*, sees no such easy marriage of feminism and Orthodox thinking on this point. While not claiming to clearly understand the basis of her objections (other than perhaps a knee jerk reaction to the word Father and an insistence that a triune God is a 'three-man show' eliminating women from sacred space), let me quote her 'Despite the relational potential of primitive Christian metaphors, such as Body in which 'we are members one of another' or the

In fact, feminist accounts of the self are much more interconnected than are other secular concepts. In the 1980's and 1990's feminists challenged the mainstream view of autonomy as being over-individualistic. Friedman states 'it presupposes that selves are asocial atoms, ignores the importance of social relationships, and promotes the sort of independence that involves disconnection from close personal involvement with others (Keller 1985; Hoagland 1988; Nedelsky 1989; Code 1991; Benhabib 1992) (Friedman 1997:40).

From Descartes to contemporary theorists the majority of traditional accounts of the self have been individualistic, built on the assumption that one can individuate selves and determine the criteria for their identity over time independent of the social context in which they are situated.

In contrast, feminist accounts of the self have focussed on the ways in which the self is formed in relation to others...such accounts view the self as related to and constructed by others in an ongoing way, not only because others continue to shape and define us through our lifetimes but also because our own sense of self is couched in descriptions whose meanings are social phenomena (Scheman 1983) (Brison 1997:14).

This feminist view of the Self is verified through the accounts of trauma victims who interestingly report an inability to remain themselves (as they were) after severe trauma. In introducing this body of research and its findings Meyers writes ...'the self is both autonomous and socially dependent, vulnerable enough to be undone by violence and yet resilient enough to be reconstructed with the help of empathetic others (1997:12).

This strongly socially situated view of the Self brings us to the important point that there is now much consensus that the self is socially constructed. We shall return to

Johannine vine and branches, and despite the indistinguishability of love of God and love of neighbour in Jesus' teaching, let alone the background of Hebrew focus on community, no persuasive doctrine of community, of interpersonal or global creaturely love, could grow amidst the teachings of the Church Fathers (1986:169) She goes on to describe the doctrine of the trinity as 'a peculiar, rationalistic albatross .' (169) Lest it be assumed that Keller is singing from the same hymn sheet as feminist writers such as Mary Daly who despair of all patriarchal religion full stop, Keller states: 'unlike Daly, I often sense within patriarchal traditions certain initially redemptive possibilities arising only to be immediately co-opted. In a symbol such as the Trinity there may be an unheard, stifled voice of revelation, inviting a non-patriarchal pluralism. If so, the power of patriarchal presuppositions to puncture even those transforming possibilities that occasionally erupt within its own terms seems then all the more virulent. (171)

this point later in this chapter and draw out some essential implications. Heather Ward (1990) in her book *The Gift of Self*, draws on the thinking of Irenaeus, and argues that the self is not a pre-existing entity but rather a capacity for receiving and responding to God. However, she also calls us to a spirituality in which division of individual and society is removed (in the Maurician tradition). I would want to argue for both an ontological reality and an element of being constituted through response to God and others (much the same as we see in the Trinitarian relations within the Godhead shortly to be examined here).

8.4 Insights from theological anthropology

There will be three prongs to our enquiry into theological anthropology. Firstly, since we are made in the image of the triune God, we can find an examination of what the Trinity means instructive to the way we are designed to be, secondly, we will look at the two-sex creation which also reflects the *imago Dei* and finally, the life of Jesus Christ as the perfect Son of God. East and West have understood the Trinity in different terms although the Eastern view taken from the Cappadocian Fathers has drawn increasing interest in the West in the present day. In fact, the concept of the Trinity is enjoying something of a revival having been very out of vogue up until two decades or more ago. Broadly, the Western view taken from Augustine is seen as a 'psychological' view based on a triadic human psychology,¹¹⁵ whereas the Eastern view is strongly social and relational. According to Fiddes

in the received tradition of both Plato and Aristotle, to be a 'person' and so to have particular identifying attributes and to be in relation with others, was something additional to the real core of one's being or one's essential nature (*ousia* or *hypostasis*) personalness was therefore a passing phenomenon. But the development of the doctrine of the trinity made the person a matter of 'ontology'. With regard to God, being as a 'person' in relation to others was now acknowledged as inseparable from enduring essence. Inevitably then this ontologising of the person, uniting persons with hypostasis, would be applied to human persons. For them too, personal relations were not just to be added to their 'real' being as an extra. The notion of 'being' itself was *made relational*: as Zizoulas aptly sums this up, 'to be and to be in relation becomes identical' (Fiddes 2000:15).

Or as Buber puts it 'All real living is meeting' (1958:11).

¹¹⁵ *Memory, understanding and will* (Cunningham 1998:229)

Trinitarian thinking has also been the subject of much feminist revisioning. Catholic theologian, Mary Grey explains the impetus for this rethinking

Feminist theology struggles towards new images of God, prompted by a new consciousness. It attempts to break out of patriarchal space, that is, out of harmful dualistic interpretations of transcendence/immanence, spiritual/material, moral/immoral, infinite/finite (1990:366).¹¹⁶

Grey posits that there are three main approaches to revisioning the Trinity within either reformist or radical frameworks. The reformist approach takes one of two directions; either replacing the persons with functions (e.g. Creator, Redeemer, Sanctifier) or by imbuing the divine figures with gender-specific imagery to include feminine images - especially the Holy Spirit, presumably as some kind of balancing act!¹¹⁷

The radical approach involves transcending gender altogether and drawing on non-personal categories in an attempt to 'loose the trinity from its moorings' (Grey 1993:99). This as feminist, Orthodox writer Valerie Karras has pointed out is contradictory as personal designations (as in the Traditional Trinity, albeit patriarchal) are deemed more feminist than the 'feminist' ones by virtue of the fact that they stress relationship over mere function (Karras 2002:248). A further, and increasingly popular solution which has strong support from Christian tradition and fits well with what is being argued here, is to see the doctrine of the Trinity as grounded in the mutuality of personal communion. Patricia Wilson-Kastner writes

The richer our expression of relationship to this God, the more we as a community open ourselves up to a fuller communication with God. As our awareness of and openness to the manifold dimensions of God increase, we draw ourselves and our world closer to the Divine mystery which made us and for which we are made (1983:143).

¹¹⁶Grey (1990: 366) cites John Donne's poem 'Batter my heart three-personed God' as a prime example of the violence that transcendence divorced from immanence can lead to. It apparently inspired the code name 'trinity' for the atomic bomb that decimated Hiroshima and Nagasaki!

¹¹⁷Pro-feminist thinkers often object that this reinforces unhelpful gender stereotypes. Grey herself objects 'particularly to limiting female imagery to the Holy Spirit and to motherly qualities - which hardly exhaust the possibilities of being female! (1990:364)' Also see Walker 1990.

This latter approach has appeal for feminist writers who hold to mainstream theology, and Grey (1990) applauds Brooks-Thistlewaite's (1983) insistence that an individual and absolutist view of the individual be challenged in order for this mutuality to become a lived reality partaken of by women as well as men in full equality. We turn to Moltmann to summarise this relationship in the Trinity. 'By virtue of their eternal love they live in one another to such an extent, and dwell in one another to such an extent, that they are one' (1981:175).

We in turn become part of that oneness as we partake of the divine life. Buber expresses it most poetically saying 'We live our lives inscrutably included within the streaming mutual life of the divine (1958:16).¹¹⁸

This concept of living in oneness leads us to consider another biblical pathway by which we are intended to understand the imago Dei: namely, the creation of a one flesh relationship between male and female (often conflated with marriage¹¹⁹). So we draw primarily from the Trinity a realisation that we are made in the image of a personal God who motivated by love lives in a communion of mutuality and openness. We should not then, expect to find a different paradigm in the two-sex relationship although influenced by Greek culture, (and fallen nature!) many commentators have interpreted the scriptures and especially the writing of St Paul to denote precisely that - a hierarchical, power relationship of domination and submission which is more in line with Hegel's master/slave model than this self-giving endlessly loving model of the Trinity.¹²⁰

McFayden is excellent here on his understanding of the Genesis paradigm - largely in so wisely and carefully avoiding many pitfalls as he unpacks what it does and indeed

¹¹⁸ Note here that what Buber and others envisage here is unlikely to be as inclusive as Whitehead's view which tends more towards Buddhism than Christianity, in my view.

¹¹⁹ McFayden states 'Marriage is clearly closely related to the paradigmatic form of humanity at creation (Gen 2:24), but they are not equated. The narrative is concerned with a primal event rather than the foundation of an institution such as monogamous marriage. Further, becoming 'one flesh' denotes neither sexual intercourse nor its product (Seth), but human existence as a whole under the aspect of corporality. It is the dialogical form of relatedness which is normative for marriage, as for all relations... (1999:35/6) It is not surprising, perhaps, to note that Pope John Paul II does not take this view but sees the Genesis account as describing sexual intercourse and therefore the marriage relationship (2002: 170-178). Letty Russell also sees man and woman created for the purpose of human communion and companionship rather than simply for procreation.(1982:66)

¹²⁰ The Arian heresy that it was in the nature of the son to submit to the Father and therefore not a matter of volition is alive and well in Melbourne, Australia (Moore College) where this subordinated view of the Son is used to buttress a conservative agenda of women being eternally subordinated to men. Kevin Giles (2006) writes against the thesis of those who would read back into the Trinity a form of subordinationism based on a cultural commitment to the subjugation of women.

does not denote. As with the Trinity, so the male-female one flesh relationship is completely inclusive, according to McFayden. Defining the 'one flesh' relationship outside the parameters of heterosexual marriage, McFayden skillfully embraces all humanity in its rich (and sometimes controversial) diversity. A lengthy quote will allow the author to show us the breadth of his awareness of the potential for exclusion in other interpretations.

Marriage and sexual intercourse are not equivalent terms for the paradigm of 'male' and 'female', If they were, then the corresponding understanding of human nature would be exclusivist. It would place those male-female relations in which neither marriage nor coitus is a part into a subordinate position and the humanity of all those unable or choosing not to enter such relations in question. The elderly, the impotent, the widowed, the celibate, the hermaphrodite, the transsexual, the deformed and handicapped [sic]¹²¹ and the homosexual would have their humanity and the humanity of their interrelationships denied them. The creation narratives do afford some special status to procreative, and therefore potent, heterosexual relations; however, procreation is construed as a blessing which is bestowed not primarily on individuals but on the species so that it can continue through generation. In short, this way of understanding the image provides no basis for the exclusion of the homosexual, the single and the variously infertile from the image (1999:38).

McFayden prefers to think of male and female as being in sexual 'encounter' rather than in 'opposition' and this seems more in line with the Trinitarian model as the number three lends itself more to mutual encounter than to opposition. Looking at the Genesis account of the rest of creation Miroslav Volf draws out an important principle¹²²

The account of creation as 'separating-and-binding' rather than simply 'separating' suggests that 'identity' includes connection, difference, heterogeneity. The human self is formed not through a simple rejection of the other - through a binary logic of opposition and negation - but through a complex process of 'taking in' and 'keeping out'. We are who we are not because we are separate from others who are next to us, but because we are both separate and connected, both distinct and related; the boundaries that mark our identities are both barriers and bridges (1996:66).

¹²¹ It should be noted that some disabled people resent a common assumption that because they are disabled they are not capable of full sexual relations. It is important to include this here simply to acknowledge that for some that may be the case and that even then they are not excluded from the image as set forth in the Genesis account.

¹²² Jane Deland asserts that 'a correct reading of the story of creation should focus on the goodness and diversity and of creation and reject the myth of original perfection and uniformity which has no scriptural basis.' 1999:52

Finally, we will draw on a theological anthropology that sees Christ in his incarnation as the paradigm of what it means to be human. Volf states

In Christ human personhood became historical reality. Christ is the opposite of an individual; he is the person *par excellence*, since his identity is constituted by a twofold relation, namely, through his relationship as Son to the Father and as head to his body (1998:84).

Writing on the work of Illingworth, Gunton states

The incarnation provides the cornerstone for his argument that human personality offers the decisive insight into the existence and nature of a personal God, not because the triune constitution of human personhood is the basis for projection of the triune being of God as the 'archetype' of humanity's potential being: 'thus the actual Trinity of God explains the potential trinity of man, and our anthropomorphic language follows from our theomorphic minds (Gunton 1991:3).¹²³

William Placher (1994) in a book entitled *Narratives of a Vulnerable God: Christ, theology and scripture*, challenges the popular notion held by those who are attracted to the idea of God and those who are not alike, that their view of God centres on power.¹²⁴ (Even Mary Daly's alternative trinity in her book *Beyond God the Father* cites power as the first key component of God: 'Most Holy and Whole Trinity: Power, Justice and Love' (1986 :127). (Admittedly a feminist view of power is different from a mainstream concept as it is power *with / for* and *to* and not power *over*. Also Mary Grey sees power in terms of '*relational dynamism*'.)

As we have seen the conundrum of theodicy posed by classical theism takes God's power for granted and therefore central to the posing of the problem. However, Placher points us in a different direction.

The Christian gospel, however, starts its understanding of God from a very different place. To read the biblical narratives is to encounter a God who is, first of all, love (1John 4:8) Love involves a willingness to put oneself at risk,

¹²³ David Cunningham makes a similar point when he claims that 'triune marks' are human construals based on what God has already revealed to us. (1998:90)

¹²⁴ Daphne Hampson as one who does not like the idea of God as traditionally conceived nevertheless knocks against the assumption that the God of the Christian and Hebrew scriptures is 'all-powerful'. (1990:376)

and God is in fact vulnerable in love, vulnerable even to great suffering (1994:xiii).

Placher argues that if God becomes human in the way in which we can see it in Jesus this should lead us to certain conclusions about how we could seek our fullest humanity 'not in quests of power and wealth and fame but in service, solidarity with the despised and rejected, and the willingness to be vulnerable in love (1994:xiv).

Feminist, liberationist, writer Carter Heyward, perhaps polarising the debate a little too much, says

Jesus did not come to reveal God's power, God's might, God's victory. Rather, Jesus came...into the pain, the passion, and the wonder of creation itself. Jesus accepted the vocation of being truly human in the image of an enigmatic God. (Carter Heyward 1982:28)

In explaining the rationale behind the formulation of a doctrine of the Trinity Fiddes argues that the Fathers were trying to make sense of their experience of God, and what they saw him doing especially in the life of Jesus.

They found God revealed and active in his Son who welcomed outcasts into the Kingdom of God the Father...They found God...opening up relationships beyond the accepted social boundaries and opening up hope for a future new creation (Fiddes 2000:5).

Before moving on to look at the social construction of selves, especially its dark side, the benefit of this Trinitarian model of relationship will be pointed out which, in contrast, leads to a very positive construction of the Self.

Lest it should be concluded that this absorption into the other denotes a lack of particularity in the way we might find in Far Eastern religion, let it be stated firmly that the concept of a person here is one that is contained within a unique particularity and yet is constituted through her/his relationship with the other and grounded in relation to Christ. Christ himself is a corporate personality who incorporates many into himself. As such, Christ is the new Adam who in his particularity bears human nature in its catholicity (Volf 1998:85). It denotes, perhaps, not so much a losing of oneself in the other as a finding of the distinct Self through the other. This issue of particularity is important because it means that I am not you or you me and as such each individual is totally unique and irreplaceable. Keller argues that there is a need

for reciprocal resistance in relationships so that we do not in fact merge into each other as is the tendency with the 'soluble self'. Even within the Trinity although the three permeate each other (perichoresis), they do not cease to be distinct persons. Volf also talks about the need both for boundaries and bridges and quotes Plantinga (1999: 29) who shows in the Genesis account an active process of 'separating' and 'binding together'. Buber also says that when we meet others we should hold our ground (1958:28). This may be more problematic for some women whose ego-boundaries may be particularly weak and permeable. Feminists have taken issue over the notion of losing the self as they claim that for women they are often being required to lose a self they have not yet even realised (Saiving 1960).¹²⁵

We see then that we are persons as we participate in the life of the Triune God which is characterised by a transcendence beyond the self always reaching out to the other in love. Being in God's image (as seen in the life of Christ) is characterised by giving and vulnerable risk-taking rather than by great acts of power and ego-enhancing prestige. (we have seen through the data analysis something of how well placed people with intellectual impairments are compared with others to manifest these Christlike qualities and lead in this manner)

8.5 The social construction of selves

The nature of persons in God reveals that, in contradiction to the Enlightenment view, what matters is not so much the ego reflecting upon itself, but a self-transcendence in communication with others, especially in the movement of love. The person lives from openness beyond itself to others, relationship being the central point.

There now appears to be a broad consensus that as selves we are socially constructed. A postmodern view of the self is that it is multiple and shifting and constructed through discourse. Although this may be at odds with an ontological perspective, Fiddes (2000) and Cunningham (1998) consider that post-modern philosophers of the

¹²⁵ [I realised that the work at Reach Out was especially disturbing for me as my own ego boundaries were not strong enough to cope with being fully immersed in the other and albeit another that I found threatening and potentially disturbing. I learnt that I needed to be reimmersed in something not alien afterwards in order to recover my sense of equilibrium.]

self such as Calvin Schrag have a useful contribution to make as they hold a relational view of the self seeing subjects as co-actors, and -co-narrators with others in the human drama. Nevertheless, there is also a down-side to a post-modern view of what it means to be human as pointed out by Vardy¹²⁶ (2003)

The attempt to argue for or impose a single understanding of what it is to be human is an attempt, postmodernists will assert, to impose an understanding which everyone is meant to accept. This, they will contend, is what Christianity has always done, using the coercive power of the media, culture, education and the Church to marginalise and oppress women, homosexuals, the poor and the different. There is considerable strength to this view and it needs to be taken seriously (2003:31).

Ultimately, the self must be seen as being profoundly affected by its environment and history. Goffman (1959) sees the place or context as central to the persona that we project and rightly alerts us to the complex relation between the personage we project and the personage expected from us (both of which may be at odds with the 'true' person, or the person as they experience themselves).

McFayden sees the development of the self in almost geological terms - describing the process as one of sedimentation with layers building through experience.

What I shall be trying to show is that individuality is socially structured. My position is that individuals are formed through social processes, their identities sedimented from histories of significant relation. The form which a person's significant relations have taken is determinative for that person's identity (1990:72).

Alarmingly, in this view, to some extent we become what we are expected to be, (limited by the perceptions of others and therefore by the types of encounters that we experience) being 'called into being by others' (1990:74). More helpfully McFayden also talks about the disciples being reconstituted as individuals through the call of Christ thus giving the two dimensions of the vertical and the horizontal (1990:49) making us less at the mercy of our social location.

Cunningham offers a different view of sedimentation taking a fluvial perspective which he argues gives more space for the concept of particularity and is less deterministic.

¹²⁶ However Vardy points out persuasively that without a conviction that there is a single human nature there would be no international law and no such thing as crimes against humanity which are considered to be a violation of basic common human nature (2003:33).

It [sedimentation] could be taken in at least two different ways, depending on whether one thinks of 'sediment' as something that creates layers of solid rock, or something that creates the rather less 'fixed' surface at the bottom of a river.' In the first case the image tends to evoke an excessively static description of personhood - a slow relentless, 'geological' process, in which our lives are permanently determined by forces beyond our control. But in the second case, the metaphor becomes quite appropriate, signifying a dynamic process that always allows for the decomposition and recomposition of previous 'sediments'. A riverbed has its own particular shape, form and composition; but its particularity is shaped, formed and composed only through an encounter with others (1998:198/199).

Hampson (1990: 373) draws our attention to the dark side of being constructed by others in speaking of Simone de Beauvoir and the influence that the work of Sartre had upon her. Sartre was convinced that our sense of self is formed by an internalisation of what others conceive us to be and this led de Beauvoir to see how women, raised within patriarchal societies, internalise their place and the same can surely be argued for other marginalised groups. Volf, quoting Taylor underscores this precise point

since the identity is partly shaped by the recognition we receive from the social setting in which we live, 'nonrecognition' or misrecognition can inflict harm, can be a form of oppression, imprisoning someone in a false, distorted and reduced mode of being [in Volf 1996:19 (Taylor1994b:25)].

Volf from the rich experience of his life in the Balkans during a period of widespread 'ethnic cleansing' is able to perceive the dynamic behind exclusion in the malign terms in which it doubtless should be construed. Drawing on the work of Foucault and Nietzsche (with which he has some misgivings) Volf asserts that they are right in seeing that the 'moral' and 'civilised' self all too often depends on the exclusion of what is construed as the 'immoral' and 'barbarous' other (1996:62). Volf (1996:68) goes further asserting that we deliberately misjudge and misperceive others because we desire to exclude. He sees nothing neutral or pragmatic about exclusion: 'exclusion' does not express a preference; it names an objective evil' (1996:68). The answer to this problem must, in part, be found in the church as the community of those in Christ.¹²⁷ Bearing in mind that from the work with trauma victims it was

¹²⁷ Historically the church has tended to be more of the problem than the solution. Inner healing practitioner and Christian writer, Leanne Payne (who does not write from feminist allegiances) notes that while society urges women to see themselves as sex objects that the church offers a no less mistaken approach of urging them to find their identity as wives and mothers. She insists that women

found that a wholesome sense of self could be reconstructed (or constructed for the first time) with the help of empathetic others (Meyers 1997:12).

The shift to a social-relational self in stark contrast to the individual and separatist view of the Enlightenment, as outlined by Descartes (see p216) heralds a transformation: an inclusive sense of who counts as human. No longer are we tyrannised by an exclusive and over-rationalistic view of humanity with its proclivity to marginalise groups such as indigenous peoples and women. Here the Self is able to transcend the purely rational and accommodate different forms of reason with aspects of emotion and embodiment. This thrust is central to the argument of this thesis as it enables us to fully value all persons irrespective of their rational powers.

8.6 Personhood and the church

Two important points are to be made from what has been said. Firstly, that the church should reflect what we know to be true about God's nature and personhood and as such draw to him. ...'if unity and multiplicity are equiprimal in him, then God is the ground both of unity and multiplicity. Only unity in multiplicity can claim to correspond to God.' (Volf 1998:193), and therefore only a demonstration of multiplicity in unity will be adequate to set forth the life of God in the community of believers.

As has been noted, the concept of personhood has a strong eschatological dimension and as such the church should provide a taste of what is to come. Zizoulas writes that 'the institutional dimension of the Church must always incarnate its eschatological nature' (1985:20). Its eschatological nature should surely include the description in Gal 3:28 'In Christ there is neither male nor female, etc' which might lead us to expect the integrity of such a position to embody sexual equality and diversity, among other things. We would expect to see this dialogic quality (vertical and horizontal) that McFayden speaks of.

and men alike must be encouraged to find themselves as complete in Christ alone and become complete as persons through practising the presence of God. (1990: 56)

The church, then, has its identity as a pattern of communication. There is listening and response to both divine Word and human words...The reality and presence of individuality is denoted by the ordering of communication in a particular form which, because this form must be concrete, is partly socially relative. Christ's personhood or individuality is Word-present in the Church and is therefore a real presence, structuring and ordering identity and relation. The nature of the Church is to be 'wherever two or three are gathered in my name.' Christ is really present in the communicational form (redeemed intersubjectivity) of this gathering (McFayden 1999 :62).

As noted earlier, in the context of recovering from abuse,' the self is resilient enough to be reconstructed with the help of empathetic others' (1997:12) and there is perhaps important work to be done for those who have been misconstrued and wrongly constructed to be affirmed within the church. Letty Russell also notes that an important ingredient in keeping human life fully human is the possibility of participation in the shaping of our future (1982:20) so it is perhaps, vital that all persons in the Body of Christ have a role to play in shaping their own particular local expression of church.

8.7 Why include a chapter on personhood in this thesis

As has been seen a Christian view of personhood is fully inclusive as it resides solely in the ability to relate as persons to other persons and not in the possession of any particular capacities. The doctrine of Original Sin argues that all persons are broken and vulnerable and this is a great leveller. As Patsy says in the focus group concerning the communion 'we all come similarly- nothing in my hand I bring'. Further, this connected view of the Self opens the door for inclusion of all persons regardless of their rational powers, and values emotion as well as intellect, this being a central building block in the argument of this thesis.

8.8 Summary

In this chapter the main elements in the debate over the nature of personhood have been outlined We have noted the separatist view proposed by Freud, Satre and others and moved on to a more connected view propounded by feminists, Jungian psychologists, and more significantly for our purposes, those with a Trinitarian theology. We have established that personhood is an ascription that embraces all

persons made in the image of God, as relational beings and is not directly related to rational powers. It is this understanding that appears to undergird the wholesome practice that was observed in the fieldwork and I argue is the basis for the full inclusion of all persons including those with intellectual disabilities in the Body of Christ. Moving on now I show how a Christian theology both of suffering and personhood can equip the church to be a model of emancipation in stark contrast to the assertions of the Disability Movement. The scene is now set to begin to formulate an emancipatory model of church that can foster full inclusion.

9. TENETS OF AN EMANCIPATORY MODEL OF CHURCH

In this chapter the notion of an emancipatory approach to disability is built upon. First the work of two disablist theologians who draw heavily on Liberation theology is acknowledged and from the work of Hannah Lewis ten tenets of a liberatory praxis are drawn out and then critiqued.

As seen the idea of an emancipatory approach to research is pertinent to the domain of disability studies. While it has been stated that an emancipatory paradigm cannot be adopted in its entirety here, this is, nevertheless, a concept which is germane to this work.

In contrasting participatory, action and emancipatory approaches to research, Mike Oliver has the following observation to make.

Thus participatory and action approaches, it seems to me, share a limited vision of the possible. To use a game metaphor, these approaches are concerned to allow previously excluded groups to be included in the game *as it is* (own emphasis) whereas emancipatory strategies are concerned about conceptualising and creating a different game, where no-one is excluded in the first place (1997:12)

So an emancipatory paradigm has at its heart a vision of a different game. We must look now at how the 'rules' might be different in this emancipatory project. Essentially, it is not about reinforcing existing power relations but confronting them with a view to changing them.

9.1 Liberation theologies

Many disablist theologians {including Jane Wallman (2001) And Hannah Lewis (2001)} Look to liberation theology as a source of emancipatory praxis. Hannah Lewis in her doctoral thesis, *A critical examination of Deaf people and the church: toward a Deaf liberation theology*, examines feminist, black and liberation theology searching for marks of a liberation theology.¹²⁸

¹²⁸ Since this thesis is directed towards the Evangelical church it should be noted that while Evangelicals have continued to regard liberation theology with suspicion, there have been some

Drawing on Hannah Lewis' analysis I take a number of her points to set down some tenets of a liberation theology in order to interrogate which tenets are appropriate for an emancipatory model of church for disabled people, including those with intellectual impairments.

9.2 Tenets of liberation theology

Lewis (2001) identifies the marks of a liberation theology, ten of which are set out below for discussion.

- ◆ It is an engaged and contextual theology
- ◆ It emerges from a context of oppression
- ◆ It starts from praxis rather than experience
- ◆ It aims for a world where each individual is free to fulfil his/her full, Godgiven potential
- ◆ It is motivated by a strong desire for justice and a commitment to social change as a demonstration of the love of God.
- ◆ It begins with the questions and issues raised by the oppressed group themselves
- ◆ It acknowledges the centrality of power issues
- ◆ It uses history as a tool to support an alternative discourse, rewriting history from the vantage point of the marginalised
- ◆ It emphasises the rule of God now on Earth
- ◆ It encourages alternative readings of the Bible

It is an engaged and contextual theology

Contextual theology challenges the assumption that there can be one theology with universal relevance and application. It is, in fact, a critique of such theologising. This is crucial as it links to the issue of bias or what one might term unexamined bias: thinking which masquerades as neutrality. Letty Russell states clearly

positive develops on this front. Ronald Sider (1980) states that Liberation theologies are probably the most significant development in recent times, regardless of whether they be feminist, black, or Latin American. However, he agrees with a critique that suggests that Liberationists accommodate too much to the prevailing culture which causes them to blur some important Biblical lines of demarcation. Nevertheless, he asserts that Evangelicals are equally guilty of the same error but in the opposite direction tending towards compromise with the values of an affluent culture. Punchily he identifies the unbalanced and unbiblical stance of many Evangelicals which claim to be committed to a *sola scriptura* position, as a 'dishonest ideological support for an unjust, materialistic status quo.' So we see that at the heart of Liberation theology there is a thoroughly Biblical agenda: God's preferential option for the Poor. Nevertheless as Roger Forster objects 'Jesus appears more as a Che Guevara with a gun in his hand than as the New Testament Christ of 'Father forgive them for they know not what they do.' (2001:11)

The emphasis on context in liberation and feminist theologies stems from recognition of the bias in the tradition itself as well as the view of the small group of largely white males who have interpreted that tradition out of their clerical and academic contexts. (1993:32)

However, those who do not see the validity of a contextual approach often criticise it for not allowing for the application of universal principles which are said to hinder ecumenical work for doctrinal agreement and church unity. That criticism must be disregarded here for as Letty Russell comments

It is true that contextual theologies are suspicious of any theology which proposes abstract statements that can be expected to hold true in every circumstance. Experience has shown those who have little voice in shaping the tradition that such universal statements reflect the understanding of reality experienced by those with the power and knowledge to name that reality. (1993:32/33)

and it must be admitted that disabled people are firmly among those who have historically had little voice in shaping institutional knowledge. Mary Grey insists on the value of contextual theology being that it teaches us the limitations of any one perspective and leads us to make more modest claims. She notes that although all stances are multi-factored that it is still better to take a stance than to take none. For she warns,

Sitting on the philosophical and theological fence has never made any contribution to human development; taking a stance, while recognising the limitations of a perspective, may actually free some space for other voices, particularly for those as yet unheard. (1993:58)

It is indeed a highly inclusive project endeavouring to hear voices which have not been heard in the past processes of theologising. It is 'aimed at altering conditions in the Church and in society that are counter to the deep intent of the Gospel.'(de Mesa 2002:1)

It is situated in a context of oppression

It is driven by real life situations where humanity is suffering and it seeks to look through the lens of those concerned. Certainly this is relevant to a study of disability and the church and many Christians who are disabled and/or Deaf will state that their context is one of oppression (Lewis 2001; Robitscher 1998; Wilks & Pestell 2003; Flynn 2003 Hitching 2004). This context of oppression can help shape our thinking

and Boff has a useful definition of liberation theology 'to think the faith in the face of oppression' (Boff 1996:9)

It starts from praxis rather than experience

Praxis can be defined as reflected-upon-action and acted-upon-reflection and this is very suitable for this context and it can be argued that this is just what the church often lacks. Wilks & Pestell (2003:4) show how the Christian establishment often thinks it knows what is best for disabled people without reference to their own needs. Feminist theologians have developed what Letty Russell calls 'the theological spiral' (appendix 1) as a form of praxis.¹²⁹ So praxis is very important yet the contrast between praxis and experience here could give the impression that experience is not highly valued which I believe would be misleading. In some dualistic theological thinking, experience is disprivileged as it is seen as 'subjective' and lower than seemingly more objective matters, such as revelation and tradition. I would want to argue against the dualistic mindset that sees everything as either or... 'the myth of dualism'. Letty Russell makes the point well

It is both possible and necessary to be an advocate of more than one thing at a time. The world is not made up of either/or's. If we stopped assuming that it was, we would discover a world full of both/and's and maybe/also's. (Russell 1993:22)

Those who are in the dominant group who have the power to name and universalise from their own social locatedness tend to be the ones who discount the experiences of those on the margins. However, within a liberatory paradigm there is acknowledgement of cognitive dissonance¹³⁰: a contradiction between ideas and

¹²⁹ Starting from a position of being connected to those on the margins the theological spiral - also known as 'a liberation social ethics methodology' (Beverly Harrison) or 'emancipatory praxis' (Katie Cannon) forms a continuing spiral of engagement and reflection. It begins with *commitment* to the task of raising up signs of God's new household with those who are struggling for justice and full humanity. From there it continues by *sharing experiences* of commitment and struggle in a concrete context of engagement. Next the critical spiral leads to a *critical analysis* of the context of the experiences, seeking to gain understanding of the historical and social factors that affect the community of struggle. Questions arise from this about biblical and church tradition which help give insight into the meaning of the Gospel for the marginalised. 'This new understanding of tradition flows from and leads to action, celebration and further reflection in the continuing theological spiral. (Russell 1993:31)'

¹³⁰ first coined by psychologist Leon Festinger in 1956 in *When Prophecy Fails* and presented in systematic form the following year 'A theory of Cognitive dissonance' 1957 Stanford University Press. Cf Letty Russell 1993:23.

actual lived experience. Also an acknowledgement of the fact that ideas and tradition have been interpreted for us in the church throughout the ages. The value of experience is primarily that it gives rise to consciousness or new forms of consciousness which Dietrich Bonhoeffer makes plain from his experience of imprisonment.

There remains an experience of incomparable value. We have for once learnt to see the great events of world history from below, from the perspective of the outcast, the suspects, the maltreated, the powerless, the oppressed, the reviled - in short, from the perspective of those who suffer. (Bonhoeffer 1972:17)

In addition reflection on experience may sometimes be what gives rise to revelation. Paul Fiddes claims that the social view of the Trinity as expounded by the Cappadocian Fathers was the result of their attempts to interpret what they experienced of the work of the Triune God in their lives.(Fiddes 2000:5) Peter's experience of the vision of the animals in the net (Acts 10) when the gentiles were coming into the Kingdom may be a further example.

It aims for a world where each individual is free to fulfil his/her full, Godgiven potential

Much is made in sermonising about the parable of the talents (Luke 19) as if we were all free to use our gifts and if not it were a matter of our own perversity. This desire for all persons to be able to use their gifts must acknowledge that the problem is not merely a personal and individual one. Thus this goal is relevant and must acknowledge the structural dimension to much that obstructs the full flourishing of all persons. This is a very useful tenet as it highlights the fact that there is a battle to be engaged in for Godgiven potential to be realised for those who do not conform to the *status quo* and especially for those who are rendered invisible in the dominant culture. As Swinton (2001:34) says of his Downs friend Stephen, the real problem is that people very often cannot see Stephen as a person, because Stephen as a disability clouds their vision. In such a case there can be no expectation that this person has gifts that are important to release for the Body of Christ. Brett Webb-Mitchell in his critique of L'Arche expresses concern that an emphasis on being over against doing, while good, leaves unaddressed the need to focus on becoming.(1988)

It is motivated by a strong desire for justice and a commitment to social change as a demonstration of the love of God.

This is central to this work as a message of the love of God in the face of injustice in the church invalidates the message itself and makes a mockery of the message of the Kingdom. Gutiérrez says: 'How can we show those who live in a situation that denies love that God loves them?' (Gutiérrez 1989:xxxiv) In acknowledging that the church should be leading the way in matters of social justice, Flynn laments 'Why in general do churches lag behind the level of understanding that exists in the market-place of the secular world. Are we waiting for the world to show us how Christians ought to behave?' (Flynn 2003:19)

Letty Russell perhaps gives us some insight into the ambiguity felt in the church. 'The connection between personal and social sin has been 'split at the root' so that the church can preach love of neighbour and yet confirm the social *status quo* that perpetuates oppression.' (1993:123)

Liberation theologies value orthopraxy over orthodoxy although this may be a false dichotomy: true orthodoxy should demonstrate orthopraxy. Elsa Tamez in her book *The Scandalous Message of James*, points out 'at no time does he (James) place the works of justice in opposition to justification. Rather he says they are the fruits of the Spirit that are born of faith.' (1990:65)

A commitment to justice and social change is at the heart of the Gospel and the nature of God and, as such, is not just an optional extra.

*It begins with the questions and issues raised by the oppressed group themselves.
It acknowledges the centrality of power issues.*

These two points are linked as an acknowledgement of power issues can lead to the realisation that we must start with the questions being asked by those who are concerned rather than naively and perhaps, arrogantly, assuming that those in a privileged position know what is needed. Wilks and Pestell (2003:4) writing on the issue of Deaf Christians state 'There is little doubting that the Christian establishment

believes it understands deafness and the needs of Deaf people.' This unfounded confidence needs to be overturned and beginning by asking those concerned to identify the issues for them is a necessary first step to show how wide of the mark this confidence often is!

Also Vanier points out that our society has embraced a Darwinian 'survival of the fittest' where a strong aggressive attitude and the need to win has been stressed. Vanier says that in contrast we need to discover our common humanity which will entail losing some of our power and privilege and even contemplating the brokenness and evil in our own hearts and dominant culture.(1999)

It uses history as a tool to support an alternative discourse, rewriting history from the vantage point of the marginalised

This may be the least useful of the tenets since for some disabled people their invisibility in history is unrecoverable. People with learning disabilities are unlikely to have recorded important details of their lives because they would not have had the education needed for such a task. However, Hannah Lewis has uncovered some important historical facts concerning Deaf people and the church. She states that in the mid 19th century Deaf men proclaimed the Gospel for all over a period of fifty years. There is no doubt some important material there for the Deaf church. Feminism employs the concept of 'dangerous memory' and much of Schüssler-Fiorenza's biblical recovery work, focused on the retrieval of the lives of women in the early Christian communities. Where possible this is an important project for marginalised people as it gives them a sense of their past and works against the otherwise all-pervasive sense of invisibility.

It emphasises the rule of God now on Earth

This may be one of its weakest points for while we must strive to achieve what we can, there are dangers in a Utopian dream. Adele McCollum (1998:184), writing from a disability perspective takes a realistic view when she says 'I am not advocating a utopian kingdom on earth but suggesting that incarnational religion can be manifested by a degree of realistic engagement with the world as it is (1998:184)

Also in a wonderful phrase she explains 'it means reaching across the back fence before reaching for the stars.'

Apart from the limitations of a vision of heaven on earth, there is a real hope to be had from a vision of the eschaton. This is because as Frances Young puts it 'Human life is subject to bondage and corruption, however unfashionable it may be to suggest this'. (1990:214)

Nicola Slee in her *Introduction to Christian Feminist Theology* ascribes to some feminists an 'optimistic vision, both of the human capacity to effect justice and right relation in the earth, and of God's longing for the world.' (2003:70) This kind of perspective derives from an over-confident and unrealistic humanism and Frances Young (also Wendell 1996; Volf 1996) has something to say on this... 'the delusion of our society is that humanity can resolve all its problems and something can be done about everything.' (Young: 1990:203)

So while it is worthy to strive to improve the human condition, even as an expression of the love of God in action¹³¹, we must not lose sight of the fact that some of what we aim for cannot yet be fully realised but we should await with expectation the completion of all things.

Feminist writer, Tina Beattie (1999) has her feet firmly on the ground here insisting that an incarnational Christian faith must 'recognise the crucifying power of this world, the treachery of the social order, and ultimately the fickle allegiances of populist movements, even those that are politically correct.' (Beattie 1999:116)

Letty Russell finds the future to be a very important theological category and brings together in an interesting way a vision of the future with a concern for the present.¹³²

She writes:

¹³¹ Alastair McGrath believes that 'by working to lessen the suffering of God's world and God's people, we are easing his heartache over their pain.' (McGrath 2000:103)

¹³² Both Pannenberg and Zizoulas see history as made sense of in the light of the eschaton. Most people see the meaning of existence by the perspective of *prolelogia* (first things). So for example, God's creation and the story of Adam and Eve are seen as showing us what is intended for human beings. Whereas Pannenberg and Zizoulas think that it is *eschatalegia* (last or final things) which make sense of our existence.

'Interpreting the Bible from a critical perspective of God's promised future leads us to begin from the other end and to engage in what might be called eschatological hermeneutics, a process of questioning our actions in the light of the biblical message of a new creation.' (Russell 1979:105)

It encourages alternative readings of the Bible

There are two separate issues surrounding the Bible. The first is that because it has been used to oppress marginal groups, some despair of its validity and capacity to encourage and therefore turn to more 'promising' texts, making it, at best, one sacred text among many. Schüssler Fiorenza says: 'If we proclaim that oppressive patriarchal texts are the word of God then we proclaim God as the God of oppression and dehumanisation.(1984:xiii)

While some have rejected the Bible altogether (which the present writer has not) others who nevertheless struggle with it (as she does) have sought a more helpful way of reading it. While abandoning the text cannot be advocated, seeking out a useful hermeneutic (like a hermeneutic of suspicion) which challenges the dominant reading, may be a helpful tool.¹³³ Letty Russell sees this as a form of 'talking back' to tradition. (1993:200) Slee talks about reading the text 'against the grain' ...engaging with the texts so that their liberatory potential is released (2003:18) 'The golden thread approach' (Hampson 1990) is useful as it advances a view that the bible can be read through the lens of a particular key notion. Liberation theologians (Gutiérrez 1988:101) argue for reading the New Testament through the grid of the Old Testament Exodus story. Radford Ruether uses liberation as a key with which to unlock the scripture. Slee says:

'Ruether sees the principle of liberation as the key prophetic-liberative principle of the bible, testified to throughout the biblical writings, but particularly in the prophetic tradition, the Exodus narrative and the Kingdom praxis of Jesus. (2003:22)

¹³³The Text refers to Job's wife as if she were some disinterested party rather like Job's dentist. She could easily be the central figure here as her plight could be construed as worse than his. She has just lost all her children, her home and their livelihood and seems to be expecting to lose her husband any moment because of his physical state. A hermeneutic of suspicion would foreground her own concerns and not just see her as someone who is 'letting the side down' and playing devil's advocate but a person whose own faith is being tested to the very limits.

Feminists as well as some disabled theologians (notably Hull) acknowledge the fact that traditional readings of the Bible can be oppressive as they seem to legitimate that which is oppressive. This kind of alternative reading

acknowledges the gulf that exists between the biblical world and our own and wrestles with 'hard texts' without obscuring the reality that some of the biblical material is deeply hurtful to women [*and others* (my words)] today (Slee 2003:21)

Furthermore, the Bible often foregrounds those who are privileged in the dominant culture, so alternative ways of reading can be used to bring out that which is hidden. Grant from a disability perspective applies a hermeneutic of suspicion to the story in John 9 of the man born blind. She argues, 'Though the exhortation 'to work the works of him who sent me' is directed to the disciples, as we will see, it is the man born blind who carries it out.' (1998: 80) [because he becomes a witness to Jesus].

Nicola Slee (1990) looks at the New Testament parables foregrounding the disruptive impact of the Kingdom as the thread running through all the parables. Pamela Dickey Young (1990:29) talks also about a hermeneutic of remembrance which seeks to recover biblical traditions from a feminist perspective by asking new questions to see where in fact the women in biblical tradition are.

Some go further in advancing a challenge to exegesis. Melcher, speaking from a disability standpoint says incisively 'although I would not recommend desacralizing sacred texts, I do think we can desacralize stigma embedded in them' (1998:69).

Melcher (1998), Grant (1998) & Horne (1998) bring sharp focus to fresh readings of biblical material that has often been used to reinforce restrictive theological understandings of disability (Eiseland 1998:33). Lest it be thought that fresh ways of reading the scriptures is a new and dubious endeavour we can take the citation that Horne gives of John Chrysostom's reading of Matthew's version of the blind Bartimaeus story. Horne says that Chrysostom (writing in the 4th century)

identifies the representative role of those in the narrative with physical impairments who embody the discipleship quality of persistence, explicitly in contrast to those with physical sight. For this reason, he says of the people with impairments 'Let us emulate them!' (1998:91).

While this thesis is not grounded in liberation theology, I hope here to have shown how relevant much of liberation theology is to the project of emancipating believers with impairments.

9.3 Summary

In this chapter some tenets of an emancipatory theology have been explored drawing mainly on liberation theology. As has been seen an uncritical acceptance of all the tenets of a liberation theology is not possible. However, much of what is proffered is acceptable and I am now in a position to begin to formulate my own emancipatory model of church to foster full inclusion of those with intellectual impairments and this is the content of the next chapter.

10. AN EMANCIPATORY MODEL OF CHURCH

While disability activists such as Nancy Eiseland may lament that the church is not sufficiently cognisant of the prevailing models of disability in society, it must be acknowledged that the church is not simply a social organisation on a par with a sports club or a political organisation. We shall look later in some detail at how we should understand the church, but inasmuch as she is intended to be the body of Christ on earth, a purely social response will not do. Merely implementing the best policies (within a model of disability that recognises the social reality of oppression which is a by-product of disability being a social construct;¹³⁴) falls far short of her calling which is to demonstrate her Lord's extravagant welcome of all with disabilities at the banqueting table. Furthermore, it leaves untapped the many theological resources available in the Gospel to enable the full flourishing of all people including those with any, or, indeed, multiple impairments.

As has been seen from the case studies, both *CGS* and *Riverside*, demonstrate communities of practice which are conducive to full inclusion of people with impairments. However, this practice lacks a robust theological framework which can truly undergird a model of disability with an all-inclusive doctrine of humanity.

In this chapter, five steps will be proposed towards establishing an emancipatory model of church which aims to be more robust than can be achieved through a mere adjustment of surface factors. Firstly, the concept of the *status quo* (a recurrent theme throughout this thesis) is problematised and turned on its head in order for Kingdom values to prevail, secondly, we look at what the church is eschatologically and also sociologically and pay due respect to the many mismatches that exist between the ideal and the lived reality, which is the basis for the criticisms of the church charted in chapter 3. Thirdly I insist that a fully functioning Body of Christ must have all its members actively participating. While there is much lip-service in churches to the concept of 'every member ministry' this model of church recognises no 'body' part of which it could be said by any other member 'I have no need of

¹³⁴ This approach also serves to reinforce disability as a marginal position something which some disabled believers wish to eliminate. See John McCorkell's dissertation 2009.

you'. This church is a two-way street with each member, both, having things to learn and to teach others in the body of Christ, as demonstrated at *Kingsway* and *CGS*. The believer with Downs Syndrome is every bit as crucial as a participant of this church as the Merchant banker or the airline pilot. Fourthly, it is acknowledged that a church which fully includes people who are so profoundly different from one another and has the capacity to genuinely embrace 'the other', without demanding any kind of conformity, must be a church that is filled with the grace of God and empowered by the gifts of the divine Spirit, for raw willpower and good intentions cannot fulfil such a goal. For an example of this see Doreen's comment on p126 about a woman who she has great respect for and who she would not have expected to know in the usual manner of things. Doreen also makes other comments on that page about people with learning difficulties which reveal this dynamic of the grace of God at work. And finally, it is shown how this church needs a spirituality of hospitality which is informed by the heart and sensitivity to the promptings of the Holy Spirit. This church must be a place of mature, reflective practice which acknowledges the need for a pneumatological imagination (Yong) in order to discern what the Spirit may be saying to the churches through people with intellectual impairment, and others who live on its periphery. This stance is most fully exemplified by the life and work of Brad Jersak (as described in chapter 3). Although the example of Brad Jersak is far beyond anything noted at either site both sites reveal a very real spirituality of hospitality: at Riverside Church (see p318) where the leaders set up a meeting for people with learning impairments in their own home, and at Kingsway (see p136) where members are included in the social life of the church and one older Kingsway member is taken on holiday with other older church members.

10.1 Problematising the *status quo*

This thesis is undergirded by a metaphysic of connection and we are seeking to see through this prism. The *status quo* has been critiqued in recent years by many groups, among them Marxists and feminists, because of its unconscious accommodation to an elitist and male dominant value system. As we move towards a connected engagement the separatist nature of this value system must be foregrounded.

The *status quo* has been seen to be masculinist in terms of perpetuating a competitive and individualistic mode of engagement. Although we might identify ‘masculinist’ and ‘feminist’ ways of operating, this relates more to culture than biology, thus males and females can fall within either camp. Anthropologist Deborah Tannen (1991), asserts that there are fundamentally different motivators for men and women’s behaviour, as evidenced in a simple situation like being lost and needing directions. Men are motivated more by competition and a need to be one up (admitting they are lost is perceived as putting them one down and so is resisted) while women are relationally motivated (asking for directions causes them to make connection with someone in an unknown area thus is construed positively). Tannen, unlike Gray of *Men are from Venus and women are from Mars*, bases her comments on observations grounded in empirical anthropological research, rather than on unfounded, popular, folkloric, conceptions of gendered behaviour. Nevertheless, some feminist sociolinguists, among them, Professor Deborah Cameron, dislike Tannen’s analysis as she seems not to be concerned with the underlying reason of why they should differ so. Equally controversial, among feminist scholars, (some of whom fear that any accommodation to ‘difference’ will feed essentialism) is *Women’s ways of Knowing* (Belenky et al 1997) who look at connected and separate ways of knowing. The authors contrast ‘knowing’ (as in the French *savoir*) with ‘understanding’ (a personal knowing as in the French word *connaitre*): knowing is conceptualised as something achieved through separation from an object and mastery over it, while understanding is viewed as involving intimacy and equality between the object and the self. This precludes evaluation on account of the need to distance the object from the self and elevate the self above it. Belenky et al contrast a form of understanding that seeks to conform to what external powers require and a form which seeks to enter the other person’s frame in an attempt to grasp the premises for their beliefs. The latter approach requires empathy and a harmonious engagement despite the presence of difference and distance. The former, following Carol Gilligan (1982), is an epistemological orientation known as ‘separate knowing’ whereas the latter, is known as ‘connected knowing’.

From a more Catholic and Orthodox perspective there is also the critique of the *status quo* offered by the existence of Holy Fools which is rich in the work of Russian Orthodox novelist, Dostoevsky. The fool has to stand outside the dominant

culture, to some degree, and through suffering receives wisdom and insight to see through the spurious assumptions of the culture. By asking penetrating new questions the Fool exposes the futile power play of the privileged which can then, activate new and more wholesome ways of living.

Catholic theologian, Mary Grey, in her book *The Wisdom of Fools*, offers a critique of our culture. She posits two myths which are conceived of in contrasting terms. The 'Logos' myth is what she regards as the dominant myth of our western culture: it is hierarchical, competitive and profit-based. It is broadly male but inevitably, there are also many women within its structures. Against this she pits the 'Sophia' myth: non-competitive, non-dualistic, relational and ecological. Sophia wisdom from the wisdom literature is a female figure yet equally there will be men who embrace her *modus operandi*. Grey, sees the Holy Fool as having the power to bring healing to the people.

Catholic priest, writer and academic, Henri Nouwen, offers a critique of the *status quo* from his experience of transition from Harvard academic to resident at L'Arche living with people with learning disabilities. He claims that this journey enabled him to begin to connect with his own heart and thus, the heart of God (1989:8). He commends

The non-competitive life with mentally handicapped [sic] people. Their gifts of welcoming me regardless of name or prestige...opened in me a place that until then had remained unavailable to me, a place where I could hear the gentle invitation of Jesus to dwell with him (1989:20).

Vanier, Nouwen's mentor, also supports this view and shows us how those who fear their own hearts seeing them only as a place of weakness where they experience chaos and anguish, will be threatened by those who live by the heart (1999:47).

From a purely secular perspective, Oliver James, in his book *Affluenza* looks at the impact of consumerism on the mental health of the world (starting in the English speaking countries and now infecting the rest of the globe) where our intrinsic desires are superseded by our superficial wants, which are constantly manipulated by a market economy. This he calls the virus of affluenza. He contrasts our real needs 'for relatedness to others and playfulness as well' with our 'confected needs' (2007:145). He also compares the virus motivation (to keep up with the Jones's) with

intrinsic motivation. The former is characterised by an excessive self-awareness and he warns, 'people with such high levels of self-consciousness are at greater risk of depression, neurosis and narcissism.' This self-consciousness is a significant feature of the *status quo*. The Holy Fool often went naked – presumably as an attempt to rise above such absorption with self-image.

We need to learn to see the *status quo* as a deficit position, because it does not derive from wholeness. John Swinton also problematises the *status quo* and valorises the world that Stephen (his Downs friend) inhabits and reveals.

Stephen embraces and lives out those aspects of human experience that are often overlooked by a society and a church that frequently places reason, intellect, and rationality above emotion, intuition and experience...Stephen reminds us of the holistic nature of human living and relating. (2001:26)

In this view, those who do not conform to the *status quo* are arguably more fully alive and more completely human. The survival of our world depends on us valuing the non-dominant myth and so in the church we need to be able to see through this lens. This will entail us owning and embracing our weakness and vulnerability simply because we are part of the broken image of God which is being transformed to the image of Christ through the furnace of life. We are called to be the Bride of Christ – not a Barbie bride, based on a mould shaped by the cult of normalcy, but a radiant, transparent and vibrant relational bride. The cult of normalcy is tyrannical as it seeks to force everything to conform to its view of reality,¹³⁵ devouring difference and destroying the beauty of God's diverse creation as it goes. The false security that such uniformity engenders, in turn, pathologises difference and diversity. In order to enjoy the 'rainbow partnerships' that Letty Russell sees as a mark of the Kingdom of God, we must be free to embrace and celebrate diversity. We must now consider some of the difficulties experienced by many in an encounter with the church.

10.2 Cognitive dissonance and the Church - Mind the Gap

There is a romantic notion generated by those who construct, maintain and inhabit the centre, that church is a great place to be. For many congregants, this proclamation

¹³⁵ In this frame reality is hierarchical with the privileged at the top.

makes them uneasy as it surfaces the cognitive dissonance that exists on a number of separate levels. First, there is the cognitive dissonance which often exists between an encounter with Jesus (life-giving and affirming) and that with the institutional church (sometimes much less welcoming and even life-suppressing); then there is the gulf between the eschatological vision of the church, which might be viewed as an idealised church, and the local experience of church in real time; further, there is the chasm between the enlightened mode in which the secular society often now operates and the outmoded top-down power relations that the church still uncritically operates in (Volf 1998); and finally there is sometimes a further dissonance created by the mismatch between what the institutional church may be saying, even shouting, and the prophetic entreaties/whisperings of the Holy Spirit. This latter point can entail a mismatch between what is heard on the vertical plane and that which is heard on the horizontal plane. It is high time that the liberating words of the Song of Solomon ‘Arise my love, my fair one and come away for lo the winter is past the rain is over and gone’ (Song of Songs 2:10-13). be heard on both planes for those whose experience is one of eternal winter.

Those who have tasted the margins, such as theologian Frances Young, mother of severely impaired, Arthur, hold a very different perspective and this needs to be given voice and acknowledged. We may not agree with blind theologian, John Hull, in his view that disabled people inhabit different epistemological worlds but certainly we all inhabit different sociological worlds according to our social location. From her vantage point, Frances Young writes ‘the trouble is that the faults of the church are so obvious – the gap between its ideals and the reality is so glaring (1990:105).

Once we face the existence of this enormous gulf then we are in a position to make the effort to bridge it rather than forever congratulating ourselves that all is as we would wish. This is the only way to make our dreams closer to the lived reality of the average church member rather than simply the wishful thinking of the average church leader.

There is a view that salvation is a three tense reality – past, present and future, yet there is also a belief that sanctification is instant upon conversion and therefore we have arrived. If we see our transformation as being ongoing then there is ample room

to acknowledge where work still needs doing and to attend to it, thus acknowledging the complexity of human life, without appearing to lack faith in the finished work of Christ on Calvary. Zizoulas and others, write glowingly of what the church is and that is fine so long as the vision of who she truly is, is in no way muddled with the institutional/historical church. Such confusion can lead to a very uncritical stance where it is wrongly assumed that any acknowledgement of the shortcomings of the church are offensive to Jesus who loves the church and gave his life for her. Andrew Walker goes further in identifying a different spirit that can exist in the church. Reluctantly, it seems, he concedes ‘ within the ecclesia, within the fold of God, we can and do find wolves in sheep’s clothing’(1996:234). We will now look at another area where the church needs to rise to a higher standard, this time in terms of full participation.

10.3 Church as a Two-way Street

Within the Body of Christ, every member is a subject and none is an object. Every member of the Body of Christ is a participating member. However, we need to engage with our critique of the *status quo* so that we see, as an encouraging sign, not them behaving more like us but the other way round. I have heard people exclaim with wonder and joy of a person with Downs Syndrome taking the microphone and speaking more fluently than usual. This is seen as a miraculous event. Be that as it may, we must consider that God may be more interested in the reverse miracle whereby the successful and worldly wise begin to behave as those who have no position to protect or reputation to enhance. A very successful man told me how he had been humbled almost to the point of tears at watching a believer with intellectual impairments worshipping God. Previously he had been rather in the mode of the man in the parable (Luke 18:11-12) who prays ‘I thank you God that I am not like this man’ From his despising superiority came the humility to acknowledge that the impaired person had something to teach and model to him! Now that is a miracle worthy of the name of Christ. Nouwen observes ‘When handicapped [sic] people pray for handicapped [sic] people God comes very near. The simplicity, directness, and intimacy of their prayer often makes me feel like a sceptical bystander (1989:37).

Apart from what they might model to us there is the very real possibility that, like the Holy Fools, they may have ‘iconic’ significance, revealing God’s ways for troubled times. Trying to get them to perform the same roles as the rest of us is to miss the mark, as each has a gift to bring and that gift is unique. In fact the whole concept of ‘them’ and ‘us’ needs to be obliterated as we bring the margins to the centre, thus demolishing the privileged centre. Since we are aiming for rainbow partnerships, the scientific reality of the rainbow can instruct us further. Cultures are accustomed to seeing the rainbow as a range of discrete colours. These range from 4 – 20+. In our culture we teach children that there are 7 colours in the rainbow. However, a rainbow spans a continuous spectrum of colours; the discrete bands are an artefact of human colour vision. Similarly, the excessive foregrounding of disability, ethnicity, etc in our rainbow partnerships is also a product of our worldview. Before the throne of God there will be every tribe and nation along with other diverse groups and the whole reflects the glory of God. We need to let that eschatological vision inform the present where we look for that diversity as the prism through which God can fully reveal God’s glory.

Soelle (1984) and Vanier (1998) stress the importance of seeing the ‘weak’ and ‘poor’ as our teachers highlighting mutuality of both teaching and learning. Valuing and embracing diversity helps align us with the future kingdom of God and demonstrate it here on earth with salvific power. In Volf’s terms all must be ‘embraced’ and this involves making space for others. Since we are not talking in the cross-cultural terms in which Volf speaks (from his Balkan background) we must take ‘culture’ to denote all that makes us see only through the eyes of those like us and fail to acknowledge the existence and legitimacy of those who are ‘other’. A lengthy quote will show us the passion that Volf rightly feels for this endeavour.

When God comes, God brings a whole new world. The Spirit of God breaks through the self-enclosed worlds we inhabit; the Spirit re-creates us and sets us on the road towards becoming what I like to call a ‘catholic personality’, a personal microcosm of the eschatological new creation (Volf 1992a). A catholic personality is a personality enriched by otherness, a personality which is what it is only because multiple others have been reflected in it in a particular way. The distance from my own culture which results in me being born in the Spirit creates a fissure in me through which others can come in. The Spirit unlatches the door of my heart saying: ‘You are not only you; others belong to you too (Volf 1996:51).

This making space for the other is a pre-requisite to developing a ‘catholic personality’ and the development of this type of personality is key in creating a church that is marked by reciprocal exchanges between equals. Once we have opened ourselves to one another then there is real hope of unity and solidarity:- the type of solidarity that Paul implies when he says that when one member suffers all suffer. (1 Cor 12:26).

The theme of solidarity must be a sub-theme of the over-arching theme of self-giving love...To claim the comfort of the crucified while rejecting his way is to advocate not only cheap grace but a deceitful ideology. Within the over-arching theme of self-donation, however, the theme of solidarity must be fully affirmed, for it underlines, rightly the partiality of the divine toward the ‘harrassed and helpless’ (Matthew 9:36)(Volf 1996:24).

So this must be a church marked by mutuality at all levels. The presence of such interdependence is the safeguard against all kinds of patronising and insulting behaviour. The Biblical vision for this type of faith community is seen in Isaiah 58:6-12.

Is this not the fast that I choose: to loose the bonds of wickedness, to undo the thongs of the yoke, to let the oppressed go free?
Is it not to share your bread with the hungry, and bring the homeless poor into your house; when you see the naked to cover him, and not to hide yourself from your own flesh? Then shall your light break forth like the dawn, and your healing shall spring up speedily; your righteousness shall go before you, the glory of the Lord shall be your rearguard.(6-8)

but even here we must guard against an approach that makes one group, the salvation of the other: Jean Vanier has been criticised for leaning in that direction.¹³⁶ This is a win/win situation: God’s virtuous circle. Or as Dorothy Soelle beautifully puts it

It suggests to us the possibility of living a different life. The text does not command ...it suggests an option instead. It leads us towards a richer, more powerful life. It shows us images of human beings who are like Kings: righteousness goes before them, and the glory of the Lord follows behind them. It shows us human beings who are like fountains and like light, normal, ordinary human beings...who have become builders of happiness (157).

Isaiah is not addressing underlings who receive his commands. He is counting on the strong, the rich, who have been slandered and denigrated so often in Christian tradition...

¹³⁶ I was in a small group at a Conference where Vanier was a keynote speaker and two disabled theologians made this criticism.

‘The text...is pure gospel It promises us a life without disdain of others and without disdain of self (1984:158).

For our purposes the pivotal verse is perhaps 7b ‘not to hide yourself from your own flesh, if we take our own flesh to denote our brother and sisters in Christ or even simply all our fellow human beings, made in the image of God, then this should be our main focus and central concern. The passage exhorts us to be freed from our self-preoccupation and be preoccupied with the welfare of the other. ‘ to let the oppressed go free and break every yoke!...to share your food with the hungry, to share your home with the homeless and to clothe the naked.’ Here there is a blurring of the sharp lines that we set up in our individualistic society: what belongs to me and what belongs to you. There is a connectedness so that whatever I have is to be shared with others who it seems belong to me in some existential way. This connection is then seen by the fruit that the giver reaps as a result. ‘Then your light will break out like the dawn and your recovery will speedily spring forth,’ the list entails, righteousness, God’s glory, answered prayer, satisfied desire, guidance and strength. It builds to a crescendo ‘And you will be like a watered garden, And like a spring of water whose waters do not fail’(58:11). Finally out of this water flow is to come a manifest work of restoration.

Perhaps sharing our homes is culturally the most challenging part of this text. As we saw earlier (chapter3 page 61) in the report from Aberdeen University people with intellectual impairments do not experience friendship beyond the church door. As we see the other as part of who we are then this may seem more natural – my home is an extension of who I am and if I open myself then opening my home will seem a natural step. As a community the end result will be that our community becomes like a perpetually watered garden where our own refreshment is also to be found. The complete mutuality of this passage precludes that this should lead to patronising acts of charity. We need to reconceptualise the notion of the weak and the strong. Soelle (1984) and Govig (1989) both recover strengths that exist within ‘weakness’ and John Swinton questions who is the weaker brother? (2001) In speaking of Stephen (his Downs friend) Swinton boldly states,

I always assumed that it was he and others like him who were ‘the least of them’ that Jesus spoke to me about and told me to care for. Suddenly, in the face of his openness and trust, I realise that it is me who is the weak and vulnerable one, afraid to show my emotions, afraid to reveal the strength of

my love for others for fear that it be perceived as weakness. When I am in his arms, I can taste the coming kingdom, and begin to understand what it might be like to live in a society where the emotional barriers that fuel my embarrassment at Stephen's meaningful caress, are torn down by the power of unspoken, unashamedly revealed love. (2001:30)

Nouwen echoes this sentiment, explaining 'Handicapped [sic] people, who have such a limited ability to learn, can let their hearts speak easily and thus reveal a mystical life that for many intelligent people seems unreachable' (1989:49).

Mary Grey sanctions that the church cannot call to repentance unless she too is prepared to commit to building right relation and repenting of all the wrongs done to all marginalised people through the centuries (Grey 1989). Moving on from here we look at some other ways in which the deep work of the Holy Spirit is essential in bringing right relation to the church.

10.4 Making Room for Grace in the Body of Christ

First, the vision of what a church truly is must be reviewed. The Church Growth Movement, as it focussed on numerical growth, as its main measure of success, it will be argued, fell short of a Biblical vision for Church. God is both unitary and multiple: Three persons co-inhering in one God and, as has been stressed throughout this thesis, we humans are made in that selfsame image and God's purpose is to produce variety and diversity in his creation not monotone uniformity. If the church, is to be the peak of that creation it is unlikely that God will be pleased with a church which is no more than a social club; at best 'a holy huddle.'

Homogeneous churches are those in which all the members are from a similar social, ethnic or cultural background. The argument is that since people prefer to associate with people like themselves, creating homogenous churches would make reaching people easier. While that may be an effective way to reach out to people initially, we should not imagine that what we are doing is building church. Indeed, people do like those like themselves and that is a fact and doubtless evidence of fallen nature. From this propensity arise all forms of prejudice: racism, sexism, disablism. ageism etc. Jesus, our role model, could not be said to have been over-enamored of keeping

company with those like himself. He spoke to the Samaritan woman which amazed his disciples. He ate with 'sinners' and was much criticised for it by the religious leaders of his day who preferred their own Pharisaical company.

In my work at *CGS* I often mused just how welcome Jesus must feel in that church as so many people NOT welcome in society at large, found such a warm and genuine embrace in that place. The sense of God's love was tangible. Now there is nothing natural about this and that must be the thrust here. We can build a political party or a sports club without the power of God at work in our fallen nature but we cannot build the Body of Christ in this authentic diverse way without an abundance of the Spirit of God deeply at work transforming our lives. As has been seen, unless we open ourselves to have a 'catholic personality' worked within us we will not be at peace among others who differ so greatly from us. If we take the image of rainbow partnerships – the homogenous principle unit is like saying 'we want our church to be orange so that everyone who loves that colour will feel good here. Unfortunately, those who God has made in any other hue will feel rejected and undervalued. God cannot demonstrate his kingdom through a 'rainbow' of one colour only. It is precisely the fact of the Church being such a motley collection of people that can reveal the power of God if that untidy group can truly love each other from the heart and welcome each other in the plenitude that humanity brings. The challenge is to love one another on account of our God given differences and not despite them. The church is intended to give the world a taste of the coming kingdom. A church that panders to our natural (fallen) proclivities is less likely to afford a taste of heaven than it is a taste of hell!

As we take hold of this 'other-worldly vision of church, we are driven far from our comfort zones, thus we are compelled to invoke the help of the Holy Spirit and cry out in earnest for God to change us. Seeing that the church of God can only be realised in its wholeness, if we all change, is crucial if we are to be motivated to seek the transforming power that the grace of God brings. This is no soft option but arguably it is the only route that can see the glory of God revealed as Jesus being lifted up is what we are promised will lead humanity to be drawn to Christ (John 12:32).

In God's kingdom there is so much diversity that we will need to be constrained by the love of God to cope with it. To humble ourselves to learn from 'the least' will involve what Vanier refers to as 'befriending our broken places'. Far from the social club now where everyone is presenting their best side— now we are unashamedly revealing who we are, warts and all. As the vicar said in a sermon at CGS 'fellowship is based on acceptance of each other's weaknesses' I will conclude this section with a quote from John Swinton's Church for Strangers.

Within the community of Christ, Stephen¹³⁷ can be seen to belong as himself, valuable and worthy *because*, not in spite, of his differences. The segregation and prejudice which is often imposed and sometimes even glorified in by the world, should be actively anathematised both in Word and prophetic action, in order that the true values of the Kingdom can reign in our churches (2001:59).

Finally, we look at the need for a deeper spirituality which has a call to hospitality at the core.

10.5 A Spirituality of Reflection and Hospitality

Developing a catholic personality will help us to embrace a culture of hospitality. As Serene Jones writes

...in terms of our relationship with other persons, our interactions should reflect the same respect for difference by resisting the urge to consume the other instead of opening ourselves to the multiplicity and complexity of 'the neighbour'. In this sense the essence of the human person is always eschatological, therefore it is always coming into being through the acts of relating that constitute personhood (Jones 1993:134).

Hospitality is more than offering refreshments, although it may include that. Reynolds opens the topic up wide,

The basic question of human existence is whether there is welcome at the heart of things. Will I be received or embraced? Is there a voice behind all other voices that says 'you are precious, and I will be there for you' Our heart's deepest impulse hankers after connection with a trustworthy creation – a purposeful macro-context that bathes our lives in meaning and value, thus cultivating a sense of being at home (Reynolds 2008:51).

¹³⁷ Stephen is his Downs friend.

At its core, hospitality is about a sense of being valued by others and psychologists know that the feeling of being valued by others is the only way in which a wholesome self-regard can be established

People with intellectual disabilities thrive on relationships and if we are to be fully orbbed persons then we too will value friendship as a vital conduit of God's love. In common with all humanity we are relational beings and this awareness can result in dignity and respect as we begin to grasp that wholeness is a corporate reality in the Body of Christ and not an individual one. We are all a mix of strength and weakness (In Jung's terms we have a shadow side too) and the presence of disabled people confronts us starkly with the reality that human beings are vulnerable and precarious. In such a community the eucharist is ideal as it is a meal that all in God's household are welcome to receive. As Patsy says in the focus group discussion 'communion is a great leveller. We come similarly – nothing in my hand I bring.' A heart-centred spirituality is also a great leveller.

As we move away from a rational, over-intellectual faith towards the childlike faith that Jesus commends to us, we will find ourselves travelling along the same path as those who were left behind in an excessively logo-centric spirituality. We will also find that we are moving at a slower pace. As we slow down we necessarily restore the Sabbath rest to our own lives which are inclined to be manic and driven, thus protecting our sanity.

10.6 Summary

In this chapter I have sought to provide a framework for an emancipatory model of church that can foster full inclusion of all persons, including those with intellectual impairments. First we looked at the need to see the *status quo* as a deficit position rather than as a desirable condition. In this context we saw the role of the Holy Fool as being iconic revealing new and better ways of being. A vision of God's creation as diverse and varied was also underscored. From here a fresh look was taken at the nature of the church on earth and the need to confront a (frequent) gulf between the

ideal/eschatological and the realised experience of church for many was acknowledged . I then examined what the church would look like as a ‘two-way street’ with every member being a full participating part of the whole. The need to value diversity, to humble ourselves and to cooperate with the Holy Spirit in creating in us a ‘catholic personality’ was foregrounded. This in turn, pointed to a need to step out of our comfort zones in such a way that the grace of God would be welcomed in abundant supply as a necessary condition for this multi-coloured population to flourish. Finally we reflected on the hospitality that marked the early church and the need to move towards a more childlike, heart-centred spirituality that would be accessible to all. The promise was also noted that as we humbled ourselves to walk alongside others, possibly at a slower pace, that the Sabbath rest would be appropriated by those who desperately need it in a fast moving, achievement-driven society.

11. CONCLUSIONS AND RECOMMENDATIONS

In this conclusion I first summarise what the thesis has shown part by part, then I address the church and then the Disability Movement. After this I make some practical recommendations for the church which draw principally from the fieldwork., although also resonating sometimes with the literature review.

In *Part One* of the thesis, I have shown how historically disabled people have been excluded both in the general society and in the church. More recent attempts to improve the situation for disabled people both in the society at large and in the institutional church have also been noted, and a trend towards full inclusion is now seen to be uppermost. The popular claims of the Disability Movement regarding the church have also been evaluated.

In *Part Two* I have explored some current day practice in the Evangelical church. Through my findings I argue that there is some good practice occurring despite a marked lack of any concrete theorisation of disability. While there is evidence of an underlying medical model of disability, the overarching perspective is implicitly informed by the theological reflexes that result from a commitment to the Gospel message, embodied in the communities of practice. Consequently a tension arises between an outdated view of disability (and the lack of a constructive discourse with which to discuss disability issues) and clear evidence of an emancipatory Gospel engagement with believers with intellectual impairments. This calls for an explicit theological formulation to account for the practical theory which is in operation in both field work settings.

Thus in *Part Three* I formulate an emancipatory model of church that can foster full inclusion of people with intellectual impairments drawing out the theological rationale of the good practice that has been observed.

11.1 Implications for full inclusion in the Body of Christ

To sum up, I note that disability has been under-theorised in the church and this is problematic as a desire to ‘help’ disabled people is not necessarily a step in the right direction as it does not challenge the prevailing medical model of disability which is so out of favour with the Disability Movement. Whether we take a social modellist view, a minority culture view, or a social-relational view, disability needs to be theorised as a civil rights issue and inclusion conceptualised along lines that challenge the cult of normalcy. In this way, the end result is likely to be much more beneficial to the full flourishing of disabled people. Furthermore, inclusion of all persons including those with impairments needs to be seen as a requirement of the Gospel and not just some culturally popular theme in the Western world of the twenty-first century. We have noted some of the dangers of people with a background in teaching young children with special needs, getting involved in ministry to adults with intellectual impairments, as it is such an easy step to start treating them inappropriately as minors. It has also been stated that the best antidote to patronising behaviour is a strong respect for and love of human beings as made in the divine image together with an awareness of the Pauline expectation that every member of the Body has something to bring to the whole. This latter view reveals the church to be deficient when people with disabilities are not able to be fully participating members of the body of Christ. It has also been noted that a medical model of disability (a deficit position) together with a doctrine of humanity strongly influenced by the Fall, can make a very negative combination, whereas a relational or minority culture view of disability coupled with a strong attachment to the *imago Dei* can produce a very life-affirming framework.

This leads to the conclusion that the church needs to be reconceptualised in order for full inclusion to occur. Nothing less than a radical overhaul of the church will suffice where the centre is deconstructed and the margins brought to the core to inform the centre thereby demolishing it. For people with intellectual disabilities to be fully included in church life, the life of the church must be put under the spotlight in an ethnographic way making the familiar strange so that church can be conceived of in totally new ways appropriate to the full inclusion of ‘the lost tribe’. A call to

repentance is also required for the church cannot call to conversion until she too is willing to model that same repentance, regarding treatment of marginal groups, and embody radical transformation. As Grey lucidly expounds

Christ lived so utterly and completely in the reality of exchanged life and love, or just relating, that his death, far from causing the flow to cease, unleashed a flood of transforming power into history... To be authentically the 'Body of Christ' the Church must be empowered by the same dynamic. (1999:172)

and this must entail denouncing injustice and elitism in ecclesial structures.

Unity must be sought through humility and Phillipians 2: 1-11 must be a key concept: that as Jesus humbled himself to come down to our level as human beings so we as his followers must not balk at the prospect of unsettling our comfort and ease by embracing those that our society tends to regard as 'lower' than ourselves. Alluding to an example from the fieldwork, I would suggest that if someone needs to be able to pray in words and then move off into train noises, or whatever the harmless, unorthodox behaviour may be, then we may need to humble ourselves to welcome this as God hears and values the heart. Further, in keeping with a vision of developing a catholic personality that values otherness and difference, we must allow ourselves to be changed and challenged.

This vision of an inclusive church is only possible where the church is not simply a rational unit but a Spirit-filled and Spirit-led organism. As we yield to the mysterious and unpredictable workings of the Holy Spirit, a level playing field opens up where we are all out of our depth and those with lesser intellect are likely to be less hindered in their obedience to the promptings of the Holy Spirit. In this environment we will have need of what Yong terms 'a pneumatological imagination' to grasp what the Spirit of God is saying to his church.

This understanding of the work of the Holy Spirit needs a reality check in a therapeutic culture. Those of us who have lapped up prayer ministry over the past decades are too easily accustomed to a move of the Holy Spirit being a warm and

comforting experience¹³⁸. Paul on the road to Damascus was not assailed by any such cosy encounter. He was struck blind and rendered totally dependent on those around him— perhaps an indication that the way he was used to seeing things and coping with life was about to change irreversibly. As Jenny Weiss Block warns us ‘grace rarely comes in the form of a gentle invitation to change. More often than not it appears in some form as an assault.’ (2002:92)

There are no second class believers, in the Body of Christ: we are all called to be on the front line. We may not be called literally to die for our faith but surely we must be willing to ‘die a thousand deaths’ in terms of discomfort and embarrassment, as Brad Jersak wonderfully models for us.

We are accustomed to majority rule in society and sadly also in the church yet the parable of the lost sheep tells us that the Shepherd leaves the 99 and goes after the one and that is the principle of the kingdom, regard for the lesser and the most vulnerable not respect for the interests and preferences of the majority. The call to servanthood is not just for a few and is central to the task of right relation. For as Grey reminds us ‘If broken mutuality and broken relation underlie all injustices, it is there that the redemptive task must begin. (Grey1999:87)

The church must demonstrate the reality of a level playing field for all. How pertinent that those with intellect ‘lose their faith’ in times of crisis because God’s ways do not square with what can be grasped with the human intellect. Arguably we are all in the same position as none can fully fathom God, and maybe people with intellectual impairments have less illusion about their capacity to grasp the realities of an Almighty God.

Moreover, we need an ever deepening awareness of the conviction of St Paul that it is the ‘weakest’ members of the Body of Christ, which are indispensable. Every member needs and is needed, every member gives and receives. I will now draw some important conclusions regarding the Disability Movement and then return to address the church once more.

¹³⁸ Even the experience of having a body massage is expected to be pleasurable yet when the masseuse comes across a very tense and knotted area the massage will be painful and uncomfortable. Perhaps this is a useful illustration of Holy Spirit ministry in our broken and dysfunctional lives.

11.2 Addressing the Disability Movement

Turning to face the Disability Movement I conclude that their popular claims that

- i) the church and Judaeo-Christian thinking is oppressive to disabled people and
- ii) that it is Judaeo-Christian thought that is the source of disability being negatively constructed do not stand up to close examination.

Further, it is necessary to point out that while passages from the Bible have been used as ‘clobber texts’, recent theologising about disability has tended to be conducted within a liberation theology context, so that clerics such as Jane Wallman and Hannah Lewis in their doctoral work have explored a liberation theology for Blind and Deaf people, respectively. Popular criticism of the church’s theology from the Disability Movement does not seem to be aware of this development and while this thesis is not conducted within that framework there is an acknowledgement here that there are yet other resources for liberation within the Biblical worldview and that the emancipation of oppressed peoples is a *bona fide* tenet of Biblical Christianity.

11.3 Addressing the Church

Addressing the church now, what has just been stated certainly raises no cause for complacency. The issue of social justice and emancipation of the ‘poor’ has been sidelined in Evangelical Christianity which has tended to accommodate itself to the comfort of the *status quo*. As followers of Jesus it behoves us to attend to his concerns and to gauge our faithfulness by the degree to which we unsettle the *status quo* and seek justice for those who are socially oppressed.

Disablist theologians have also done much to shift the way in which some of the healing narratives have been interpreted, or misinterpreted. Aside from liberation theology, others have conceptualised Jesus as a disabled God and certainly as a vulnerable and abused saviour as he was broken on the cross and still bears those marks. This causes us to see God not as a distant deity who causes terrible suffering on his creatures for undisclosed purposes, but as one who identifies with us in our sorrows and bears the grief with us. Furthermore the experience of suffering can

promote the development of deep compassion for others. Nevertheless, the church must guard against any glorification of suffering as that can act to perpetuate pain and injustice rather than to abolish it.

Now, to those churches who take a strong position on the healing work of the Holy Spirit in the church today, there is a challenge here not to be reductionist in their understanding of that work, for while the Spirit of God may sometimes bring physical healing to those who desire it, the Holy Spirit always brings life and transformation whether impaired or ‘non-disabled’/‘temporarily able-bodied’ people are the recipients. Brad Jersak’s testimony of the Holy Spirit at work in people with learning disabilities is a sobering corrective to the unexamined assumption (based on an uncritical acceptance of the cult of normalcy) that God always wants to bring physical healing. This view lurks in many charismatic churches and undoubtedly, can cause oppression to people with impairments of all kinds.

Finally, it is critical that there is equality between believers whether they have impairments or not, so that respect is given to what each believes God is doing in their lives. This is vital as so much that argues against us accepting our situation leads (as with Job’s comforters and their effect on Job) to bitterness of soul and an inability to yield to God in his loving purposes. In short, the myopic view of other believers (among them some preachers) can spark an open rebellion against God, which is not the sort of fruit that the church is called to bear.

11.4 Implications for further research

These case studies were conducted in the Home Counties and in Evangelical congregations. It would be useful for some research to be conducted in a more diverse setting. Theologian Frances Young remarks that her son, Arthur, was always very well accepted when she took him with her when preaching in Black churches in the Birmingham area. It could be that Black culture is less controlling and comfortable with a higher level of unsolicited vocal contribution. Black majority Pentecostal churches may reveal interesting findings.

Further it would be helpful for more parents of children with learning disabilities to be interviewed as the one case I was able to explore confirmed what I had read in the literature that having a disabled child in our 'normalising' society leads to much personal suffering.

11.5 Limitations of the Research

Two case studies were useful for a contrastive analysis, however, these studies would undoubtedly have been richer had it been possible to widen the net to research more sites where ministry among people with intellectual impairments had been established. Nevertheless, as already observed, (Yin 2009:61) two case studies are considered to be better than one. Other types of data analysis had been envisaged at the start including some life histories but these had to be dropped for ethical reasons. It could be argued that the fact that no people with learning disabilities were interviewed is a weakness of the study but the issue was so fraught with difficulty that it was not attempted – again largely on account of ethical concerns, not least gaining consent. The study may have been more robust had triangulation been carried out. Many more focus groups could have been included to triangulate with interviews and participant observation. In a bigger study this would have been possible as there would have been more leaders and helpers to form the focus groups. However, constraints of time and cost, not to mention energy, are always a reality in empirical research, and to have extended the study considerably would have run into such difficulties and may have been at the expense of depth.

One matter that needs further consideration is to revisit some of the ethical issues that have surrounded and shaped my research progress. When I started my research in 2004, King's College London did not mandate the need for ethical clearance through the University. Indeed, King's College did not set up a research ethics centre until the following year. For a variety of reasons (changes in supervisors, ill health and family bereavements) my work continued without my having gone through the formal process of obtaining ethical clearance. This is extremely regrettable and constitutes an omission in the research trajectory. However, this does not mean that ethical issues were not in the front of my mind.

All research has an ethical component and this was very much the case with my work in such a vulnerable and sensitive area. I regularly discussed issues of access, informed consent, on-going issues of particular location, the need to conceal sites and individuals with my supervisors. For example, I was concerned about issues of participation and positionality; a matter that I have discussed elsewhere (see 4.8 p 114) In many ways, it might be argued that obtaining ethical clearance is only the first point in the proceedings. ‘Ethical practice is an ongoing interaction of values in shifting contexts and relationships rather than something delivered by a signed consent form or adherence to a static set of principles’ (Hughes, 2005: 231). Ethical issues are continuous – through analysis, writing up and in any future publications.

11.6 Recommendations

I now offer eight recommendations, two of which relate to people with intellectual impairments and six of which relate to the church.

1. I have noted the limitations of a rhetoric of rights and seen that friendship is, in fact, the ground for participation and full inclusion. I therefore recommend prioritising friendship over caring and help. Incorporating people into all appropriate church groups and inviting people with learning disabilities into church members’ homes as guests.

2. From the empirical work I noted the danger of regarding people with learning disabilities as children, exacerbated sometimes by using helpers with training in teaching children. The members need to be seen as adults at all times which will include preparing them for real life challenges alongside other church members – e.g. marriage preparation, bereavement courses etc. Also encouraging them to use their gifts in the Body of Christ, including ministering in their own meetings and where possible in the wider church.

3. The entire congregation needs to be reorientated to a spirituality of both the heart and the head so that trite answers are not given but congregants are able to respond with compassion to one another: ‘weep with those who weep’(Romans 12:15)

4. Disability issues need to be theologically foregrounded in the congregation so that there is consciousness raising of both disablist hermeneutics and ecclesiology.

5 A strong Trinitarian theology needs to be in place as the basis for embracing all persons in the Body of Christ.

6 A theology of suffering also needs to be recovered in order to de-stigmatise suffering.

7 The church services need to be linguistically accessible and non-verbal means of communication should also be used.

8 The church must be prepared to dialogue with the secular Disability Movement in order to find best practice together.

Summary of recommendations:

With regard to people with learning disabilities:

- ◆ Prioritise building genuine friendship groups
- ◆ Always treat them as full adults

With regard to the church

- ◆ Raise awareness of disablist hermeneutics and ecclesiology.
- ◆ Develop a spirituality of the heart and the head.
- ◆ Build a strong Trinitarian theology.
- ◆ De-stigmatise suffering through teaching its normativity in human life.
- ◆ Make services linguistically accessible also using the visual and tactile.
- ◆ Seek to dialogue with the secular Disability Movement to enrich the debate.

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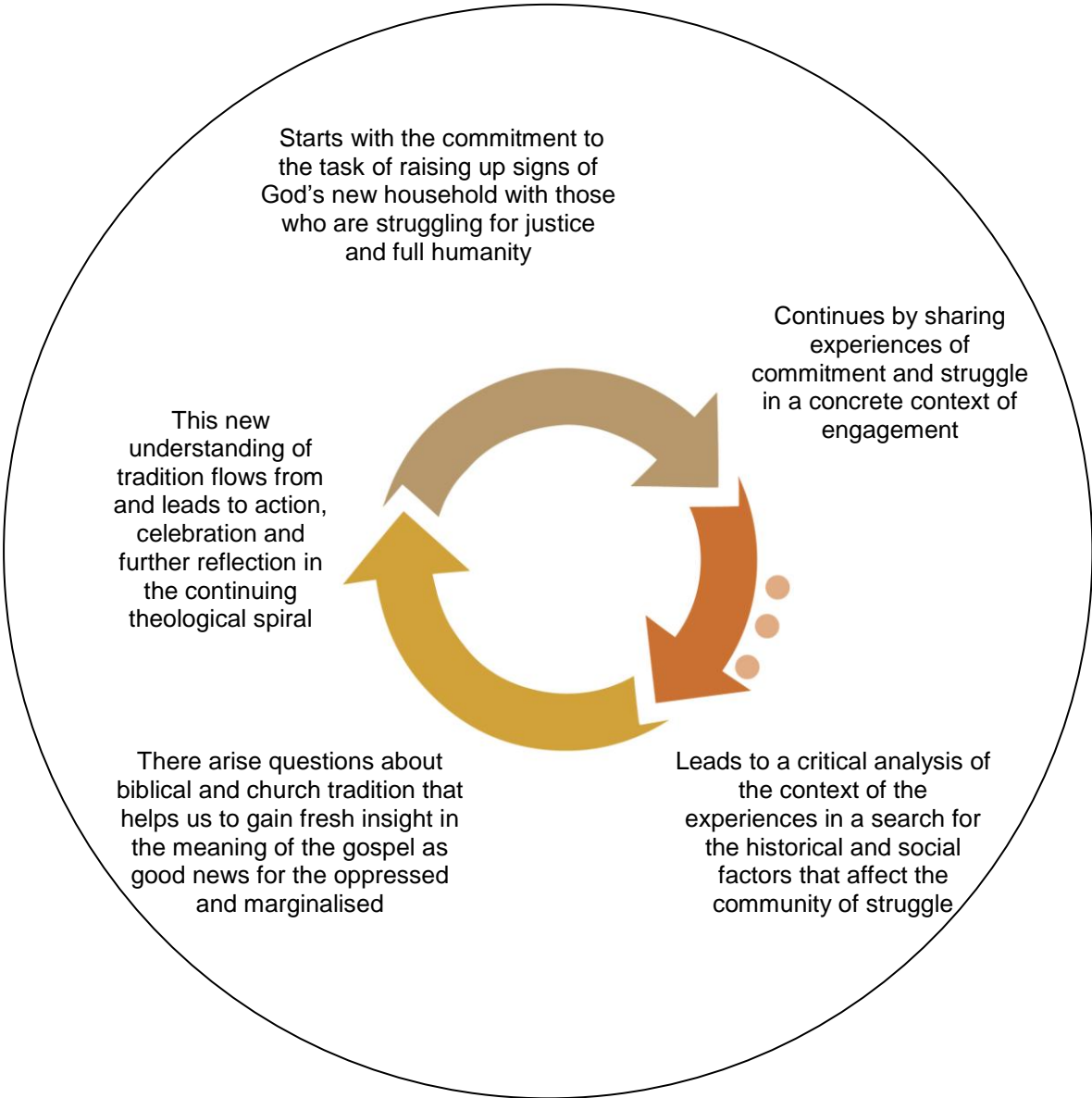
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APPENDICES

Appendix 1 – Theological spiral

THE THEOLOGICAL SPIRAL

A continuing spiral of engagement and reflection



Appendix 2a Schedule for interview with carers and parents.

How long has _____ been coming to this group?

Does s/he enjoy coming?

IF so why do you think that is? IF not, why not?

IS there anything you believe they would like done differently?

Do you belong to a church?

IF so, do you both feel welcome in that church?

What other church involvement has s/he had? How does that compare?

Can you tell me a painful experience you have had as a parent of a disabled child, or perhaps an encouraging one, or both?

I am going to read you four 'disability is' statements (like the old love is: idea) and then I will read them again one at a time and ask you to comment on which is closest to your view and which is farthest from it.

Disability is: 1 A sign of God's goodness and blessing.

2 A social construct (explain using example of Groce's work with the Deaf Community in Martha's Vineyard)

3 The result of some deficiency

4 A consequence of sin.

Is there anything else you would like to say?

Appendix 2b Schedule for interviews with leaders/helpers

1. How did you first get involved with people with learning disabilities or disabled people more generally?
2. What connection do you make between the subject of disability and Christian faith?
3. What in your background, in your opinion, helps equip you for this type of work?
4. Do you see anything in your background that could hinder this type of ministry?
5. Can you recall an encouraging and/or a discouraging incident in your work with disabled people?
6. What do you hope they get from the group?
7. What is your vision for the church in relation to people with impairments?
8. I am going to give you 4 cards which each start with the statement disability is: I will give you time to read them through and then I will ask you to comment on each one indicating which one best fits your view of disability and which one least suits your perspective.

Disability is: **A sign of God's goodness and blessing**

A social construct (illustrate, if unclear, with Groce's account of Martha's vineyard and the population learning to sign to accommodate the high level of Deaf people)

A result of some deficiency

A consequence of sin

9. Is there anything else you would like to add?

Appendix 2c Initial questions/probes for focus group

- ◆ *How can we best meet the spiritual needs of people with learning disabilities?*
- ◆ *How can we gauge their spirituality?*
- ◆ *What can we learn from the work of Jean Vanier and the L'Arche communities?*
- ◆ *What experience has anyone had that they would like to share of encouraging the spiritual development of a person with learning disabilities?*

Appendix 2d Indicative account of open coding

Emergent themes: **Models of disability** **sameness and difference**

Personhood

adult/child mode

Theology

inclusion

Where a text can be coded in more than one way the first and last word of the extract is highlighted in the second colour.

INTERVIEW WITH MOTHER/CARER FROM REACH OUT

F So Eileen how long has Colin been coming to Reach Out?

E At least 5 years

F Does he enjoy coming?

E Yes

F What does he enjoy about it?

E He likes being with people like himself so he can understand what's happening. He likes the atmosphere, with it being so friendly. He can join in all the activities and he certainly likes the food at the end.

F o.k. that's nice. Do you belong to a church?

E Yes

F And how does he feel in church?

E He's not comfortable at all. He won't come now. He used to come as a child and as a young adult but now he's 25 and he really will not come.

F Has he had any other church experience?

E Occasionally at a Methodist church and it's a little bit better but he is the only person with learning disabilities, so I can tell he doesn't feel he fits in. There's no-one he can relate to.

F Is there anything that he'd enjoy that he doesn't get in a church kind of setting?

E He's been to Causeway Prospects and Spring Harvest and he is absolutely fine but in the ordinary church he doesn't understand what's happening.

People might speak to him but they might be quite unkind to him. Comments that wouldn't bother me seem to upset him.

F Can you think of anything that has upset him?

E Well, it sounds quite trivial but one day they were singing Happy Birthday to everyone and they knew it was his birthday but for some reason they didn't do it for him. Maybe he is too old now but not until we said did they include him. But I think that was the last straw for him.

F Yes, that doesn't sound silly to me at all. I think this birthday thing is very important.

E At church he couldn't understand what was happening so he sat with the little ones but as they get older it really isn't appropriate. So he didn't feel included.

F Didn't feel included as an adult.

Do you mind me asking you how you felt when he was born and you realised he had learning disabilities? Don't answer this if you don't want to.

E You go through various stages. I got a lot of help from the Downs Syndrome Association. I found the best thing was to be positive and realise that he could do lots of things. Going into a church isn't so bad at first because they are still a child. The gap gets bigger and now his understanding has reached a peak. He still enjoys children's television.

F So do I! (both laugh)

E In a church situation, you can't expect to sit in a meeting when they don't understand. It's a bit pointless.

F It's more than pointless, it's alienating.

E All children rebel and that happens with people with learning disabilities. He is very aware that he is different and hates people staring at him and treating him as different but he doesn't like being ignored. One or two people in the church are very nice to him. Social events are better and I can take him to meals. I don't think it is just our church.

F I doubt it. Did you get a lot of help from your Christian friends?

E Well I wanted to be treated just like any other mum.

F Of course.

E I have two older girls. So I knew what it was like to be a mum. The things people say they don't mean and don't understand but sometimes unexpected things hit you and upset you a bit. It is different now he is older - you've gone through that stage. Someone gave me a poem about how he was like a

little angel and how God had specially chosen me to have him as an honour and I didn't like that.

F No , it means they aren't human. I wonder what they would have said if you had said you wanted to pray for them to have this special blessing too!

E Yes, I think it says more about them than me so I tried to close my ears to lots of things. My mother hurt me the most. Colin was in intensive care at one time and very ill and she said maybe it would be better if he died and I said I couldn't take that and in fact I prayed that he wouldn't die. But she was of that generation when they just put them away in institutions. You can't do that now as they have all been closed down.

F Yes, there are still some very odd ideas around about disability and I'm going to read out 4 statements about disability and ask you to comment on each of them. At the end I'll ask you to say which one is closest to your position and which is farthest from it. I'll read them through first and then come back to each one.

No 1. Disability is a sign of God's goodness and blessing. No. 2 Disability is a social construct - that means that if society adjusted better then there wouldn't be any disability. No. 3 Disability is the result of some deficiency and No 4 disability is the consequence of sin.

So can you comment on each one. No1 Disability is a sign of God's goodness and blessing. I will just say that this was said by a disabled person as one person really reacted to this one.

E I think it can bring out goodness and blessing. Disability is just a fact isn't it? I can't believe that God intends people to be born in that way - to be lacking - but as we accept it, our helping them, our care and love brings out God's goodness. And when the disabled person feels this love and feels happy it brings out a lot in them. They will say that God is good because of how loved they feel. It reminds me of something I heard Pope John Paul say. He was washing people's feet. I think it is once a year that he washes the feet of the poor people and disabled people. Someone asked him why people were born disabled and he didn't really answer that, but he did say that having disabled people to care for brings out a lot in mankind that we wouldn't see otherwise.

F That's very interesting and I agree with him but I was at a conference and Jean Vanier was saying some similar things and some disabled people really objected and they said 'Don't make us your (non-disabled people) salvation.' I really heard them say that so I thought I must be careful not to take it too far and give that impression.

E I haven't heard that and Colin wouldn't have the understanding to see that.

F No, these weren't people with learning disabilities. One was blind and I think the other may have MS or Motor Neuron but they are academics. Let's move on to no 2. Disability is a social construct.

- E You could say that about all sorts of people. Children in school who don't fit in. We are all supposed to be in a certain way.
- F So society creates outsiders, then.
- E **If we were with people with learning disabilities all the time and we just accepted them then it would be different, yes.**
- F No 3 Disability is the result of some deficiency.
- E I don't understand deficiency - in who, us?
- F No it means something inadequate, lacking.
- E **That's true isn't it? If you have a lower IQ, it is a deficiency.**
- F No 4 Disability is a consequence of sin.
- E I don't know, I wouldn't like to think that but I don't really know.
- F Did anyone try to tell you that when Colin was born?
- E No, I was upset by a Christian group who came to talk to us in the army. They used the word retard, I think it's American.
- F Yes, it is.
- E It is a term of abuse and really upsets me.
- F We're not allowed to use those sorts of terms over here now but in America mental retardation is still considered a correct term. It almost means reject - and for you it is your son!
- E Have you been to Gateway Club - really good things happen there. There is acceptance. Colin's girlfriend at the moment is a lovely young lady in a wheelchair and he doesn't seem to notice. They are so accepting and they just see the person.
- F So which statement is closest to your view then?
- E **No 2 the social construct.**
- F And which is the farthest?
- E no 4 I think as it means we don't have to bother - they have no value and are not part of God's equation.
- F Thank you very much. Is there anything else you'd like to say?
- E No, I don't think so.

Appendix 3 Research settings in greater detail

In this chapter I give a little more detail of the two sites so as to create a sense of what the two ministries felt like. I include here two important sections on the origins of the ministry to people with learning disabilities in each place. The tone of this section is more personal as I am attempting to reveal some important aspects of the ethos at these places.

Church of the Good Shepherd

Origins of a ministry for people with learning disabilities

Later when I interviewed the Kingsway leader, Greg, I learned of the origin of this ministry. He shared some photos with me of the three first people with learning disabilities who came to the church. He said it was in the late 1980's when he had been church warden that a man with learning disabilities had turned up at the church one week. He was a very friendly man and he had got talking to Greg and then invited him back to his home (institutional) for coffee. Greg being open and friendly decided to take him up on his offer. Once at that home (called Kingsway) he was introduced to others. Eventually three of them started to come to the church regularly (2 of them are still there, the original man having died about 8 years before). One Sunday when the vicar was away, Greg, as church warden, was greeting people at the door when an elderly lady who was a member of the PCC came up to him and said she had been thinking that if the church had house groups for everyone else that they should have a similar group for these people. Such an idea had not occurred to him but he took it seriously and decided they should put the idea to the people who lived at Kingsway House - there being about eight of them at the time. Greg invited the elderly lady to come with him to approach the warden of the home who then arranged for them to speak with the residents about the proposal. It was warmly received and thus the Kingsway group was born. Greg also extended his own awareness of people with learning disabilities when this same man who was the catalyst at CGS, had a serious road accident and after a prolonged period in hospital where his healing was very slow, was transferred to a place, adjacent to the hospital,

that was still functioning as an institution for people with learning disabilities. Before the Care in the Community Act he had lived there so he was now able to meet up with some old friends who Greg referred to as being more impaired than he was. Characteristically, Greg was quick to get involved and visited every Sunday afternoon, sharing Christmas lunch with them on one occasion. He met a lot of this man's friends and became acquainted with the institutional side of life for people with learning disabilities as it was at that time.

Another important strand in the development of a ministry to people with learning disabilities at GCS was the arrival of a retired Canon who had become a type of self-appointed 'Chaplain' to the local branch of Mencap. Together with Mencap and the blessing of the vicar, this Canon put on a special Christmas carol service at the church each year and in order to do this he enlisted the support of the youth group. At this time Greg was the Youth Group Leader and so he first got involved in that capacity, enlisting his youth group to provide a number of key services for the carol service to function well. At the time I was doing research the Carol Service had been owned by the whole congregation and Greg took the view that without that level of commitment it would not be possible to run it year in and year out.

At first, I made a chart of the seating plan and attempted to log where the People with learning disabilities sat and who sat near them and interacted with them. After some months I gave up on this¹³⁹ as the layout of the chairs was only generally the same each week and not set out exactly the same. I also noted a fixed pattern which was that the members of the Kingsway group sat, as a Youth Club might, together in a big block in the central aisle 2 or 3 rows deep. A number of carers and other church members sat with them. Greg explained that a lot of them had poor hearing or eyesight and for that reason needed to be to the front of the church. Another woman who came from an institutional home with a friend sat by a pillar each week and it was noticeable that often there were spaces around them. Later on the friend stopped coming and the original woman began to sit with the Kingsway group. She seemed to take an interest in another older woman who aside from age probably had nothing in

¹³⁹ I was able to discern some important things from the set of seating plans that I made over the first 6 months, some of which I will refer to in the discussion section.

common with her. The young Downs man who I had noticed sitting alone on my first visit continued to sit apart from the others thus confirming a sense that he did not feel excluded but merely liked his space. He would arrive and greet everyone warmly and then move off to a place usually at the end of a row.¹⁴⁰ Another reason why I stopped doing the seating plan was that I was dependent on being told who had a learning disability if they were not part of the group I knew. On one occasion Lisa came up and pointed out that among a group of children who were doing drama and teaching a song to the congregation there was a child with learning disabilities who had been included in the task of teaching the congregation.

One of the Church Wardens regularly talked to me and enquired about my work. If members of the congregation asked me about my work they were generally able to give me more information¹⁴¹ again confirming a view that the congregation as a whole were interested in this group and even others with learning disabilities who were not part of the Kingsway group.

The first Sunday of the month was communion and I planned to observe the interaction during the peace of the Lord. David Potter had noted some problems of people with learning disabilities hugging and kissing strangers which was not well met in our culture. I was wondering if this possibility might deter the congregation from engaging with them. I was also taking the view that it is not normally permissible to kiss strangers in British society and while keeping half an eye on the Kingsway group I began to engage with the people sitting around me. The young man in front of me (who seemed to be a regular member of the congregation and unknown to me¹⁴²) took my hand and then lunged forward, invading my personal space and kissed me on the cheek. Such irony as that was the sort of behaviour I was expecting from 'them' and I was certainly taken aback. At this point I thought it would be easier to video the interaction during 'the peace' but later ruled it out as it

¹⁴⁰ I later learnt that this young man was a server at communion in the church.

¹⁴¹ One morning (April 2006) a woman sitting next to my husband asked him if he was a visitor. He said he was with me and mentioned my work. She quickly pointed out a woman who was not part of the Kingsway group and who attended the earlier service who had learning disabilities and she knew her by name.

¹⁴² I never got a chance to ask anyone about this man It is of course, possible that he did have learning disabilities but I have no reason to assume so.

would be highly conspicuous. It was therefore decided that sitting nearer to the group would enable me to observe the interaction naturally. The difficulty with this was that while wanting to observe fully, the people around me also expected me to participate. I found the two demands difficult and on one occasion cold-shouldered the people behind me in order to move into the area with the Kingsway group and observe and participate with them only. This must have seemed very strange but felt unavoidable. I hoped they might notice my notebook and make some educated guesses about what I was doing and therefore excuse my behaviour. On other occasions I noticed some of the people with learning disabilities who were not part of the Kingsway group move forward to greet people there during 'the peace' Greg told me that they used to do 'the peace' in the Tuesday group but as numbers grew it took 20 minutes or more and it was critical for no-one to be left out. It was therefore dropped for pragmatic reasons despite being popular.

The Kingsway group met in a room for coffee which had a more functional feel about it than the other room where the meetings were held. However the friendliness of the people there offset the sense of coldness exacerbated by large expanses of glass windows. Biscuits were served with the hot drinks and some of these which were at the cheaper end of the market were popular with them as they are with some school children. I also noticed that they were being asked if they had put their money in the pot thus giving me the false impression that they were expected to pay for the refreshments. Later, however, when it was reported that the church had raised enough money for 16 water filters for Africa and that their group had probably raised enough for two, I realised that this was what the money in the pot was for: they had been fundraising along with every other group in the church.

On my first visit a young man with Downs opened in prayer and welcomed me as a visitor making some comments about me. Later he insisted that they prayed for me. Greg put his hand on his knee firmly and said 'no'.¹⁴³ However, when he launched into prayer he did indeed pray for me and then turned to the group and in a little

¹⁴³ I had read that people with Downs could get a little obsessive about people and I wondered if Greg was concerned that he might get a bit obsessive about me as a visitor and was keen to nip it in the bud.

sermonette told them they were to be happy for me. On one occasion Barry jumped up and made the sign of the cross and started to give the blessing, as George used to do before he was ill and could no longer come. Greg had just given a closing blessing so it was surplus to requirement but it was allowed. One or two others in the group were also keen to take initiative in prayer. One of the older members who had Downs Syndrome regularly gave the final blessing at the end. Members also frequently requested choruses and were often asked to say why they liked that particular one. The atmosphere in the group was remarkable as there was a tangible sense of love and acceptance of each as an individual. The singing was hearty if painfully out-of-tune. (a point alluded to by two of the helpers too in interview). This fact was borne home to me when I returned to the group after a 12-month break as I was struck then by how gustily they sang whether they could sing in tune or not, and the majority could not. The songs were those which would have been familiar to them from school days. Initially, I got the impression that they could all read. Later I noticed them needing help in finding the numbers; so if they were singing the words they must have learnt them by rote at some point in the past. Certainly they knew the traditional version of The Lord's Prayer by rote. 'All things bright and beautiful'¹⁴⁴ seemed a firm favourite, as was 'Jerusalem'. After this time of singing, the older lady – Doreen - who had been playing the piano and who had a very gentle and loving manner, led some Bible teaching. Sometimes she held up a picture to introduce her topic and then she gave out handouts which sometimes had sections in capital letters which indicated that they were to be read aloud together. They included pictures as well as words from the Bible passage under review. The emphasis on the visual alongside words was very intentional and something that Greg mentioned when I interviewed him at the end. The teaching was often a simplified version of what had been taught in church.¹⁴⁵ Although simplified for this group the tone was never patronising nor simplistic. She regularly asked comprehension questions and concept questions to ensure that the teaching was interactive and not just 'talk and chalk'. She

¹⁴⁴ What was lovely here was that unlike the society at large they did not seem to favour things or indeed people who were 'bright and beautiful'. I noted a genuine love and acceptance of the things that the world usually casts off. On one occasion Betty had her 75th birthday. One young man with Downs came over to her, kissed her on the lips and told her that he loved her. Another woman came over and hugged her too. This woman was frail, with wispy grey hair and no teeth. Their love for her was profound and genuine.

¹⁴⁵ The Kingsway group was formed from as many as 6 different churches in the area so the teaching was not tied to the sermons in any particular church.

encouraged them to think for themselves and not just parrot back something that had been said. She was supportive when they ventured out to reply to her questions and seemed aware of the dangers of 'right answerism' (as it is termed in education): a practice of basically requiring people to read what is in one's own mind and provide the 'right' answer rather than genuinely exploring the question. She exuded a genuine love and respect for the group. Also I was present on one occasion when, over coffee, one of the group came and talked to Doreen about what they had been reading in the Bible. She was very encouraging of his attempt to read the Bible alone. Greg was particularly keen for them to cover a topic that had been done in church which took the view that we are not so much just sinners as saints who sin. He felt this was a very affirming view and therefore good and upbuilding for the Kingsway group.

On one occasion while Doreen was teaching, Greg thought that someone wanted to speak. He was right and pointed it out to Doreen who realised that she had found the reference that had been mentioned earlier. The evening usually concluded with the older man with Downs, George, giving the blessing, which he did very confidently as if he had been a priest for 20 years or more. The meeting would end at 9.00 prompt when lifts home began.¹⁴⁶

Riverside Church

Origins of a ministry for people with learning disabilities

There was also a ministry for/with people with learning disabilities (Reach Out) hosted at the church once a month that was part of a broader programme of social concern for the community which was the special responsibility of the Deacon for Social Concern. When I first met this deacon he told me the origins of this ministry and also reiterated this important information at a focus group which I was recording. Many years back there had been a big inter-church evangelistic event in the town. Counsellors were prepared to deal with any respondents. Since this was soon after the introduction of Care in the Community (Griffiths Report 1988), a lot of people

were living in the community who until recently would have been in institutions. The counsellors noticed that there were a lot of people with learning disabilities coming forward and were concerned, in order to help them within the framework of their remit as counsellors, not to over-persuade as they seemed rather impressionable. As I have understood it some of the people with learning disabilities who responded to Christ at that time were fed into the nurture groups at the site B church the same as everyone else but this led to particular strain on the leaders as some needed extra input. After a while a special house group was set up for these people with learning disabilities and the notion was for them to have a secure base from which to venture out into the main church meetings and if it did not work out they could come back and feel safe and grow in confidence.¹⁴⁷ The Sunday afternoon meeting once a month seems to have developed after that as a response to the new needs of 'care in the community'.

In the whole congregation there were probably only about three people who I knew who had learning disabilities. I tried to locate them and note how well integrated they seemed (relationship-wise) in the life of that congregation. When I moved to the balcony to observe the signing group, I had a better view of the whole congregation so could search for the people I knew with learning disabilities. One male and one female member of the house group were regularly in evidence there. She had a job in a shop in the town so was well-integrated in society generally. Each time I saw her she was sitting at the heart of the congregation with others around her. A few times she had a person with obvious learning disabilities sitting to one side of her. The man I was observing was much less well integrated. I wondered if he had depression as he seemed very sleepy a lot of the time. Sometimes he was actually asleep in the service. Another time, this man, Peter, came in late and sat down. Another man came and sat with him and a friend came over to converse with him but seemed to ignore Peter. It looked a bit like the friend was lending moral support to the man for sitting with Peter. On another occasion, I noticed Peter sitting among a group of people,

¹⁴⁷ A similar thing has been noted for women that because girls have not been socialised to engage in the public domain, as boys have been, that women sometimes need special groups to learn these skills and to grow in confidence to speak up in order to be able to integrate into a church that has generally only encouraged men to be vocal. (This was not as true in the nineteenth century as it was in the twentieth century, and is unlikely to be the pattern in the 21st century either).

fully integrated. More often though, even if he was seated with others he was a bit of an island with others appearing to give him a wide berth.

In terms of the actual service, colourful banners were available for use during the worship. I did not see people with learning disabilities having any clear ministry in the church but being a free church there are no servers for communion so it is not possible to say whether they would use any of the people with learning disabilities for that if they were an Anglican church. One of them told me that she practises a musical instrument in the church sometimes but I do not know if she has been asked to play it in the service or indeed if it would be appropriate.

The chairs for Reach Out, were set out in different formats each time according to the purpose in view: sometimes in straight rows facing front, if there was a film to watch, or in a circle, or a double circle if the intention was more participative.¹⁴⁸ The venue had a functional feel rather than a homely ambience. There was a coffee lounge farther away on the ground floor which did not have the same feel to it as there were comfortable chairs in that area and it was carpeted.

The general appearance of the members was very variable. Some of them were stylishly dressed whereas I noticed a couple of older people who had clothes which did not make their sexual identity clear. There was one man who I initially took to be a woman and equally one woman who I had thought was a man.

One man often came in late and went directly to kiss the women doing the worship, regardless of how involved they were with this task. I never saw him rebuffed although I did see him make a lunge at Felicity and she deftly turned her face to ensure that he caught the side of her face or ear. They were all very accepting of him. I didn't notice him trying to kiss any of the female members, just the leaders.

¹⁴⁸ One of the helpers told me the chairs used to be in rows but then they decided they preferred them in a circle so that became the standard format.

I assume that each term there was a theme or a series of studies from a particular part of the Bible, as after my first visit I received a detailed programme of the next few months' studies. The theme was presented with visuals, realia and everything necessary to set the scene. Drama was a key element in the presentations and much preparation went into getting a range of suitable props. When a previous theme was picked up and developed from an earlier session there was always a short recap as the time lag would be four weeks and on occasions even more. One of the leaders, Carol, told me that the weeks she was not leading but doing transport she always used the time in the car to get them to refresh their memories and recap on what had gone before and where they had now got to.

To give the flavour I will recap on a meeting I went to. There were 53 people present, 30 adult members (13 female and 17 male) and the rest were helpers.¹⁴⁹

Once the worship started there was enthusiastic participation with various noisy instruments. There was also lots of colourful banner waving and actions and a very relaxed atmosphere. One chorus was led by three women who tried to sign it and get everyone to do the signing too. We sang 'Even in my weakness you consider me lovely' and the worship leader reinforces the point saying 'He does delight in ALL of us doesn't he?' Felicity, joined in now for the next round of worship. She got them all to stand up and dance about a bit. She is exuberant and not at all self-conscious and seems popular.

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There was then a prayer time led by the woman who had introduced the foot-washing. There were some hypothetical questions : 'Imagine if you had come in here and no-one had welcomed you?' I heard one person say 'I wouldn't be very happy'. There was then a dialogue with a waitress speaking on the phone complaining how Jesus had not been welcomed properly because his feet had not been washed. This led into a drama with the woman pouring oil on Jesus' feet. Music was playing softly. They are asked why the woman was upset and they reply with such responses as 'Tears' 'crying'. They are told that she is sorry for doing bad things. They are then asked if they do wrong things. One person says she broke a vase and others quickly begin to give examples.

¹⁴⁹ I distinguish helpers from leaders as the leaders are the ones taking control and shaping the event whereas the helpers simply do as requested.

Felicity then came forward and talked about 3 important words 'Sorry' 'thank you' and 'please' which led into the activities. Before this a woman (about 50 years old) was invited to come and tell the group about something exciting that had happened to her the previous day. She talked about a visit to see Santa in a neighbouring town. She was allowed to say what she wanted with no intervention or coercion to go in particular directions. This was seen as a very affirming thing to do (one of the leaders made this point to me later on) and she was clearly pleased with the opportunity to share with the others in this unscripted way.

At 4.15 they split into groups and there were 4 choices of activities which was generally the case. The possibility of colouring in was always there and was a firm favourite with some. This week there was also the foot-washing drama to be done again, writing prayers of 'sorry' 'thank you' and 'please' or they could do the verse again by sticking the key words onto a card.

At the end all the groups were given a chance to show the whole gathering what they had done. After this tea was served. Plates of sandwiches and cakes were given out and cups of tea brought round.(A set of matching church china was used for this so they could have been in a tea room) One young woman with learning difficulties always served the tea in the kitchen and appeared to be in charge (although the planning was done by Felicity). For some, the tea appeared to be one of the highlights of the afternoon and a few cunning people got second plates full as some of the helpers willingly relinquished the chance of tea for themselves.

After tea one teenage boy asked Felicity if he could play his new CD. He was allowed to and he just stood in the middle of the floor and danced to it. Felicity said to me 'I hope it isn't too awful!'. He clearly enjoyed the chance to play it and get up and dance although no-one else joined in.

The house group was an additional group which was set up by Felicity and James with another concerned female member of the congregation and had been held at the couple's home for eighteen years (at that time, 2005) I was able to attend this meeting once and it should be said that his was probably a lot closer to the Kingsway group at

CGS than the Sunday afternoon monthly meeting as it fostered a freer form of participation and therefore would have made a better site for comparison. However, because of the relative intimacy of the home group I was invited to attend but once and would have been an unwelcome intrusion on their affairs on a regular basis. I was generally introduced as coming from a particular local church that I attend which I felt was to protect the members from feeling any undue interest in them. I respected this greatly and historically there has been a problem with researchers objectifying disabled people, which I was also keen to avoid.

The evening I attended was not a regular house group, as such, for house groups had been suspended in the church and being pastorally inclined they were continuing their support of this group by meeting for a meal once a month. As it was a meal it was not possible to take any notes¹⁵⁰ so this was written up from memory straight afterwards.

First of all, the couple's home was clearly a place where the members felt at home and welcomed. Felicity was lively and affectionate, while James was a gentle loving presence more in the background.

We sat down together to eat, there were four helpers/leaders and four members with another four people absent through illness. Felicity asked them to tell me what they had been doing over the eighteen years in which they had been meeting. Members of the group listed a number of memorable social activities - for example sailing at a nearby seaside resort followed by fish and chips, a country walk followed by a drink in a pub, curry evenings, and other foreign food events. Apparently they always have a Greek evening in the summer. There were camping trips too. Felicity was keen to draw out from them some of the more spiritual input they had had as they had also had Bible studies and worship evenings.

As a group they all tended to dress similarly in trainers and jogging pants or jeans. I noticed that two of them left the physalis with which I had decorated the dessert I made. It may have been an unfamiliar fruit to them. They seemed to enjoy the jacket

¹⁵⁰ This had been specified to me before attending.

potato and quiche and Felicity made some comments to them about the importance of a balanced diet.

After the meal we retired to the lounge for coffee and Felicity took up the theme of teaspoon = tsp = thank you, sorry and please.¹⁵¹ They went round the room and said thank you prayers. One person said 'pass' and that was respected; there was no pressure. There was a time of silence for sorry to respect privacy, and then one more round for please. There was a lot of initiative taking here and they shared matters for prayer. One man asked for prayer for a man whose life has been spared after major surgery. One of the women commented that he may come to know Christ if they pray for him but added that it was up to him and others agree that it may happen. Felicity took the lead.

¹⁵¹ Rather typical Evangelical formula - no room for anything untidy, like lament. Possibly a Sunday School formula. What about thank you, sorry, please and why?! As the root of Lament is the Hebrew word for Why?

Appendix 4 Disability in cross-cultural context.

Here we see disability as it is constructed in diverse cultural settings throughout the world.

In the early 1980's Ingstad and Reynolds Whyte lamented the lack of literature available on people with disabilities in the developing world, noting that most of the serious work concerned itself with North America and Europe.¹⁵² (1995 x) It is clear that Western views cannot be generalised from, and Bedirhan et al (2001:5) were also concerned with the possibility of an uncritical transfer of disability concepts and terminology across diverse languages and cultural settings which would likely produce confusion without a proper understanding of each culture.

With WHO funding, a network of studies on beliefs and attitudes on disability, in different cultural settings, was set up (Ingstad & Reynolds Whyte 1995). This was one of the first collections of anthropological studies that focussed on the social perception of disability.

Later, in recognition of the fact that disability is a culture-bound concept, an international study was conducted by Bedirhan et al to assess the cross-cultural applicability of linguistic terms in current use for classification and assessment of disability. Again the study was funded by the WHO, qualitative work was done to establish the similarities and differences across cultures and was seen as a prior requirement to the meaningful application of quantitative approaches. (2001:ix)

In the early 1990's WHO assembled a global network of collaborating centres in order to eventually establish a consensus on a serviceable and empirically grounded model of disability that could accommodate both the medical and social models 'to produce a robust and flexible construct that [could] be employed in many sectors and for many different purposes' (2001:7)

¹⁵² This lack of material includes the lack of autobiographical accounts and a serious dearth of life histories (Ingstad & Reynolds Whyte 1995:20)

What emerged is the ICIDH-2 which rather than being a classification of persons with disabilities as its forerunner was, is a classification of functionality at three levels, understood strictly in neutral terms.¹⁵³ This enables the user to identify, not simply problems at the level of body, person and society but also the absence of problems and crucially, the presence of strengths. (2001:8)

Western view.

Looking at different cultures in juxtaposition is a well established method in anthropology of gaining perspective of one's own location. (Marcus & Fischer 1986:157ff)

Contrastive analysis makes it clear that underlying the Western discourse on disability is an assumption that equality is the desired goal and this, problematically, is construed as synonymous with sameness or similarity. Ingstad and Reynolds Whyte (1995:7) note that the terms *handicap*, *disability* and *rehabilitation* themselves provide clues to this supposition. They explain

Etymologically, 'handicap' was originally a game, a kind of lottery, in which the winner paid a forfeit; the umpire held the money in his hand in a cap. Later the term came to be used in relation to competition in which unequal competitors were weighted so as to make the match more equal. Thus the word has connotations of competition and efforts to create equality.

Dumont (1980) and Striker (1982) both draw attention to a worrying prospect for this emphasis on equality, namely, an intolerance of innate diversity and individualism leading to the denial of the social nature of persons. Striker is so exercised by this prospect that he states his own position as believing that the love of difference leads to a humane social life whereas the pursuit of similarity leads to rejection and repression.(1982) Striker has some important insights on the Western construction of disability. He observes that it is the context of a centralist state that conceptualises infirmity as a category that it never previously was and accords it definition, criteria and degrees of severity. He notes the paradox that people with impairments become a

¹⁵³ This allows for the acknowledgement that disability is a universal condition affecting all humanity.(Bickenbach, Chatterji, Badley et al 1999) As shall be seen later this insistence on universality is in tandem with diversity and not in opposition to it.

marked group with a social identity the purpose of which is to render them invisible and unmentionable. (Striker 1982:149)

Robert Murphy, in his analysis of North American society notes that disability is regarded as invisible and unspeakable as evidenced in the fact that children are raised not to point or comment on people's impairments in their presence. He sees a paradox in that nobody is meant to 'see' the one person whose presence is dominating everyone's consciousness.(Murphy et al 1988:239) This again is because differences are meant to be compensated for in order for the goal of equality (conceived as similarity) to be maintained. Linked to this intolerance of difference is the concept of stigma (Goffman 1963) Aud Talle in her research on the Maasai of Kenya notes that the term is not applicable to their context as in the western context the notion is heavily charged with implications of social inferiority. (1995:58)

As we look at diverse constructions of disability we need to remember that definitions are not neutral but usually reside in the hands of those with social power who use them to enforce their meanings to maintain their powerful position.¹⁵⁴ So we need to ask as Keesing suggests 'who creates and defines cultural meanings, and to what ends?' (1987:161)

Differences across cultures:

The many differences found in the literature can be divided into four sets. First, we will look at *disability, attitudes and beliefs*, second, *disability and stigma*, third, *disability and gender* and fourth *disability and personhood*.

1. Disability, attitudes and beliefs

Bedirhan et al (2001:317) note that issues raised by genetic causes of disability, and whether they are present at birth or not, are complex and viewed differently in societies where beliefs such as the doctrine of karma prevail.

¹⁵⁴ Of course the practice within the Disability Movement of the 'powerless' defining the more powerful as in calling able-bodied people 'temporarily able-bodied' is an unusual exception and derives from the desire to subvert the usual order.

Robert Edgerton (1985) showed that attitudes toward people with mental impairments varied greatly across non-Western cultures, among the Punan Bah persons with mild mental impairment are considered half-human *stenga linou* and the impairment is said to be caused by the soul being no good. All forms of impairment range from negative discrimination along to acceptance and right up to the positive attribution of supernatural powers (as seen with the Songye of Zaire who elevate some intellectually impaired children to the status of 'ceremonial', giving them special ceremonies believing them to have healing powers (Ingstade & Whyte 1995:96).

Although, attitudes and beliefs can be plotted on a scale from total rejection to full acceptance, some cultures may demonstrate a mix of these as in the case of the Maasai of Kenya who believe that disability is the result of social and cosmic disorder¹⁵⁵ yet have strong moral codes dictating that a child is to be treated well whatever its condition and that all children should be treated with equal regard.(Talle1995:69)¹⁵⁶

The scene across India was found to be diverse, Bangalore demonstrating most support for disabled people, in contrast to Chennai where there was widespread stigma especially associated with mental impairment. (Bedirhan et al 2001:116/117) Also, a study of randomly selected villagers in Vellore in southern India, which examined attitudes towards individuals with physical impairments, revealed that 82% of these attitudes were positive (Bakheit & Shanmugalingam 1997) (2001:11) Historically India has taken a positive attitude to persons with impairments and there are records of centres offering special care. In the entire country, only 20,000 persons with mental impairments are in specialised institutions. All the rest are living in the community with their families (2001:116)

¹⁵⁵ *Enkanyit* translated 'respect' or 'obedience to structural superiors' is seen as a principle of social order for the Maasai. Similarly a Sri Lankan friend of mine who has a disabled child was told by her mother-in-law that the disability was the result of her son (the child's father) talking back to his parents when he was young. This thinking seems to derive from a similar worldview.

¹⁵⁶ Lest this review of cultures should give the impression that those of the developing world are less 'enlightened' than the Western world, this point must be seen as a sobering rebuke to the pragmatic and materialist attitude to human life often demonstrated in the Western world and often advocated by the medical profession - see Sarah Williams 2007.

On the negative side of the scale societies made negative assessments of the reason for disability from i) ancestral displeasure (Punan Bah of Sarawak who believe that every new birth is the rebirth of an ancestor and an impaired baby an expression of displeasure) to ii) evidence of sexual sin (Songye of Zaire and Punan Bah believe that the breaking of sex taboos, e.g. couples having sexual intercourse during the woman's pregnancy may lead to impairment. The Punan Bah also see twins as evidence of the breaking of this taboo and the evidence of an insatiable sexual appetite) to iii) generational sin (Nigeria; Maasai of Kenya (Ingstad & Reynolds Whyte 1995); also Greece, India and Japan (Bedirhan et al 2001) to iv) individual wrong doing and bad karma (Cambodia, Romania, Japan, (Ingstad & Reynolds 1995) and v) the result of sorcery (the preferred explanation of the Songye. (1998:99)

On the positive side, some cultures demonstrate full acceptance of the disabled person as a full person and others see the person as a divine gift. This latter point should be seen critically and is probably not unconnected to the prevalence of negative explanations for disability. Ingstad (1995:254) notes from her research in Botswana

Another way to avoid the stigmatising label is to claim that the child is *mpho ya modimo* 'a gift from God'. In line with Tswana tradition of giving children a name that is meaningful for the life situation of a child born into, or for the parents' wishes or expectations, several of the children in my sample born with visible impairments had been given this name. The Tswana traditional God Modimo, and even the Christian counterpart that has taken over the same name, is mainly seen as a distant omnipotent power that demonstrates trust in people by giving them such special challenges.

We will look finally at the belief that a disabled person is to be valued like any other human being. For the Songye of Zaire this positive view is a consequence of a more flexible and accepting attitude towards the vagaries of life in general. Devlieger (1999:95) remarks

...a continuous effort of improving and accommodating the living conditions of persons with disabilities is basically a Western idea that is foreign to Songye thought. Instead the Songye have developed in their culture alternative ways and means of coping with disability. Living within the limits of the disability rather than surpassing them seems to be the most important norm.

We should note here, perhaps a freedom from the 'superman' myth so popular in Western values. Among the Punan Bah of Sarawak disability is not unspeakable as it

is in Western society and people speak freely in the presence of those with impairments and the impaired concerning their own. People are not singled out by nicknames connoting their impairment, largely because they have a soul and are recognised as full persons (Nicolaisen1995:48). However, Aud Talle notes that among the Maasai the naming of bodily characteristics does not have derogatory undertones; rather, such practices reveal a cultural acceptance of differences.

2. *Disability and stigma*

From our own cultural location it is easy to assume that disability entails stigma in all settings. Even within the current U.K. context it is found that stigma is attached to mental illness far more than other forms and this is seen to have been enhanced by media attention since Care in the Community became policy and an unjustified assumption that violence and mental illness are linked.¹⁵⁷ In Japan, as in Romania (2001) all forms of impairment lead to stigma. Bedirhan et al (2001:154) argue '... it is a consistent finding that people[in Japan] would say something negative about a person appearing in public who is obese, or intellectually slow'¹⁵⁸ In contrast it is found that the Dutch have a high level of tolerance for people with impairments who appear in public with the exception of those who manifest 'disturbing behaviour' (2001:171) In India there is a high tolerance of 'deviant' behaviour and relatively low stigma unless, as in the Netherlands, the person's behaviour is disturbing.(2001:116) In Turkey people with physical or cognitive impairments are reported to encounter less stigma than persons with alcohol and drug related -problems.(2001:230)

3. *Disability and gender*

Gender, like disability, and indeed, a host of other things, is a social construct. Let us begin with an exotic example from the Punah Bah of Central Borneo who believe that men and women have more than one soul; one has six and the other seven and as is customary in patriarchal contexts, it is the woman who is one down and thus

¹⁵⁷ As has already been noted if there is a link it is the opposite direction to what the media imply and people with mental health issues are far more likely to be victims of violence than perpetrators of it.

¹⁵⁸ This presumably does not include the very overweight Sumo wrestlers who are revered in Japanese culture.

deficient. From this starting point we now look at disability as it intersects with gender in different societies.

Among the Maasai it seems that when blame is being apportioned it is not uncommon for the woman to be singled out as the guilty party. The ill health of one child was assumed to be the result of the mother's misconduct (1995:65) At least in this case the mother had admitted some misconduct rather than the evidence of the sick child being regarded as concrete proof. Elsewhere the relations between co-wives is regarded as fertile ground for seeking the cause of disability (Devlieger1995:100). Talle (1995:65) notes that beliefs can be very forceful and especially when they concern the morals of women.

Robert Murphy, an American anthropologist who is a wheelchair user notes that he developed some very good relationships with women after the onset of his illness and he elects not to put this down to a stereotypical mothering instinct in women but rather to the removal of sexual threat (which he believes is always present in women in the presence of men) he insists, 'it forecloses an ancient power struggle and puts an end to 'male superiority' Murphy 1995:152)

Whereas in Western culture physical attractiveness is prized most highly for wives, in some African countries [Kenya, among the Maasai and Botswana (1995)] hard work, efficient management and sociability are of primary importance (1995:137) and this would have implications for how disability is viewed.

4. Disability and personhood

As we shall see features of disability vary hugely depending on a culture's concept of personhood. Halatine & Berge (1990:58-59) list Tamasheq terms for a number of impairments including, excessive freckles, protruding navel, absentmindedness and flabby or small buttocks. Most of these, unsurprisingly, are not on the WHO list as they do not fit with a biomedical view. The point to note is that these do not relate to classification but to the view of personhood as understood by the Tamasheq. In Western society personhood is tied in with individual capability and accomplishment: among the Punah Bah of Central Borneo it is associated primarily

with social relations as is the case in many societies based on kinship. (Nicolaisen1995:47) In a good number of societies being a member of a family and having children are of greater importance than having the capacity to work or possessing good looks. The contrast between egocentric and sociocentric concepts of personhood provides a useful comparative framework. (Geertz 1973; Schweder & Bourne 1982) Among the Punan Bah of Sarawak, 'personhood is essentially the fulfilment of a socially significant career, of which parenthood is the alpha and omega' (1995:50)¹⁵⁹

Of particular interest to the framing of this thesis is the Barbadian concept of personhood which emphasises a balance between autonomy and connectedness. Goerdts (1984:88) notes,

At the same time that one should demonstrate autonomy, one must not be too independent of others....for the unity of the group depends not only on the contribution of each member, but also on each member's willingness to accept help from others.'

Finally it should be noted that attitudes are best when a society recognises something of intrinsic worth in any given individual regardless of their condition. The Punan Bah believe that all offspring are reincarnations of ancestors and therefore must be respected because they see 'someone else' inside that body. This is of similar help to a Christian view that sees in each person the image of the Triune God. In this case too the person is to be well treated because of that status. This is a point that will be expanded later.

Universalism and diversity

The writers of the studies drawn on here are fundamentally at odds on this matter. Ingstad & Reynolds Whyte (1995) argue against the possibility of universality in the case of disability claiming that the notion is itself the result of a Western mindset with a strong attachment to a) universalistic biomedical sciences and b)

¹⁵⁹ We see here that this is a very real aspect of disability in contexts where persons are accorded a liminal state, neither child nor adult but an in-between person., in such a state. (1995:50) Social constructions of disability depend on concepts of personhood. 'Restoration' was a similarly patriarchal culture that rendered unmarried persons, especially women, liminal beings. In the cross-cultural understanding of disability this is regarded as truly disabling.

individualistic conceptions of personhood. Bedirhan et al (2001:15) insist 'it is not implausible to argue that, despite linguistic and cultural differences, a transcultural understanding of disability is possible. They (2001:320) go further in arguing for the necessity of this view, for to insist that disability is the result of environmental factors and resist the possibility of a universal construct (as many researchers do) is, in their opinion, self-defeating

since the claim of environmental causation will remain a political slogan rather than a confirmed scientific hypothesis unless the measurement work can be done to demonstrate quantitatively how the environment causes the disadvantages of disability, and how we can change the environment to eliminate or alleviate these disadvantages.

While it is not conclusive that Judaeo-Christian beliefs are injurious to disabled people, it cannot be stated with such confidence that disabled people have not been treated badly by people who believe they understand the Hebrew and Christian scriptures. Having seen that the concept of disability varies across cultures it must also be argued that there is a strange level of accord that finds the need to make causative links between moral conduct and disability.¹⁶⁰

¹⁶⁰ Fontaine (1995:293) points out that proverbs express the unexamined folkloric beliefs of a group that are felt to be of universal relevance that an explanation is no longer needed. She notes that such a proverb finds its way into 2 Sam5:8.