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# **Faith and Disability: Comfort, Confusion or Conflict?**

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How does the adoption of Christian faith influence the lives of people who identify as 'disabled' in Britain in the 21st Century?

**Rachel Allen**

September 2010

## **Summary**

### **Faith and Disability: Comfort, Confusion or Conflict?**

This dissertation project seeks to explore two major elements of identity, faith and disability, and understand the relationship between them for disabled people who are Christians. An extensive literature review was undertaken and nine people (eight women and one man experiencing a range of physical and sensory impairments) were interviewed for the purpose of exploring the main research question:

**How does the adoption of Christian faith influence the lives of people who identify as 'disabled' in Britain in the 21<sup>st</sup> Century?**

As a Christian and a disabled person, this area of research was of personal relevance and interest. The themes of comfort, confusion and conflict emerged through the literature review and were consistent with interview analysis. Analysis has been organised according to the research sub-questions. These focus on identity, biblical interpretation and life with impairment.

Exciting areas for further research have been suggested through this research. For example, the need to explore connection between the 'journeys' of being a Christian and experiencing impairment. The need to refocus discussions about the meaning of impairment in a Christian context and biblical interpretation of impairment and disability were also identified.

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## **Chapter 1: Introduction**

### **How does the adoption of Christian faith influence the lives of people who identify as 'disabled' in Britain in the 21<sup>st</sup> Century?**

This dissertation project seeks to explore this question and offer insights from Christians who are disabled people, an underrepresented voice in the current literature. As a disabled person and a Christian, I was motivated to undertake this research to offer a perspective that goes beyond debates about sin and impairment or disability as punishment (which offer little that disabled people can positively relate to or gain insight from) to discover the experiences and perspectives of those who are disabled people with Christian faith. Though experience of impairment and faith are two central aspects of identity, little is known about how they relate or balance. I wanted to maximise this research opportunity to compare lived experiences with the academic literature and existing research analysis.

#### **Background and Definitions**

Traditionally, 'disability' has been understood in negative terms. Disability has been perceived as 'tragedy', an object for charity, and as the disabled person's 'problem'. This has been described as the 'medical' or 'individual' model of disability. The 'social model' (Oliver, 1981) perspective of disability advocates disability as a form of social oppression. The Union of Physically Impaired Against Segregation (UPIAS) has defined disability as:

“the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and this excludes them in the mainstream of social activities... Disability is therefore a particular form of social oppression” (UPIAS, 1975:unpaged)

This project is based on a social model understanding of disability. This is important to make clear as the general perception that disability is inherently negative is rejected, and the possibility of a positive disabled identity asserted. In order to have a disabled identity, positive

or otherwise, it is necessary to have an impairment. Impairment refers to the medical diagnosis, condition or difference in the person's body, senses or mind.

A 'Christian' in the context of this research is someone who identifies themselves as a Christian, "simply someone who follows Jesus" (Mattison, undated:unpaged) and believes Jesus is the Son of God. This is distinct from the 'Christian identity' movement (linked to racist and anti-Semitic extremism; Robinson, 2006:unpaged) and other faith identities such as Muslim (belief in Allah and follower of Islam; Barrow, undated [a]:unpaged), Buddhist (follower of the teachings of Siddhartha Gautama; Barrow, undated [b]:unpaged) or Jew ("physical and spiritual descendents of Jacob... by birth or by conversion"; Rich, 2009:unpaged).

Though the terms 'religion' and 'faith' are connected, it is important to distinguish between them (Zinnbauer et al, 1997). Zinnbauer et al (1997:549) found that "the ways in which the words [spirituality and religion] are conceptualised are often inconsistent within the research literature" and that this is "mirrored in the [different] ways that religious and spiritual believers themselves define the terms" (1997:550). Miller and Thoresen (2003:27) defined religions as "social entities or institutions" and Zinnbauer et al (1997) distinguished between the spiritual (personal) and the religious (collective). A similar understanding of terms will be applied. 'Faith' is therefore the spiritual identity within the person, emphasised in this study, including for example their relationship with God and beliefs about God. The 'religion' includes 'actions' of faith such as attending church services. The term 'spirituality' has been avoided because it has diverse meanings (Miller and Thoresen, 2003).

Identity is defined as "the set of personal and behavioural characteristics by which we identify ourselves as belonging to a social group" (Essien, 2009:63). This can include 'collective identity' (Galvin, 2003), such as with the disability rights movement or faith community; and innumerable individual and personal factors such as being male or female or ethnicity.

## **Research Questions**

The research questions were inspired by applying the social model in a Christian social context. The literature review was central to the formation of the main research question and sub questions, which are:

- How does the adoption of the Christian faith impact on a disabled person's self-identity?
- How do disabled people who are Christians interpret and explain references to impairment and disability in the bible?
- How does the adoption of the Christian faith influence the experience of living with an impairment in a disablist society such as the UK?

These sub-questions address three central elements influencing the lives of Christians who identify as 'disabled'; understanding of the bible (basis of faith), understanding of self, and the day-to-day balance of the physical and spiritual experience.

## **Research Focus and Approach**

The research questions address gaps in the current literature, discussed in Chapter 2. Through the literature review it emerged that Christian faith and identity could be described by three themes: comfort, confusion and conflict. These themes could be said to reflect the reality of living as a disabled person and a Christian, in a spiritually and physically divided society or even spiritually and physically divided identities; comfort felt from a relationship with God can be confused by biblical references to disability; conflict about the God's role in impairment perhaps confusing the call to trust in him.

As a researcher using the 'interpretive' paradigm, when analysing the literature I was aware of my own identity as a disabled person and a Christian. Though this helped to critique my assumptions, I found myself personally affected by some of the texts. The most significant example was Schumm and Stolfus' (2007) *Chronic Illness and Disability: Narratives of healing in Buddhism and Christianity*, which compared the Christian and Buddhist perspectives related to impairment. Like those described by Locker (2008:90), I was "faced with the task of making sense of the onset of chronic illness... why me?", over eleven years after being diagnosed with

Myalgic Encephalomyelitis (ME). Schumm and Stolfus (2007) described the Buddhist belief in life connections, that a single 'cause' of impairment cannot be ascertained because of the innumerable factors involved in any one of us; family, ancestry, and environment being examples. This was then applied to Christian beliefs about healing and the need for redemption. Therefore having ME wasn't necessarily because of this or that reason, but perhaps simply because my body exists within a broken and decaying world. I include this personal insight as it highlights not only the importance of presenting accessible research but also the importance of research for enrichment, enlightenment and encouragement; not only for individual readers and interviewees, but for the faith organisations and wider society in which we interact.

Chapter 3 describes the methodology for the research. This was undertaken interpretively, using semi-structured interviews to gain stories, narratives, and understanding (voices) from the interviewees. Nine participants took part in semi-structured interviews, and were recruited using contacts through 'snowball sampling'. Ethical considerations were prominent throughout the research design, as the successful project would need to be of benefit (Angen, 2000) not only for literature, but for those participating in the research.

### **Organisation of the Project**

The timetable for research began when commencing the literature review in November 2009. Interviewee recruitment began in February 2010 and the interviews took place between March and June 2010, with all transcripts agreed by June 2010. Discourse analysis was then applied to the interview discussions, and conclusions drawn during July 2010.

Discourse analysis was used to analyse the information gained from the individual narratives and experiences. Chapters 4, 5 and 6 explore interview data through the research sub-questions. The project concludes by examining what has been learned from the interviewees' insights.

## **Chapter 2: Literature Review**

### **The Christian Faith and Disabled Identity: Comfort, Confusion or Conflict?**

The literature review began at an early stage of the project. The literature was used to form the research questions, make methodological decisions, and refine focus for the interviewing process. The academic literature in respect of Christian faith and disability in the UK was limited (Selway and Ashman, 1998), arguably because “the field of disability studies has paid scarce attention to religion” (Creamer, 2008:78). Literature related to religion and Christianity was predominantly recent (post-2000), and this can be taken as evidence of this claim. Over 50 papers were read from various peer-reviewed journals sourced through online searches, and the review also included over 6 books and non-academic literature such as internet articles. The review was ongoing throughout the project, in order to continuously evaluate and analyse interview findings.

All scriptural references are taken from the Holy Bible, New International Version.

#### **Identity**

Identities are not fixed, rather they are “constantly evolving” (Watson, 2002:511) and are often dependent on context (Reeve, 2004; Rhodes et al, 2008). Identity is not neatly defined, with “several kinds of difference, such as gender, race, class and age” (Barnes and Mercer, 2001:531) influencing an individual’s sense of self. Creamer (2008:31) described the flexibility that was part of her disabled identity, for example ‘feeling’ disabled when severely affected by impairment but the next day perhaps not. Whilst de Wolfe (2002:258) argues that the “experience of disability and that of illness are often inextricably intertwined”, Barnes (1992a:unpaged) argues that “disability and illness are not the same thing and should never be confused”. Extending this debate, what is the significance for Christians in identifying as either ‘ill’ or as ‘disabled’?

## **Acquiring Impairment**

If 'disabled' is perceived as 'fixed' and 'ill' as 'fluid', how do the fixed or fluid, congenital or acquired, and other aspects of impairment affect the disabled identity? People who identify as disabled when impaired by chronic illness, which can fluctuate in severity and have uncertain prognosis (Locker, 2008), can become "opaque mysteries even to those who are closest to them" (Schumm and Stoltzfuss, 2007:6), and perhaps also to themselves. Sutherland (1982) describes the process of gaining a disabled identity as 'coming out', however those with chronic illness can find their identity rooted within a blurred boundary of being ill or being disabled (de Wolfe, 2002), making understanding and affirming a disabled identity difficult. Fox and Kim (2004:334) suggested that "all disabilities must pass through some level of medical understanding before being more widely understood". For disabled people not able to gain 'medical' understanding of their impairment, or with uncertain prognosis, forming a disabled identity can involve additional complexities; 'getting there' as well as 'coming out'. A positive disabled identity can also be contradictory to experience of severe discomfort and pain. As de Wolfe has stated, "illness should not be romanticised. It ruins lives" (2002:263).

Family attitudes, educational experience and other social factors will all impact on understanding of what 'disabled person' means and therefore sense of self. Those acquiring impairments may have previously internalised the view that being a disabled person is a 'tragic' or negative experience (French and Swain, 2004:4), which can mean "rejecting a great deal of conditioning" (Sutherland, 1982:unpaged).

## **Developing a Disabled Identity**

Whilst Christianity has been understood to place the 'cause' of impairment as punishment, wider disablist society can be similarly judgemental, for example a 'hierarchy of impairments' (Reeve, 2004) has been described. The social acceptance (or lack of) for particular impairments can also be explained by their associated 'stigma'. Impairments can be visible to others, invisible to others, or signified by other variables (such as using a walking stick). For some, this involves others' "frank curiosity" (Reeve, 2004:unpaged), or other's disbelief or confusion about

the basis for disabled identity. How do disabled people not perceived by others as 'disabled', or who's disabled identity is socially undermined or constantly reinforced, internally respond?

Goffman's (1963) *Stigma* described 'stigma cues', visible aspects of impairment, that 'discredit' individuals within society. If "social and personal identity will vary greatly according to whether those in his presence know of him" (1963:85), social factors have great significance for the disabled identity. Churches, synagogues and mosques are subject to social context as are families, workplaces and schools; all contributing to "psycho-emotional pathways of oppression" (Reeve, 2004:unpaged) or "dominant social milieu that devalues and discriminates" (Eiesland, 1994:58). Ethnicity and gender are examples of biographical differences that also impact on individual identities (Vernon, 1999). Identities cannot be separated from the personal and social contexts in which they are formed and developed (Watson, 2002).

"Class background, as well as the degree and severity of impairment, ethnicity, sex, sexuality and age can exacerbate or modify the experience of disability"  
(Vernon, 1999:394)

### **Positive Disabled Identity**

Essentially, a positive disabled identity rejects impairment as negative; there is no "something wrong" (Oliver, 1981). Traditional, medicalised, views of disability perceive disability as an individual's problem. A positive disabled identity views impairment as an inherent part of the whole person, and negativity related to impairment as society's problem. This is very much linked to the social model of disability (Swain and French, 2000). Whilst this project focuses on individual identities, it is also important to note the importance of collective identity, particularly in the context of a 'collective' faith (Gordon, 2009). Vasey (1991) has argued that culture and identity closely relate, so it is important to understand how faith culture impacts on disabled identity.

"Disability is not caused by impairment... but the oppression of people with impairments in a disabling society" (Swain and French, 2000:571)

Mason (1990) argued that all disabled people suffer from ‘internalised oppression’, the absorbing of external disablism. Internalisation of oppression and identity itself can be difficult concepts for people to articulate or describe (Hernandez, 2005). Whilst having an impairment is necessary for a disabled identity to develop, impairment does not necessarily result in a disabled identity (Reeve, 2004). Watson (2002:514) interviewed a total of 24 disabled people and found only three “incorporated disability within their identity”. Does faith negate or encourage a positive disabled identity or internalised oppression?

### **Christian Identity**

As identity is “the product of conscious action” (Watson, 2002:520), how do disabled people who are Christians internalise their spiritual and physical experiences? In England, about 70% of people identified themselves as ‘Christian’ in the 2001 Census (Office for National Statistics, 2004). Church attendance and membership are generally declining in the UK, though there are denominations such as Pentecostal and Greek Orthodox which are growing (Hughes, undated). The influence on adults of childhood religious experience has been debated. Cornwall (1989:589) found that parental church attendance had “significant direct impact on adult belief and commitment” while O’Connor et al (2002:731) concluded that “adult experiences, not earlier religious upbringing” were of most significance. Major life changes or events such as the onset of impairment can be interpreted as “a second chance at life, a wake-up call, a blessing” (Hernandez, 2005:124), however any relationship between onset of impairment and becoming a Christian is not generally discussed in the literature.

### **The Bible and Impairment**

“Disability is interpreted as punishment... a test of faith, an opportunity to build character or to inspire others, an occasion for the power of God to be made manifest, a sign that one lacks faith, or simply a mysterious result of God’s will”  
(Creamer, 2008:50)

Caution must be taken in analysing biblical texts as it can be difficult to discern spiritual and cultural context, use of language, and intended meanings (Creamer, 2008). It is important to

remember that Jesus “became flesh in a particular time and place” (Eiesland, 1994:99), “extensive biblical interpretation... has not yet been written” (1994:70), and the “study of religious textual reference to disability is in its infancy” (Selway and Ashman, 1998:432); and a variance of interpretations and conclusions about impairment, disability and healing were expressed in the literature.

Many of the texts discussing religion, God or spirituality focused on the relationship between sin and impairment (Miles, 1995). There was reference to study participants’ understanding of impairments caused by evil or evil spirits (Rozario, 2009), karma (Naemiratch and Manderson, 2009) or God’s will (Braathan and Ingstad, 2006). Implication that such a belief was somehow inferior to a medical or scientific explanation, particularly in studies based outside the UK, for example, “religion or traditional beliefs may *seem* to provide logical explanations” (2006:609; emphasis mine), was frustrating. In the UK disabled people have greater access to medical professionals and diagnostic equipment, yet the question ‘why me?’ is not answered in hospitals. Medical explanation may indeed be comforting but does not resolve the confusion about God’s role in impairment. Rozario (2009:178) articulates this in stating that “even if people understand the genetic explanation... it does little to answer the question of personal meaning of what has happened”.

By focusing on the cause, or ‘blame’, for impairment, the literature undermines positive disabled identity. Disabled people in the UK, whose different bodies already conflict with a disablist society, may well find religion a further source of struggle (Rosmarin et al, 2009). Historical religious interpretations have influenced past attitudes (Rhodes et al, 2008). For example, the church’s history of charitable involvement (Eiesland, 1994; Stainton, 2008) is an influence contributing to the ‘tragedy’ view of disability (French and Swain, 2004).

Treloar (2000:15) found that “participants reported questions concerning the relationship of disability to sin, the judgement of God, adequacy of faith, and miraculous healing”. Associating sin with impairment is theologically difficult for Christians. Christians believe that God is “both one supreme being, and three distinct persons... God the Father, God the Son (Jesus Christ) and God the Holy Spirit” (2000:10). For Christians, “the acknowledgement of sin is not a shameful

thing” (Eiesland, 1994:70). The concept of God using impairment as punishment contradicts Jesus’ sacrifice on the cross, as “there is no longer any sacrifice for sin” (Hebrews 18:11). Indeed, everyone sins, but not everyone experiences disability (Eiesland, 1994; Schumm and Stoltzfus, 2007). However, Webster (2007:23) argues that Christianity almost takes for granted a “direct link between disability and sin”, which may be evident by the prevalent confusion regarding the relationship, if any, between them.

Writers such as Deland (1999) discuss the confusion around Old Testament passages relating to impairment, for example Leviticus 21:17-23, where lists of impairments unacceptable to God are presented. Explanations for such passages include impairment as challenging God’s divine creation or perfection (Rose, 1997), cultural or historical context and theological misinterpretation (Abrams, 2007).

One major area of conflict for disabled people in the New Testament is healing. The confusion of developing a positive disabled identity whilst desiring the negative effects of impairment to be ‘healed’ needs recognition. Epperly (2003:81) felt interpretations of Jesus’ healing often “judge, demean and exclude” disabled people. Healing was so central to Jesus’ ministry, (“at the heart”, 2003:82) that he is nearly always “either actually healing someone, or has just come from healing someone, or is on his way to do it” (MacNutt, 1974:80). Deland (1999) questions if disabled people can relate to this image of Jesus.

Healing isn’t necessarily about removal of impairment but includes holistic approach to health, including the physical, emotional and spiritual aspects of identity. Gockel (2009) and Epperly (2003) have distinguished between healing and curing. Locker (2008:84) emphasised the importance of “maintaining or improving quality of life” as opposed to eradicating illness. Jesus’ healing of physical impairments had positive social consequences (Schumm and Stoltzfus, 2007), and in modern times perhaps the simple experience of loving community and social acceptance count as healing ministry. Jesus used physical touch (Matthew 14:36) and divine command (Luke 17:14) to heal blindness (John 9), leprosy (Matthew 11:5), paralysis (Matthew 9:1-8), bleeding (Matthew 9:18-26), and other conditions.

This, however, perhaps offers little comfort to those who desire physical healing but do not experience it. When inferences are made about cause of impairment or reason for not experiencing healing, such as lack of faith (Deland, 1999) or the impairment being God's plan (MacNutt, 1974), how is this internalised by disabled people? 'Seeking rectification' is often a natural response to the onset or deterioration of impairment (de Wolfe, 2002) but can one pray for healing and at the same time hold a positive disabled identity? Hernandez (2005) has noted that the onset of impairment can prompt 'spiritual awakening'; it cannot be assumed that all Christians accept modern interpretations of physical healing. Disability is "not an entirely negative experience" (Vasey, 1989:unpaged). It could be argued that the church perpetuates the 'inherent assumption' that disabled people want to be non-disabled (French and Swain, 2004), even asking disabled people to reject their disabled identities.

### **Christian Experience and Impairment**

Eiesland (1994:25) argued that the 'community of God' needed to renew symbols and practices in order to be inclusive, and Gordon (2009:59) described the inaccessibility of "worship, prayer, service and witness" and argues for more 'generous' definitions of Christianity. Creamer (2008:36) gives the pulpit, inaccessible to those unable to climb to it, as an example. Lack of accessible church environments was highlighted elsewhere (Healy, 2009), but also access to the Christian community in respect of attitudes toward disabled people. Rush (2004) articulates this as he describes his experience of political activism and Christian journey. Webster (2007) criticises the alienating nature of Christianity's 'symbolic language'. It should be noted that Christianity has numerous denominations, worship styles and practices (Treloar, 2000), and therefore experience of 'church' is highly individualised. For many Christians, emphasis is not church but "personal relationship with Jesus Christ" (2000:14). Christians are collectively called to say 'no' to conflicting values and assumptions from the secular world (Wolfensburger, 1983), but it can be difficult to differentiate between the non-Christian and the Christian response to disability.

If it is true that religious practice has changed significantly in recent decades (Gockel, 2009), how has church practice changed toward disabled people? Creamer (2008:35-36) argued that

“religious communities have often been unhelpful, and even harmful, in relation to [disabled people]... Christian communities frequently ignore [disabled people] altogether”. de Wolfe (2002:257) expressed the vulnerability of her quality of life, how it “may be destroyed by a simple act of stupidity”. It is interesting to note that some writers expressed specific negative experience, for example from a particular church (Rush, 2004) or a particular person (Eiesland, 1994:34). For Scambler and Hopkins (1986), this would be ‘enacted stigma’, contributing to a much more internally damaging ‘felt stigma’, or “fear of enacted stigma” (1986:33), affecting the disabled person’s identity.

Levine (2008) identifies that for many Christians, the mental process of prayer can help with emotional and intellectual adjustment. “Religious support can be a stable coping strategy” (Treloar, 2000:8), and asking “to pray at once expresses emotional support” (Levine, 2008:87), offering comfort from the congregation unlikely to be found in secular society. Communion (or Eucharist) is a sacrament during which Jesus’ body is ‘shared’ through the taking of bread and wine. Communion held deep significance for several writers (for example Eiesland, 1994; Caygill, 2008; Harren, 2009), perhaps because of the unique physical and spiritual link found in remembering Jesus’ crucifixion and resurrection.

Watson (2002:519) argues that “separation of self and body for disabled people is part of their biographical narrative”. However Eiesland’s (1994) *The Disabled God* is centred on reconceptualising the body and what it means to be ‘embodied’. Eiesland (1994) highlights the significance of Jesus’ embodiment as God in human form; his being ‘disabled’ by his wounds on the cross. She extends this by depicting Jesus in a “sip-puff wheelchair” (1994:89), finding that this image makes it possible “to bear a nonconventional body” (1994:105). However, this would contradict Epperly’s (2003:91) view that “Jesus the healer is a friend of those who are called disabled”. Identifying with either the ‘healing friend’ or ‘disabled God’ is likely to impact on both the disabled and faith aspects of identity. Does God want the disabled body to be different, healed? Or is God disabled, wounded and disfigured by the cross?

## **Conclusion**

This review of the literature has sought to explore existing understanding and debates relevant to the relationship between Christian faith and identifying as a disabled person. It is not clear from the literature if adopting Christian faith has positive or negative impact on a disabled person's identity. Biblical interpretations about reasons for impairment and God's role in impairment have not drawn consistent conclusions. Greater insight is therefore needed about how Christians who are disabled people relate to the comfort, confusion and conflict described in the literature. The following chapter will describe the research design and methodology for undertaking further empirical research.

## **Chapter 3: Methodology**

### **Paradigm, Participation and Practicalities**

In order to further explore the comfort, confusion and conflict in relation to faith and disability discussed in the literature review, it was necessary to form a research design. This chapter begins with explanation about the research paradigm and considers the practicalities involved with undertaking research, such as sourcing participants and interview venues. Decisions in regard to methodology are discussed and explained.

#### **Research Paradigm**

The research paradigm, the basic set of beliefs (Guba, 1990), for this project is interpretive. This perspective advocates that reality as we understand it is 'subjective', gained "through the meanings and understandings garnered from our social world" (Angen, 2000:385). In contrast to positivist research, the interpretive approach advocates that "reality exists only in the context of the mental framework (construct) for thinking about it" (Guba, 1990:25). "The essence of human experiences about a phenomenon as described by the participants" (Creswell, 2009:13) is important.

Oliver (2002) discussed three research paradigms (positivist, interpretive and emancipatory) and their relationship to disability research, illustrating that the positivist paradigm relates to disability as an individual problem (for example, the medical model) whilst the interpretive paradigm relates to disability as a social problem. The social model interprets disability as a "situation caused by social conditions" (UPIAS, 1975:4). Positivist research has been the 'dominant' paradigm (Oliver, 1992) and positivist emphasis on value-free and 'objective' research has been considered oppressive (Zarb, 1992).

Oliver (1992:106) has argued that interpretive research has been as oppressive as positivist research because "the social relations of research production have not changed". By choosing a topic area I can identify with personally, I hope to negate any oppressive aspects of research production through a more 'equal' research relationship (Hanley, 2005:viii; Essien, 2009). Whilst having an impairment is not a necessary 'qualification' to research disability (Barnes,

1992a:121), being a disabled person and a Christian is more likely to help participants feel comfortable and understand my motivation. This raises concerns that as a researcher I may 'over identify' with participants but, like Essien (2009:70), I feel that "sharing [my] experiences with participants [will mean I am] more sensitive to their needs".

### **Research Method**

The methodology, decisions for research, are rooted in the formulation of the research question (Purse, 1996). Though associated with a positivist paradigm, I considered using a quantitative method alongside qualitative methods. Zinnbauer et al (1997) used a questionnaire within a positivist paradigm in a study of religion, spirituality and biographic elements of identity. However, as this project focuses on identity, it would not be appropriate to phrase the research questions quantitatively. Miller and Thoresen (2003:25) have stated that "some features of spiritual experiences... may never be adequately captured by scientific methods". Indeed, Zinnbauer et al (1997:562) concluded that future studies "must go beyond the use of single-item self-report measures and scales".

Qualitative methods have "often been denied a scientific status" (Kvale, 1983:189) by those advocating positivist epistemology. This is because of issues relating to replication of data and the influence of the interviewer on the interviewee, but writers such as Kvale (1983) have argued that this can have positive benefits. Qualitative methods, such as semi-structured interviews, are recommended for areas where "little research has been done" (Creswell, 2009:18) and for "small scale studies" (Barnes, 1992b:116). Semi-structured interviews have been defined as "neither a free conversation nor a highly structured questionnaire" (Kvale, 1983:174), allowing participants to flexibly expand or explain areas of particular interest or insight. This would be very limited by a quantitative method, as qualitative methods are "concerned primarily with meaning and interpretation" (Barnes, 1992b:115), and this project sought to learn about the meanings and interpretations from participants, not quantifiable information (Kvale, 1983).

Interviews are not considered scientifically 'reliable' because the results would not likely be replicated (Kvale, 1983). However, this can be seen as a strength of the method, because the

interviewer uses their insight and relationship with the interviewee to enrich the depth of data collected (1983). Kvale (1983:191) defined validity as “whether one has in fact investigated what one wished to investigate”. Traditional, ‘realist ontology’, evaluations of validity are problematic for qualitative methods (Angen, 2000); for example “specific methodological criteria continues the positivist assumption of an external foundational reality” (2000:383). Though encouraging participants to review and amend transcripts has been criticised as a means to improve validity (2000), this will ensure participants agree transcripts reflect their ‘truth’.

Faith is wider than Christianity, however practical constraints prevented a comparative study between the understanding of those with different faiths and beliefs, or different Christian perspectives and backgrounds. Whilst Oliver (2002) has asserted that providing individual accounts of disability is not sufficient, it is a start. The purpose of this study was not to draw general conclusions about the experience of faith and disability, but to offer depth of analysis (Gockel, 2009).

### **Participant Recruitment**

I used ‘snowballing’ to source nine participants for interviews. Snowballing “consists of identifying respondents who are then used to refer researchers on to other respondents” and is suitable for qualitative studies using interviews (Atkinson and Flint, 2001:1). Whilst snowballing is less predictable than other recruitment methods, there was a relatively large possible sample and a relatively small number of participants required. The local area I planned to interview in was biographically diverse (Merton Council, 2009:9), and it was therefore more likely that the ‘random’ nature of the snowball would result in a biographic mix of participants.

I aimed to recruit an equal number of men and women, with physical or sensory impairments, of varying ages. Inclusion of those with other types of impairments was outside the scope of this study and was therefore a limitation. Most participants were female, with one male participant, ranging from 29-67 years of age (Appendix One). This may be attributed to one of the deficiencies of snowball sampling, as selection bias (Atkinson and Flint, 2001:2), tended towards female referrals. However, given the practical constraints and specific identity criteria,

snowballing was the most “economical, efficient and effective” (2001:2) way of identifying participants. To avoid bias, I wanted to avoid recruiting participants known personally and the ‘participant pack’ (Appendix Two) was distributed via over thirty personal contacts to provide information about myself and the project, the interviews and the questions I planned to ask. It was later distributed to Christian charities and organisations with contacts in the locality.

Potential interviewees were asked if they identified themselves as a Christian and if they identified themselves as a disabled person. Having an illness or impairment doesn’t necessarily result in a disabled identity (Barnes, 1992a). Defining Christianity for potential participants may have excluded those who may not ‘practice’ or express their faith in traditional or religious ways. Definition was not the only problematic issue relating to language. As Blaikie (1993) noted, participants may not understand the language used by the researcher, and this was considered when recruiting and interviewing.

### **Interviewing Participants**

The semi-structure of interviews allows “all participants to be asked the same questions within a flexible framework” (Dearnley, 2005:22), enabling interviewees to describe individual experiences and explore areas of particular insight. I collected data about the age, gender and type of impairment from the participants at the beginning of interviews to ‘ease’ into questioning and allow for later comparison. An interview guide, with questions and prompts, was formed inductively during the literature review and is attached as Appendix Three. A ‘test’ interview took place before interviews with participants commenced in order to test the recording equipment and suitability of potential venue.

It was also important to consider the ‘fluidity’ (Creamer, 2008) of the research topic and the influence this may have. Neither faith nor disability are fixed elements of identity. For example, if the participant felt negative because of high levels of discomfort or pain, and therefore answered negatively, this would be no less ‘truth’ than if answering positively because of low levels of pain. Rather than invalidate the results, this variability reflects the lived truth of living with impairment and being committed to faith, as “there is no static truth to which the results of an interview can be compared” (Angen, 2000:383). Healy (2009:10) has described faith

communities as a “microcosm of a particular faith tradition at a given moment in time and place”; and results were intended to reflect a ‘microcosm’ of the experience of faith and disability. All participants were invited to review transcripts after the interview and suggest amendments. Due to the long length of transcripts and potential distress to participants of verbatim copies (Dearnley, 2005), ‘summary’ transcripts were also available in addition to the full transcript. All participants were offered a copy of the final dissertation in full or summary as preferred (Joseph Rowntree Foundation, undated).

I considered my strengths and weaknesses as a researcher when evaluating what research methods to use, and felt my interpersonal and communication skills were suited to interviewing. While recognising that my relationship to the research topic was a strength of the project, this would be heavily criticised by positivist researchers who argue that researchers “must stand behind a thick wall of one-way glass” (Guba, 1990:19), be ‘value free’. However, the way researchers are ‘perceived’ (Goodley, 1996) is important to data collection, not only to enable honest communication but also because interviewer and interviewee “reciprocally influence each other” (Kvale, 1983:178).

### **Practical Considerations**

I also considered the practicalities necessary for conducting successful interviews. As a disabled researcher I needed to consider my own needs and those of participants. The interview venue needed to be private and comfortable (Dearnley, 2005) so the participants would feel relaxed. I gained permission to use meeting rooms within my workplace, and three interviews took place there. However, most participants expressed preference to conduct interviews in their homes and these requests were met. One participant was interviewed within my church building. Interviews varied in duration from 20 minutes to over an hour.

I recorded interviews and then transcribed them in written format afterwards. This was time-consuming (Pope et al, 2000; Dearnley, 2005), taking two to four days to transcribe each interview verbatim. It was also considered that an interview is an ‘unnatural’ setting and using a recorder may have made participants uncomfortable or influence response (Tuckett, 2005).

However, recording enabled engagement with participants during discussion, and all interviewees were advised prior to the interview about recording.

### **Ethical Considerations**

As well as offering opportunity to share experiences, the interviews also gave participants a forum to explore the faith and disability aspects of their identities. Note was taken of the Department of Health's (2005) *Research Governance Framework* which states that "the dignity, rights, safety and well being of participants must be the primary consideration in any research study" (2005:7). Discussing faith in relation to experiences of impairment is potentially emotionally challenging; "we cannot separate the tale from the telling" (Goodley, 1996:345). Angen (2000:388) argued that research needs to answer the "so what question", and my aim was that any emotional consequences would be positive whilst recognising that "distress is not necessarily equivalent to harm" (Faulkner and Tallis, 2009:57) and "allowing participants to tell their stories represents a form of pastoral caring" (Treloar, 2000:25).

Before undertaking participant recruitment I sought pastoral guidance. I did not ask any participants to take part directly, agreeing to interview was made only after initial referral and opportunity to review the participant pack (Appendix Two). The pack allowed participants to prepare for the interview in advance, for example by discussing participation with their faith leader or other source of support. Before interviews, participants were advised they could withdraw from the research process "whenever and for whatever reason" (British Sociological Association, BSA; 2002:3) at any time before the end of the interview. After the interviews were transcribed interviewees reviewed their transcripts. Consideration was also given to protect personal data (BSA, 2002) and pseudonyms to protect anonymity were agreed with participants at the start of every interview.

### **Analysis**

Discourse analysis of the statements made by participants during interviews was undertaken. Discourse is "language use in context [or] real language use" (University of Sussex, undated:unpaged), and analysis includes comparison and examination of recurring themes and

experiences using “analytical categories to describe and explain social phenomena” (Pope et al, 2000:114). As I conducted and transcribed the interviews, familiarity with the transcripts eased the categorisation and analysis process (Pope et al, 2000). As Mason (1996:2) has explained, “the function of the categories is to focus and organise the retrieval of sections of text, or elements of data, for the purpose of some form of further analysis”. I derived categories inductively, “gradually from the data” (Pope et al, 2000:114), presenting results that connected recurring or prominent themes or experiences related by the participants, as well as highlighting differences in the individual’s narratives.

A difficulty considered with discourse analysis is distinguishing whether the actual words or the meaning behind them (Kvale, 1983) are being analysed. As language and the meaning of words is fundamental to discourse analysis, it was very important to ensure the meaning from the participant was understood, for example by sending “the interpreted meaning back” (Kvale, 1983:181) during the interview to the participant; continuously interpreting before formal analysis takes place. A further difficulty with discourse analysis is the “time-consuming and stressing” (1983:179) process and this was incorporated into the project timetable.

## **Conclusion**

Following the research design described here, interviews were undertaken with participants. The results of these interviews and how they relate to the comfort, confusion and conflict described in the literature review now follows in the next three chapters, beginning with discussion about the impact of Christian faith on interviewees’ identities as disabled people.

## **Chapter 4: Christian and Disabled Identities**

### **How does the adoption of the Christian faith impact on a disabled person's self identity?**

The following three chapters explore and analyse findings following interviews undertaken as described in the preceding methodology chapter. Whilst Chapter 5 focuses on the bible and its interpretation, and Chapter 6 life experience, this chapter explores the identity of interviewees. Disabled and Christian aspects of identity development, identity stereotypes and meaning within identity are discussed.

#### **Identity Development**

From a social model perspective, “disability is not caused by impairment... but the oppression of people with impairments in a disabling society” (Swain and French, 2000:570). It has been claimed that to develop a positive identity as a disabled person it must be rooted in the social model of disability (French and Swain, 2004), in order to negate the oppressive and disabling social context in which identity develops. While the interviewees did not deny this, neither did they confirm it. It has been argued that the importance of the social model is “that it no longer sees disabled people as having something wrong with them” (Oliver, 1981:unpaged), and perhaps adoption of Christianity has a similar importance for disabled people. The social model was referred to in the participant pack, but only one of the interviewees (Mr X) asked me to clarify further and none raised the social model during our interview. None of the interviewees referred to their ‘impairment’, preferring phrases such as ‘my disability’. Writers such as Reeve (2004) have distinguished between having an impairment and identifying as a disabled person. While use of language may not have conformed to ‘social model’ understanding, interviewees clearly articulated disabled identities.

Rhodes et al (2008) have argued the contextual dependence of both individual and collective identities. This analysis focuses on the Christian context. Though experiences of Christianity differed for interviewees, experiences of becoming a Christian shared some similarities. All had some Christian influence during their youth, though not necessarily from immediate family. For

example, Ms R and Ms P started attending church through 'Girl's Brigade'. O'Connor et al (2002) found parental influence to have a weak relationship to adult church attendance and Stolzenberg et al (1995) found early religious influences weaken over time. However Cornwall (1989:589) has argued that "parental attendance [has] significant direct impact on adult belief and commitment". Indeed, Stolzenberg et al (1995:84) argued that "families provide children with their initial religious identity" but Ms P was clear that it was her impairment that inspired a sense of God and not parental influence:

*'We're not from a Christian family... I think I better say thank you to [God] that I didn't die. And so I, was my first prayer, and I, so I honestly think that God actually used my disability to get my attention'* (Ms P)

Disabled people may therefore have influences impacting on Christian identity that may offer interesting insight in comparison to non-disabled people.

O'Connor et al (2002:723) stated that "research has found that church disaffiliation occurs most often in the teenage years and early 20s" and several interviewees described a time between youth and adulthood before (or while) the decision to become a Christian was made, for example:

*(Ms M) 'It was such a feeling of loneliness, which brought me to what my parents was teaching me... to the Christian teaching, y'know, when I was that much younger...'*

*(Rachel) 'So it sort of kicked in?'*

*(Ms M) 'It kicked in, that's right, yeah'*

Ms C, Ms P, Ms R and Ms J all described attending Christian holidays during teenage years and Mr X attended a 'Christian' school. O'Connor et al (2002:730), in a study comparing youth influences on adult church attendance, found that 'church youth programs' were the only "aspect of youth that proved to be a significant predictor".

Ostrander (2008:595) found "that social contexts create internal battles among identity components", and while this was not explored in-depth interviewees generally seemed to have

reconciled different identity components within their faith. Seven of the nine interviewees were over 50 years of age. As decline in physical health is an expectation as we age, this may well impact on how older adults understand their experiences of impairment (Ardelt et al, 2008). It has been argued that a particular concern for the identity of disabled women is the social expectation of marriage and motherhood (Vernon, 1999). Female interviewees were not asked directly about their marital status or children; however, four mentioned this. One (Ms G) describing not being able to have children as a difficulty connected with church, as church was family-orientated. Neither of the interviewees who identified as mothers described difficulty fulfilling that role in regards to impairment, though both had developed impairments when their children were young. Three female interviewees spoke about being married and spoke positively about their husbands, for example their practical support.

### **Identifying as Christian and a Disabled Person**

Five interviewees had had impairments since infancy (two of these interviewees later developed additional impairments) and four had developed impairments during adulthood. Interviewees experienced physical, neurological and sensory impairments. Becoming disabled or developing an impairment during adulthood changes lives (French and Swain, 2004). Interviewees did not express negative impact on their lives or identities, though they were honest about changed limitations and lifestyles. Interestingly, though four interviewee identities were constructed in an ablest social context (Swain and French, 2000), all four had also been Christians before their impairments developed. All interviewees were aware of their disabled and Christian identities; neither seemed an abstract or difficult concept. This contrasts with the literature, where previous studies on identity have shown disabled participants unlikely to identify as disabled people (such as Hernandez, 2005), and is also interesting in that religious meaning can “[saturate] personal and societal understandings of disability” (Creamer, 2008:79). Several interviewees emphasised the Christian aspect of their identity as most important, in contrast to Healy’s (2009:232) statement that “the disability becomes more important than the person”:

*'I'm happy to be deaf and I'm also happy to be a Christian. I accept what I am... You don't have to think about, err, deafness, you have to think of love and peace as the priorities' (Ms T)*

*'they're both part of me... I think the main part is being a Christian... MS, y'know, it's just a material thing and, but being a Christian is the main, the main thing' (Ms J)*

*'worst my disability becomes, I think the stronger my faith is' (Ms M)*

Interviewees' statements would suggest that this identity balance is a choice, in answer to Vernon's (1999:391) question, "which aspect of your identity do you prioritise and which do you leave out?" For the interviewees, faith provided another or further opportunity for identity construction. In a disablist society that also devalues Christianity (Healy, 2009), interviewees positively affirmed both aspects of identity. "Our sense of self is constantly evolving" (Watson, 2002:511) and this includes the self in relation to God. Several interviewees also described the importance of time to their understanding of identity:

*'I used to find it very hard, I found it hard as a child but as I've got older I've found it easier to accept and just carry on' (Mr X)*

*'you're learning all the time. It's like, you're learning about how to cope with my arthritis, and you learn about God... sort of learning curve all the time' (Ms M)*

### **Identity Stereotypes**

Reeve (2004:unpaged) has described "psycho-emotional pathways of oppression which are sustained through imagery, cultural representations and interactions with others". For interviewees, these pathways were generally positive in the context of their faith. In her book 'The Disabled God' Eiesland (1994:89) presents an alternative view of God, "God in a sip-puff wheelchair... not an omnipotent, self-sufficient God, neither a pitiable, suffering servant". Harren (2009:278) echoes this, learning "to view the world and God in a different way". None of the interviewees suggested an alternative model or view of God. Jesus did not seem to present confusion or conflict to the disabled identity. Though Ms T had experienced barriers during

childhood to understanding Christianity from lack of sign language interpreters, she asserted that her understanding of Christianity was 'the same' as for non-disabled people.

The importance of visible impairment was expressed by only two interviewees, Ms R and Ms P, twin sisters who were born with cerebral palsy. Ms R developed a blood disorder as an adult, and both sisters shared the contrast in experiencing visible and invisible impairment:

*'I feel that my twin sister's got so many struggles that people can't see on the outside... I've felt that people have looked at me with an obvious disability and not felt comfortable with that'* (Ms P)

*'it's fairly obvious that I've got a slight problem walking but my other, my other illness isn't really obvious. It's what I call a hidden illness... I'm not actually feeling that well but because I look ok I find there's often misunderstanding'* (Ms R)

Ms P and Ms T emphasised the importance to their identities of being born with, rather than acquiring, impairment:

*'I may repeat myself here but I think it's so hugely different to, to becoming disabled or unwell later on in life, because to me it's who I am'* (Ms P)

*'If I was born hearing and I grew up and then I became deaf, maybe I'd think "why, why, why?" but because I became deaf at a young age I've never had to think "why?"'* (Ms T)

Reeve (2004:unpaged) has stated that "people may identify as disabled in one setting but not in others". None of the interviewees described identity conflicts in non-Christian settings or a need to 'pass' as non-disabled (Goffman, 1963). Four interviewees mentioned their job(s) or professional employment. For Ms P work was intrinsically linked to both impairment and faith. Ms T mentioned 'a job' but did not elaborate further, Ms J described continuing to run her own playgroup until it was 'too much' and Ms M was working as an Orthopaedic Nurse. Interviewees were not asked about ethnicity or 'race', but did represent various 'racial' backgrounds.

Creamer (2008:5) has argued that “disability identity... depends a great deal on the interpretations of others”. Several interviewees described the importance of Christian friends and the importance of encouragement from such friendships. Gordon (2009:54) argued that “personal relationships where individual identity as a self, and community identity as group, form and inform one another”. None of the interviewees seemed to emphasise their denomination of Christianity as important, but several highlighted the importance of other Christians to their experience:

*‘I have got a Christian friend at church that’s very influential... although she’s had several problems herself, physically, she’s so very strong, erm, spiritually... she has been sent to help me along as well. I feel lots of good people have come along’ (Ms J)*

*‘I have some good friends that are Christians’ (Ms W)*

*‘I think my biggest impact definitely would be talking, just talking to, is genuinely talking to other people and their experience and stuff’ (Ms C)*

(Ms R) *‘...Christian camps for teenagers which helped me a lot as well’*

(Rachel) *‘How did they help?’*

(Ms R) *‘Well, erm, just being, being with other people’*

### **Identity and Meaning**

Epperly (2003:84) has stated that disabled people “are often blamed for their illness, they are also often criticised for lack of faith”. Schumm and Stoltfus (2007:9) described the ‘spiritual burden’ arising from others’ suspicion of disabled people’s ‘spiritual condition’. For Ms R, this suspicion was very significant. After sending the transcripts for review, Ms R replied in writing emphasising the experiences she described were ongoing:

*‘I also wanted to make it clear that people’s need to look for reasons for my illness when praying for me continue to this day and did not just occur in the early days when praying about my cerebral palsy’ (Ms R)*

For Ms P and Ms C also, negative experiences of healing had had significant impact. Hunt (2000) compared some healing services to stage plays following scripts, and some interviewees identified being 'typecast'. While "affirmations rather than negations" (Epperly, 2003:85) elsewhere had helped interviewees with overcoming these experiences, the destructive potential for blame, criticism and general ignorance towards disabled people should not be ignored. McNair and Sanchez (2007) have highlighted confusion from church leaders about why people experience impairment. The interviewees seemed to emphasise the roles other Christians and friends had on their relationships with God, rather than faith leaders, and this would be an interesting area to explore further.

"While God permits suffering, God does not cause it, explain it, or apologise for it" (Deland, 1999:59). Similarly, interviewees had a general understanding of God's involvement with their impairment not of cause but perhaps allowance:

*'Not why me, but why not me? The Lord must think I've got, I've got enough support from him to be able to cope... I think he allowed me to have it because he's waiting to pick me up when I fall' (Ms W)*

*'I don't know the reason, but I know that I have got it, and I know that God knows that I have got it. So he will help me through it' (Ms M)*

*'I know that God's got his hand on me. Y'know, he wouldn't have chosen for it to happen but for some reason he's allowed it to happen' (Ms R); 'I find that I just accepted that that's how God made me really... With my illness that's occurred in more recent years, erm, I don't know how to answer that really' (Ms R)*

A sense was gained of God being very close in the experience of impairment, but more distant when discussing the reason or cause for impairment. Perhaps this is the influence of socially negative connotations with impairment, resulting in interviewees' reluctance to directly associate 'positive' God with 'negative' impairment. As Creamer (2008:112) has asked, if "humans are created in the image of God, we must then ask what it tells us about God that humans are limited?"

Several interviewees echoed Treloar (2000:17), who found “the participant’s purpose in life was use by God; this provided meaning for disability”:

*‘he’s given to me because I can cope with it and I am strong enough. And people that I go to my therapy centre with aren’t strong enough and they don’t have any firm beliefs... maybe he sends me in to try and help them’ (Ms J)*

*‘I honestly feel that God’s put me on this earth as a disabled person for a certain reason... I suppose to be an example to other people, to able bodied people and that kind of thing’ (Mr X)*

Epperly (2003:89) has argued that only a ‘diabolical’ God would cause pain in a person to ‘help others’, however this almost assumes disability is negative and impairment painful. Ministering to and helping others has been suggested in the literature as a possible reason for impairment, as has ‘spiritual maturity’ (Hersh and Hughes, 2006:91) and empathy. Swain and French (2000) also suggested that experiencing impairment could increase understanding and empathy towards others experiencing oppression, so this view is not limited to a Christian context.

A conflict does arise here, as it is difficult to understand God willing the experience without also being involved in the creation of it. None of the interviewees expressed desire to be non-disabled, ‘cured’ or ‘healed’ of their impairments, perhaps reflecting deeper convictions not only about ‘full social membership’ (de Wolfe, 2002:259) but full Christianity. The powerful connection between faith in divine plan and identity as a disabled person should not be underestimated. Hernandez (2005) found that acquirement of impairment could be viewed as a ‘blessing’ or opportunity to re-evaluate life, and Ms T answered affirmatively when asked if she saw being deaf as a blessing from God.

Miles (1995) has described the importance of the ‘meaning’ of impairment in religious context, and for the interviewees it seemed such meaning was not about the cause but rather the effect. It may be true that “physical disability has confronted the church most significantly as a theological challenge” (Eiesland, 1994:67), however interviewees didn’t express confrontation or challenge. Confusion was apparent but interviewees did not seem to agree that finding

meaning was of paramount importance. Deland (1999:55) has suggested that “suffering is felt to have meaning if it can be related to God’s presence and purpose”. However, Caron (2002:16) has argued that in the context of chronic illness, “not everything has meaning” and Schumm and Stoltzfus (2007:17) add that “why questions are particularly problematic in many cases involving chronic illness”. While the literature may be heavily focused on ‘meaning’, disabled people who are Christians may not share this emphasis. As Healy (2009:213) has argued, “only the storytellers can really understand what their stories mean to them”.

Eiesland (1994:34), recounting Diane DeVries story and “her grandmother’s belief that someone needed to be blamed for her existence”, explains that “DeVries refuses to give some special explanation for her birth”. A focus on meaning can therefore be a further form of oppression for people who are Christians, compelled to provide ‘special explanations’ for their identities.

### **Conclusion**

Interviewees related positive Christian and disabled identities, indicating a positive view of disability through Christian eyes. There is perhaps a unique alternative disabled identity available to Christians, not available to others. The role of God in impairment was of importance to interviewees, with an emphasis on the effects rather than cause. Relationships were a positive influence on identity, but negative effects and potential for harm were also noted and those related to ‘healing’ will be discussed in the next chapter.

## **Chapter 5: The Bible, Impairment and Disability**

### **How do disabled Christians interpret and explain references to impairment and disability in the bible?**

As all interviewees described some form of Christian influence during childhood connection with the bible and experience of impairment has lasted through most of their lives. This chapter explores interviewees' understanding, interpretation and experience of the bible. Interviewees were asked about positive or encouraging scriptures, then about negative or unhelpful scriptures. Healing and the relationship between the interviewee, the bible and God were also explored.

#### **Positive References**

Interestingly, when asked which verses or passages were particularly helpful or comforting, several interviewees did not quote the bible exclusively:

*'but one... scripture that comes to mind is the, the Footprints in the Sands [poem attributed to Mary Stevenson]' (Ms M)*

*'I tell you I get very touched with certain hymns' (Ms J)*

*'various hymns have sort of a lot of meaning' (Ms G)*

Is it therefore the case that the interviewees primary source of guidance and comfort was somewhere other than the bible? Different denominations of Christianity may interpret scripture differently (Treloar, 2000) and this may have been a source of confusion; interviewees were from various (and sometimes unspecified) denominations. Many Christians relate to God through music and worship so it cannot be assumed that disabled people who are Christians have moved from the bible to other resources because of confusion or conflict about impairment.

Scripture choices were eclectic, with references to 'Psalms', a collection of poems and songs attributed to David (second King of Israel), mentioned by five interviewees. Almost all the

Psalms offer praise to God, though many begin with cries of anguish or torment. Ms G, Ms P and Ms R spoke about Psalm 23, often known by the lines:

“though I walk through the valley of the shadow of death, I will fear no evil, for you are with me, your rod and your staff, they comfort me” (Psalm 23)

Ms R and Ms P also made specific mention of Psalm 139, which contains the lines “for you created my inmost being; you knit me together in my mother’s womb” (Psalm 139). Ms P described particular poignancy in the lines “my frame was not hidden from you when I was made in the secret place” (Psalm 139):

*‘I know that literally that means our bones and our body but I’ve taken it to be a walking frame! And I really felt that God said that to me, that he knew from the outset that... I would have a walking frame and a disability and it was actually part of his plan, so that’s been very encouraging’ (Ms P)*

New Testament sources of encouragement included the gospels and other New Testament ‘letters’. Paul’s ‘thorn in the flesh’ (2 Corinthians 12:7-8), discussed in the literature (for example, Epperly, 2003; Creamer, 2008) was discussed by two interviewees. One (Ms P) also raised the theological debate about what this thorn was (often believed to be visual impairment; Hersh and Hughes, 2006). Paul needed not only to contend with the thorn, but the attitudes of those who attributed it to “a demon, divine anger [or] his own sinfulness” (Epperly, 2003:92). The lack of certainty about what his thorn was, why he had it, and indeed his pleading for God to remove it, would seem to offer comfort to those not able to understand their impairments or suffering as a result of them.

Only two interviewees (Ms R and Ms P, who had both made notes prior to the interview), mentioned more than two specific scriptures when answering what particular passages had been helpful or encouraging. Epperly (2003:86) has called for re-examination of “the healing stories in the light of the totality of Jesus’ ministry”. Reliance on the written biblical text, particularly dissected into singular verses, for evidence of God’s role in impairment is

incomplete. If “the word of God is living and active” (Hebrews 4:12) then neither Christians nor researchers can examine the ‘written’ without considering the ‘living’:

“[is it] the letter of the text or it’s ‘spirit’ that is to be interpreted... is what matters to get at the expressed meaning or at the intended meaning?” (Kvale, 1996:211)

### **Negative References**

When asked about passages that were unhelpful, responses from interviewees were mixed, with three each mentioning only one verse and six not able to recall any specific verses. Presentation and interpretation of scripture, however, was significant:

*‘that disturbs me a lot, because I say, show me in the bible where it says that you cannot take blood from someone else... you’ve taken away a transcript from here and put it into your, your interpretation into, and made your own bible’ (Ms M)*

*‘I can’t remember. I mean, there are some things that I think “he couldn’t really have meant that”, y’know, when you think about these things... I have to think about it again, and there must have been a reason for preaching that’ (Ms J)*

*(Ms P) ‘this verse was quoted as part of a sermon by a well known Christian speaker... I had huge problems with it...’*

*(Rachel) ‘Was it the verse itself [2 Samuel 3:29] that you found difficult or was it the way it was interpreted and presented to you in the sermon?’*

*(Ms P) ‘I think it must be the way it was interpreted and presented, yeah’*

Given the focus in the literature on Leviticus (for example, Creamer, 2008; Eiesland, 1994), it is interesting that only one participant (Ms P) mentioned Leviticus. Eiesland (1994:70) has highlighted the need for “an extensive biblical interpretation as it regards [disabled people]” and there was evidence from the interviewees that this would be beneficial. If it is true that theology has not engaged with or been undertaken by disabled people (Creamer, 2003) or not

positively considered 'different' bodies (Caron, 2002), is it unsurprising that interviewees' greatest source of biblical confusion was from interpretation?

Language was raised by Mr X, who described dislike of the word 'crippled', particularly in a biblical context. Ms R also described difficulty with language, with an emphasis on the interpretation and application of Old Testament passages. There was no evidence from interviewees that they felt symbolism in biblical or Christian language had 'alienated' them (Webster, 2007). In regard to healing, it has been argued that passages are often "interpreted in ways that judge, demean and exclude persons with disabilities" (Epperly, 2003:81). Mark 2: 1-12 describes how a man's "friends bring him to the place where Jesus is staying [and] they find the house inaccessible to them" (2003:82). Interestingly, Ms J interpreted this passage more positively:

*'he was so understanding and so kind. And he didn't have any fuss or bother, he just said, "let them come to me", y'know'* (Ms J)

### **Healing References**

Jesus "healed lame, blind, mute and/ or epileptic persons" (Webster, 2007:26) and when asked about Jesus' healing ministry and experiences of healing, responses were significantly mixed:

*'I had what... to be a miracle through modern science and technology... [God] gave people pharmaceutical knowledge to help other people to make the tablets to take your pain away'* (Ms G)

*'you have to have a positive faith to help you with the healing'* (Ms T)

*'Well, I'm open to it if it happens but if it happens, great, and if it doesn't then that's his will, meant to be. I think I possibly have more struggles when it doesn't, when it doesn't happen for other people'* (Ms C)

*'I believe those stories. Erm, I really believe them. But I can't think that anybody could do any healing now, in me, or you, physical'* (Ms J)

*'Part of me wants to believe and, but the other part of me questions it. Erm, maybe healing for you, your, your being healed is a state of mind. Maybe you weren't fully as, as afflicted as you thought you were... I'm between yes and no'*  
(Ms M)

Schumm and Stoltzfus (2007:13), comparing the Buddhist and Christian perspectives on healing, stated that for Buddhism "healing is not an individual but a relational and interdependent process". Though individual perspectives on healing were very different, the 'interdependence' and importance of relationships was expressed by several interviewees:

*'just the three of us used to meet and pray. Pray about my, my leg and the pain I was getting'* (Ms R)

*'he came, and he prayed with me... as soon after he'd prayed with me the pain went away. So I suppose that is a form of healing isn't it really?'* (Mr X)

(Ms C) *'I think people asking is really nice, when people ask you first, and that's had, I've had positive and negative experiences in that I think'*

(Rachel) *'So, it's not so much the healing itself but the way somebody approaches it?'*

(Ms C) *'Yeah, I think so, yeah'*

Schumm and Stoltzfus (2007:16) went on to describe the importance of 'relational dependency' and how this defies "medical and restitution narratives". Ms C, Ms P and Ms R all discussed both positive and negative experiences of healing, emphasising that the way other people approach healing is of utmost importance:

*'I don't want to be made a spectacle of, y'know, I just don't like the fact of, depends how it's done'* (Ms R)

While there was a general openness about healing and a lack of objection to other's praying for their healing, none of the interviewees described praying for their own healing. This may represent a similar conflict to that raised by de Wolfe (2002:263), to "wish to join the world of

the well and the wish to be granted exemption from it"; interviewees were open to others' prayers but did not pray such prayers themselves, they were called to 'be open' to the possibility whilst assured of 'God's plan' for them. Selway and Ashman (1998:433) discussed the perception that in the New Testament, "disability was something to be healed, not accepted", and the interviewees directly contradicted this:

*'when I became a Christian I didn't expect to become hearing or anything like that ... No, that's not Christianity, that's not what it's all about'* (Ms T)

*'I've got better from broken legs, y'know, but I think healing my [cerebral palsy], I don't really think about it'* (Ms C)

*'more and more I've come to see that it isn't actually God's will for me to be healed but it's quite difficult when other people seem to, seem to expect that'*  
(Ms P)

New Testament references to healing did not seem to offer much comfort to the interviewees, but neither did they seem to present a conflict. Confusion in regard to Jesus' healing ministry was attributed more to understanding the modern context than on the content or meaning of the passages. This may also be linked to difficulty connecting the 'healing' image of Jesus to the actual experience of disabled people (Deland, 1999).

All interviewees had attended a 'healing service' at least once, and along with Eiesland (1994:117) "experienced the negative effects of healing rituals", along with positive experiences:

*'there was the laying on of hands in the service, and I thought it was, it was lovely of the Vicar to feel like this and to feel that the Spirit has, was there to, but I didn't necessarily believe it'* (Ms J)

*'Some of the ways people do that aren't necessarily [laughter] very helpful I've had, I've also had some experiences where I've been, I've been completely comfortable with it... Don't care about the space next to you and stuff and that I don't find particularly helpful when people do that'* (Ms C)

*'I didn't, didn't really sort of feel too much at the services' (Ms W)*

Ms G had prayer for a ganglion to be healed and Ms T had been healed of some back pain. Mr X had asked a friend to pray after a shoulder strain. Temporary injuries or conditions therefore seemed to be perceived differently to permanent impairments by the interviewees. This may be a reinforcement of the 'disabled' part of identity, in that the basis for the disabled identity did not require healing, but other injuries or conditions were viewed differently. Hunt (2000:83) asked "why [do] individuals purposely place themselves in a potential position of vulnerability and manipulation?" It seemed that, as healing wasn't sought for the impairments that resulted in their disabled identities, there was no more 'vulnerability' than for a non-disabled person. The assumption that a disabled person desires healing for their impairments, the "inherent assumption... that disabled people want to be other than as they are" (French and Swain, 2004:14), was denounced with strong affirmations from interviewees. Interviewees did not want to be healed of their impairments:

*'I want to make sure I'm being really honest with you, I don't think I've, honestly, ever sought healing of my cerebral palsy' (Ms P)*

*'I'm quite happy being deaf and that's it... Deafness isn't being ill' (Ms T)*

(Rachel) *'Is healing something you've ever asked God for?'*

(Ms W) *'Not really'*

(Rachel) *'Is it something you would want or do you feel that the MS is kind of part of you?'*

(Ms W) *'Yes, got it right there'*

This may be somewhat surprising, given that some interviewees' experience of impairment included pain and severe discomfort; and for some not being able to enjoy activities undertaken before impairment developed.

It has been argued that "healing does not necessarily include curing" (Gockel, 2009:219), so "what does physical, moral and spiritual healing mean when a cure is unlikely" (Schumm and Stoltzfus, 2007:8)? The mental and emotional results of 'healing' prayers need to be

considered. Epperly (2003:83) has described Jesus as a “healing companion on... journeys toward wholeness” and it was the connection between healing and wholeness, rather than healing and ‘cure’ that several interviewees articulated:

*‘I’d stood up thinking I was responding for God to, y’know, touch me physically ‘cause of my leg and that, and, and obviously God had a different agenda because the people started praying for me and I... Just had the most incredible like emotional release... I was just crying and crying and crying for probably about half an hour... I went away with exactly the same physical problem that I’d gone with, but emotionally I felt that God had healed me’ (Ms R)*

*‘it’s part of the healing that, that comes, not, not necessarily physical healing but in accepting who, who we are, who I am and, erm, God’s purpose in who I am really’ (Ms P)*

It could be argued that prayer is a unique form of social support (Ladd and McIntosh, 2008) and that the power in it is not jumping up from wheelchairs but the quiet loving touch of another human being and the few moments of care and attention from another shared with God. Here there is conflict, because if the outcome of prayers is disappointing, prayers can become “devoid of any sense of spiritual energy” (2008:30). Also important is allowance for “lament and realistic hope” (Caron, 2002:20) and open expectations. Ms R described the role others’ expectations had had on her experiences:

*‘they were very much wanting my leg to straighten out... they had high expectations and I felt I had to go along with it, erm, y’know, not disappoint them really... I think these days I wouldn’t be like that’ (Ms R)*

### **References and Relationship with God**

Interviewees expressed connection between ‘rights’ and healing:

*‘Internally, really, if I was to be healed [sighs]? Well, right now I would say to myself I would not be worthy... I feel that although I have tried to live the life that Christ asked, tried, I’ve failed dismally’ (Ms M)*

*'I remember thinking no, should I pray for myself?... Saint Paul had a certain amount of pain or an infirmity throughout his life... What right have I not to have it?'* (Ms G)

*'I don't feel that, err, why I should be healed more than anyone else really?'* (Ms W)

The literature has discussed negative relationship between faith and healing (Epperly, 2003), but not really explored this 'right' or 'worthiness'. Perhaps it is rooted in "moral confusion within Christianity" (Wolfensburger, 1983:98)? It has been argued that:

*"theology has spoken to us... of sin and evil, of the nature of God, and of the healing ministry of Christ in ways that do not make sense in light of the experiences of [disabled people]"* (Creamer, 2003:64)

Similarly Deland (1999:48) argues that our theological perspectives "result from our physical experiences as much as from our mental and spiritual understanding". The subject of sin cannot be avoided, not only because redemption from it is a main biblical theme but also because of prevailing insistence that "disability is linked to sin" (Caron, 2002:10) and sickness with punishment (Creamer, 2008). Has the 'medical model' view of disability somehow become entwined with Christian understanding, so that individual responsibility for sin has somehow become an individual's blame for impairment? Such confusion could be attributed to a lack of consistency through Christian denominations and theological perspectives (McNair and Sanchez, 2007).

Only Ms M referred to God punishing people:

*'sometime ago I thought God punished... and I thought, no, he's not punishing me. Because we are all sinners, you have pain, y'know, whatever, you die. It's part of our life'* (Ms M)

No other respondents mentioned sin or punishment when asked about their understanding of God's role and their impairment. Therefore, it seems that although interviewees did not link sin and impairment directly (as the literature does) perhaps feelings of unworthiness stemming from both being sinful and being impaired have confused the biblical narrative.

## **Conclusion**

Hymns, songs and Psalms are not direct instructions or parables through which meaning must be interpreted. Arguably, perhaps this makes them less open to social interpretation and less a source of accusation to someone identifying as a disabled person. The connection between healing and wholeness was identified. For interviewees, difficulty with the bible, impairment and disability related to others' interpretation of scripture. This was not only in relation to statements others had made or preached, but actions also. Therefore the literature's current focus on bible references may need to shift towards misinterpretation by others of bible references.

## **Chapter 6: Experiencing Disability and Relating to God**

### **How does the adoption of the Christian faith influence the experience of living with an impairment in a disablist society such as the UK?**

When discussing disabling aspects of society interviewees tended to relate this to their Christian experience, which may of course be attributed to the topic of the interview. Therefore this chapter examines interviewees relationship to Christian ‘sacraments’ (particularly significant forms of Christian participation), and how Christianity offers comfort whilst living in a disablist society.

#### **Sacramental Living**

Communion or Eucharist, “sacrament of sacraments” (Healy, 2009:214), was identified in the literature as being of particular significance; perhaps because of the way this physical and sensual act conveys a spiritual truth (Bunch, 2001), experiencing God in the physical body (Caron, 2002), or simply remembering God disabled by the cross (Rappman, 2004). Webster (2007) has also argued that sin and disability are linked by Jesus’ death on the cross. Participating in ‘religious rituals’ has positive outcomes (Pargament et al, 1990:815), however Eiesland (1994:25) has called for “new symbols, practices and beliefs” and “deconstruction of dominant symbolic meanings and a reconstruction of those symbols” (1994:98). Christian sacraments seemed to have significant positive impact for interviewees, however Caron (2002:19) has highlighted the potential for sacraments to be “oppressive forces or means of grace”. Ms G and Ms J illustrated this conflict. For Ms G, Communion was a source of exclusion, echoing Eiesland’s (1994:113) statement that “for many [disabled people] the Eucharist is a ritual of exclusion and degradation”. For Ms J, it was an encouraging encounter with God:

*‘there were a couple of us who couldn’t physically kneel to take Communion, which meant that we stood... And to stand up, I did feel out of place... I found it off-putting, I felt everyone was looking... looking at me, because I had to stand up... and that was another reason why I was made to feel sort of excluded’ (Ms G)*

*'when I haven't been able to find the strength to go up to the alter to take Communion, I stay in my, my pew and they come down to me with it. And that makes me cry my eyes out... the whole thing of them coming down to me and bringing the bread and wine... that's very, very emotional. And I feel very strong, feel very, very close to God'* (Ms J)

None of the interviewees specifically mentioned the sacrament of marriage. One (Mr X) mentioned (adult) baptism. Interestingly the oldest interviewee (Ms J) and the youngest (Ms C) both described the impact bereavement had had on their lives in the context of their faith. Ms M and Ms J described the significance attending funerals had had on their relationship with God. Pargament et al (1990) argued that there has been little research into coping with negative life events with religion, and also found perception of "God as a supportive partner" (1990:814) important to coping positively, and interviewees offered insights into this:

*'if one can speak of a service, a funeral service, as uplifting [pause], very spiritually fulfilling. It was the most powerful service that I've been to'* (Ms M)

*'Like the fact that he didn't get better I struggle with... it was a very big deal for me to the point where I didn't really, I didn't really have faith... you have to come back and need to work through it gradually... 'cause the car accident that I had it could have, like, ended up being, like it could have been worse... I think I just sort of avoided dealing with anything for quite a, quite a while. Certainly like, kind of made me re-evaluate things again'* (Ms C)

*'and when it was time to follow the coffin out of the church, I got my walker and walked out. And if that wasn't him guiding me along, I don't know what was. Everybody was staggered'* (Ms J)

### **Supported Living**

Interviewees emphasised both God's presence and his practical help as supportive:

*'I know that he'll help me... he's found a therapy centre for me to go to... he's found somewhere for me to move house... he's found churches'* (Ms J)

*'I always know that the Lord's with me wherever I go and he protects me... I just know he's with me and he's a tremendous help to me'* (Mr X)

*'I think he helps me through everyday, from my waking moment to when I go back to sleep. Ok, it's like it's a normal thing but I think God is there with [me] every time'* (Ms M)

References to impairment were in the context of everyday experience rather than a 'separate subject' of prayer or relationship with God. For example, Ms P described asking God for help finding a parking space, a form of assistance that many could relate to, whether experiencing impairment or not! Locker (2008:90) suggested that those with chronic illness may live lives revolving around "the work and effort of solving illness-related problems", but interviewees did not seem to emphasise the 'work and effort' of impairment in daily life. Ladd and McIntosh (2008) identified that God can provide social support, and talking to God through prayer could be understood in this way.

Whilst control has been cited as a reason for seeking God through impairment (Ardelt et al, 2008), participants seemed to contradict this by asking God to equip or give strength to assert their own will, their own control:

*'I'll be asking him please to help me to, to err, y'know, have the strength or to be able to get from A to B'* (Ms P)

(Ms W) *'I just ask him to continue giving the strength where he has done so far'*

(Rachel) *'What kind of strength?...'*

(Ms W) *'Well, the ability to do any and everything that I need to do'*

Levine (2008:85) argued that prayer could be "an active form of coping" and for the interviewees it indeed seemed an active and vital part of their lives. Interviewees did not seem to agree that prayer is only a form of emotional release and expression (Levine, 2008):

*'I would stop hitting my foot against a stone or pavement, and I wouldn't fall, where I feel that I should have fallen, but I don't... I just steady myself and I think "thank you dear God, you saved me there"' (Ms M)*

*(Rachel) 'Do you think things work out differently because you've prayed?'*

*(Ms C) 'Yeah, I think sometimes it, not always the way I wanted, wanted to or expected to but, definitely, yeah. Definitely, definitely'*

### **Social Living**

Prayer can be 'public' (with others) or "a very private aspect of religious participation" (Cornwall, 1989:580). For disabled people who find it more difficult to practically assist others, prayer can be a form of giving and 'emotional hospitality' (Gordon, 2009:60), a means of not only communicating with God but of community participation. Levine (2008) argues that prayer can be comforting through the adherence to religious instruction and norms. Prayer is a part of Christian life that those with physical or sensory impairments are able to engage with, whereas other activities such as reading the bible and attending church may present barriers. For example, Mr X and Ms J both mentioned difficulty reading when discussing the bible. McNair (2007:54) has argued that "Christian social construction is prescriptive in a different way than typical social constructions", and Ms G highlighted an example of where the 'social construction' of Christianity seemed to be conflicting:

*'I also believe my caring commitments are important to God... you look after the old, you help look after elderly neighbours... it's the two clashing. And though, I couldn't sort of carry out my Christian actions, if I attended church' (Ms G)*

Stolzenberg et al (1995) identified that it was possible to be very committed to faith and yet not attend church services. Interviewees had mixed approaches in regard to church attendance; six participants were members of particular churches and had been for several years. Ms M visited several churches, Ms G had stopped attending and Ms C participated in 'e-church' (online). Ms G and Ms C both described negative social interactions at church before they stopped attending, though these interactions were not directly related to impairment. Several interviewees regularly participated in additional 'church' related events such as 'house church'

and days out. Ms P was a Deacon at her church. It may be that the comfort gained from Christian friends and congregations is in opposition to the “dominant social milieu that devalues and discriminates against [disabled people]” (Eiesland, 1994:58). However, the question of whether churches “foster negative or patronising attitudes” (Selway and Ashman, 1998:436) does present some confusion. Experience of church in relation to impairment was generally positive and evidenced from some interviewees having attended the same church for years or even decades.

However, whilst there were hints of “barriers of architecture and attitude” (Creamer, 2003:59), only two interviewees described more than two or three other disabled people in their congregations. This observation echoes that of Bunch (2001:37), in that “the congregation of Christian churches on Sunday morning does not reflect the prevalence of [disabled people]”. Writers such as Healy (2009) have highlighted the inaccessibility of church buildings, but none of the interviewees expressed significant experience of this. However, barriers to participation in services and worship are concerning as being able to participate in religious activities directly relates to quality of life (Rose, 1997). Caron (2002) has identified such barriers for disabled people, for example the requirement to stand for long periods.

*‘Whereas I have to say outside of the church I think that attitudes towards those with very obvious visible disabilities and, and being accepted as a normal person... is much better than it used to be, so it’s a bit sad really I think’ (Ms P)*

Ms P echoes Rush (2004:68) who stated that “accessibility and acceptance can be found in the secular world”. Churches may therefore find challenge to ‘norms’ of worship and participation. Assumptions based on physical ability need to be re-evaluated, but perhaps not to the extent that “most settings for worship, prayer, service and witness... are all but inaccessible” (Gordon, 2009:59).

Ms R and Ms P further highlighted the attitudinal barrier that may further explain the positive experience but small statistical representation of disabled people in the interviewees’ congregations. When discussing healing, Ms R and Ms P both related negative encounters with

other Christians. For example, the assumption that healing impairments was always God's will. Both sisters related a particularly distressing incident:

*'we were about 17/ 18 and away on a, erm, bible week, a conference thing, and, and a man there decided that, well, he felt that God had told him I was going to be healed and an awful lot of pressure was placed on me to, to stand up... I stood up and my legs were just the same as they were before, at that point, you, I immediately think well it must be my fault, then I must be wrong... it was frightening, wondering what was going to happen and the feeling of failure and everyone looking at you'* (Ms P)

*'I found that very distressing because I was obviously concerned for her... that she was distressed by it. Plus, no body seemed to be thinking that it could have any effect on me at all... They didn't seem to think... that I'd got a disability as well and so therefore, y'know, the healing might be for me as well... I was distressed by it as well'* (Ms R)

This may reflect a 'hierarchy of impairment' (Reeve, 2004:unpaged) within Christianity. A warning, perhaps, that Christianity can reflect "life style preferences" (Hunt, 2000:84) rather than offer alternative. As Ms P later advised during our interview:

*'I think, erm, the biggest things are not so much have you got a ramp?... It's to do with just accepting the person, not making an assumption... Don't make assumptions. Err, one of the biggest things when you're praying for or with anybody I think is to ask them... "how would you like me to pray?" Not just look at the immediate situation and dive in!'* (Ms P)

### **Disabled Living**

Just as Sutherland (1982:unpaged) stated "that there are more important things to life than medical cures", perhaps Christianity needs to reinterpret approach to healing to avoid faith leaders becoming to the social model what Doctors are to the medical model. Creamer (2008:76) has argued, "barriers of attitudes... may prove to be greater obstacles than staircases

everywhere". Disabled people who are Christians may feel the impact of society's negative assumptions, only to then find other Christians reinforcing this by assuming a desire for healing or non-disabled identities. There should be no "assumption that disabled people want to be 'normal'" (Swain and French, 2000:573). Disabled people, particularly those impaired by chronic illness or invisible impairments, are "not invited to tell the truth about [their] lives" (Caron, 2002:11) and the church is perhaps uniquely placed to offer respite from this "expectation of silence" (2002:11) rather than merely reflecting disablist culture (McNair, 2007).

Locker (2008:84) has emphasised the importance of "maintaining or improving the quality of daily life" rather than curing or 'healing' impairment. Though "no amount of social accommodation can totally compensate for lost quality of life" (de Wolfe, 2002:261) perhaps for interviewees 'faith accommodation' provided a means to reclaim 'quality of life' from the disablist society around them. If environment is inextricably linked with quality of life (Locker, 2008), perhaps the Christian environment, socially and emotionally, provides a viable positive alternative from, or means to inclusion with, wider society and culture.

It would be interesting to understand more fully how disabling the experience of 'secular culture' had been for the interviewees in contrast with Christian culture (McNair, 2007). Arguably, the age of most interviewees would have influenced cultural experience, as expectations associated with impairment and lifestyle change through our lifecycles (O'Connor et al, 2002). However, Ms P described not being able to qualify as a Teacher because of impairment, and feeling that work she was undertaking with children (such as with children with 'special educational needs') had been opened to her by God through being a disabled person. Ms C described how her Mother had been offered no choice in enrolling her in 'special' residential education and also how Christian holiday camps had been a source of encouragement and continued to be through enduring friendships. So whilst disablist society was certainly very relevant to interviewees, the influence of faith was prominent.

### **Comfortable Living**

Several interviewees made references to 'getting older', sometimes humorously, during their interviews, possibly hinting that comfort with disabled identity is connected with aging:

*'I do get tired quite easily... I don't know whether, I think it might be age actually as well [laughter]' (Ms G)*

*'I'm much more open and much more comfortable with my own spirituality than I have before. Erm, maybe getting older is a, is one aspect of it... you get bolder as you're older [laughter]!' (Ms M)*

*'... it's slippery outside and that, so that makes a bit of a problem as you get, as you get older' (Mr X)*

When developing impairment during adulthood, a shift in identity will likely occur (Caron, 2002). A comparison with those of younger age (at 28 I was younger than all nine interviewees) and those acquiring impairments more recently would have been interesting but was outside the scope of this study. Ms C was born with her impairment, but at 29 had the least years experience of impairment of all nine interviewees. Therefore all interviewees responded from decades of experience, not only of impairment but also of faith. This may show that comfort with oneself as a disabled person is attained over time, in a similar way to peace as a Christian is gained through one's 'journey' with God. Caron (2002:15) has argued that using 'journey' image is negative "when mobility is impaired and energy constrained", but here it is used positively, in the sense that mobility and energy are not prerequisites for participation.

This 'journey' was suggested by respondents describing their Christian and disabled experiences in similar ways, for example comparing initial and later understanding:

*'I wouldn't be being honest with you if I didn't say to you that in my late teens/ early 20's I did struggle with my disability... I've received so much healing, not of my legs but of my insides, and how I view myself' (Ms P); 'A lot of the time, this may be surprising, I honestly don't think of myself as being disabled... I don't really think about it' (Ms P)*

*'it was just through school that made me realise what being deaf meant. Then I'd go home and communicate with my family and it was really frustrating, they didn't sign to me' (Ms T); 'I went to the deaf church and the deaf Priest was*

*teaching me, y'know, about Jesus... Before that I didn't really understand Christianity' (Ms T)*

*(Rachel) 'Has your understanding changed then since you first developed the arthritis...'*

*(Ms M) 'Oh yes...'*

*(Rachel) "til now, do you feel?'*

*(Ms M) 'Oh yes, yeah. I'm much more comfortable. I'm much more spiritually comfortable with myself, with my belief, yes, with my Christianity'*

This connection between relationship with God and relationship with impairment is potentially a major key to understanding the influence of Christian faith on living with impairment, yet is strikingly absent from the literature.

### **Conclusion**

In Chapter Four, interviewees' prioritisation of the Christian element of identity was discussed, and here the impact of this choice has been explored. Though interviewees seemed aware of and affected by the disablist society around them, focus seemed to be on how their relationship with God and others enriched life experience. Church experience was generally positive but attitudinal barriers were highlighted. The connection between journey of faith and journey of disability was identified as an exciting area for further research.

## **Chapter 7: Conclusion**

### **Comfort, Confusion or Conflict?**

Being a disabled person and being a Christian may not be the conflicting paths that the literature depicts, but complimentary journeys. I was originally motivated to explore this topic because the arguments in the literature did not reflect my own understanding and experiences, and I wanted to learn from other disabled people who were Christians. There was something missing that the authentic voices of disabled people who are Christians could fill, and I hope that this project has offered fresh and helpful insights to the literature.

While I would still argue that discussion about Christianity's relationship to disability is weak without including the experiences and perspectives of disabled people who are Christians; however, essentially, what the literature is missing are answers. The arguments offer insights into particular biblical passages, dissect the language used and historical context, discuss how churches should include and respond to impairment and disability, but offer no answers. One could even speculate that it is impossible for the literature to do so, the answers being individually unique or only gained from the journey itself, not necessarily the 'station' of identifying as a Christian and a disabled person.

Treloar (2000:12) reported 'questions concerning relationship of disability to sin, the judgement of God, adequacy of faith, and miraculous healing' and what the interviewees' responses do highlight is that the literature's major debates aren't necessarily those of disabled people who are Christians. References to impairment and disability in the bible weren't necessarily comforting but neither were they a source of conflict. Leviticus was discussed by only one interviewee, and more generally Old (and New) Testament instruction and interpretation was confusing. The Psalms and music were of particular comfort, as much for the grief of losing loved ones as the experience of impairment.

For the interviewees, being disabled was not negative but it was individual. Just as impairment is an individual experience but disability social, Christianity advocates an individual relationship with God but social responsibility. Helping others, perseverance and empathising with others

were described by the interviewees. Disabling barriers, discriminatory practice and others' perceptions most prominently related to 'healing', though were perhaps indirectly hinted at elsewhere. I would therefore suggest that this project has begun to reveal a major gap in understanding the 'coming out' process (Sutherland, 1982) of developing a positive disabled identity; the process of identifying with God.

None of the interviewees felt their impairments were evidence of condemnation or God punishing them. None of the interviewees felt that their impairments defined who they were or their limitations. Interviewees felt a strong positivity both about their faith and their disabled identity. Theological debate about biblical text and academic discourse about identity rooted in the social model seemed very distant from the discussions that took place. Though undoubtedly relevant, perhaps there is a significant difference between being a disabled person and being a disabled person who is a Christian. Rather than an intellectual and theological divide or uneasy alliance, interviewees seem to suggest a deeper emotional process. A process the literature may have missed, and will continue to miss, simply by neglecting to ask disabled people who are Christians about their lives.

The results of these interviews cannot be generalised, but rather provide a 'microcosm' of nine identities around South-West London in the summer of 2010. Miles (1995:15) asked if 'religions do actually enlighten our thinking about disability' at this time? The experience of faith certainly seems to have been enlightening for the interviewees, and continues to be, but less clear is how such enlightenment has influenced academic and social thinking. If individual stories, such as those explored in this project, remain a minority topic a major opportunity for enlightenment is missed. Christians may well be able to offer disability studies, the social model and indeed society surprising perspectives it may not be expecting.

## **Bibliography**

- Abrams, J (2007) *Misconceptions About Disabilities in the Hebrew Bible* **Journal of Religion, Disability and Health**, Vol. 10, No. 3, pp. 73-84
- Angen, M J (2000) *Evaluating Interpretive Inquiry: Reviewing the Validity Debate and Opening the Dialogue* **Qualitative Health Research**, Vol. 10, pp. 378-395
- Ardelt, M; Ai, A L; Eichenberger, S E (2008) *In Search for Meaning: The differential role of religion for middle-aged and older persons diagnosed with a life-threatening illness* **Journal of Religion, Spirituality and Aging**, Vol. 20, No. 4, pp. 288-312
- Atkinson, R and Flint, J (2001) *Accessing Hidden and Hard-to-Reach Populations: Snowball Research Strategies* **Social Research Update** (University of Surrey), Issue 33
- Barnes, C (1992a) *Disabling Imagery and the Media: An Exploration of the Principles for Media Representations of Disabled People* **Disability Archive UK**, University of Leeds, (<http://www.leeds.ac.uk/disability-studies/archiveuk/Barnes/disabling%20imagery.pdf>) [accessed 5<sup>th</sup> October 2008]
- Barnes, C (1992b) *Qualitative Research: valuable or irrelevant?* **Disability, Handicap and Society** Vol. 7, No. 2, pp. 115-124
- Barnes, C and Mercer, G (2001) (Chapter 21) *Disability Culture: Assimilation or Inclusion?*; Albrecht, G; Seelman, K; Bury, M (2001) *The Handbook of Disability Studies* California, Sage Publications Inc pp. 515-534 <http://www.netlibrary.com/Reader/> [accessed 24 May 2009]
- Barrow, M (undated, a) *Information on Islam* **Woodlands Junior School** <http://primaryhomeworkhelp.co.uk/religion/Islam.htm#4> [accessed 20<sup>th</sup> August 2010]
- Barrow, M (undated, b) *Buddhism for Children* **Woodlands Junior School** <http://primaryhomeworkhelp.co.uk/religion/buddhism.htm> [accessed 20th August 2010]
- Blaikie, N (1993) [extract from] *Approaches to Social Enquiry* Cambridge, Polity Press [https://vlebb.leeds.ac.uk/webapps/portal/frameset.jsp?tab\\_id=\\_2\\_1&url=%2Fwebapps%2Fblackboard%2Fexecute%2Flauncher%3Ftype%3DCourse%26id%3D\\_68613\\_1%26url%3D](https://vlebb.leeds.ac.uk/webapps/portal/frameset.jsp?tab_id=_2_1&url=%2Fwebapps%2Fblackboard%2Fexecute%2Flauncher%3Ftype%3DCourse%26id%3D_68613_1%26url%3D) [accessed 16<sup>th</sup> October 2009]
- Braathan, S H and Ingstad, B (2006) *Albinism in Malawi: Knowledge and beliefs from an African setting* **Disability and Society**, Vol. 21, No.6, pp. 599-611
- British Sociological Association (2002) *Statement of Ethical Practice for the British Sociological Association*

[https://vlebb.leeds.ac.uk/webapps/portal/frameset.jsp?tab\\_id=\\_2\\_1&url=%2Fwebapps%2Fblackboard%2Fexecute%2Flauncher%3Ftype%3DCourse%26id%3D\\_68613\\_1%26url%3D](https://vlebb.leeds.ac.uk/webapps/portal/frameset.jsp?tab_id=_2_1&url=%2Fwebapps%2Fblackboard%2Fexecute%2Flauncher%3Ftype%3DCourse%26id%3D_68613_1%26url%3D) [Accessed 17<sup>th</sup> October 2009]

Bunch, W H (2001) *Toward a Theology of Inclusion for Those with Disabilities* **Journal of Religion, Disability and Health**, Vol. 5, No. 4, pp. 37-44

Caron, C (2002) *Glimpses of Resurrection Through the Lens of Chronic Illness* **Journal of Religion, Disability and Health**, Vol. 6, No. 1, pp. 7-22

Caygill, M (2008) *Have you Recovered from that Little Lapse you Had?* **Journal of Religion, Disability and Health**, Vol. 12, No. 1, pp. 58-68

Cornwall, M (1989) *The Determinants of Religious Behaviour: A theoretical model and empirical test* **Social Forces**, Vol. 68, No. 2, pp. 572-592

Creamer, D (2003) *Toward a Theology that Includes the Human Experience of Disability* **Journal of Religion, Disability and Health**, Vol. 7, No. 3, pp. 57-67

Creamer, D (2008) *Disability and Christian Theology: Embodied limits and constructive possibilities* Oxford Scholarship Online  
<http://www.oxfordscholarship.com/oso/public/content/religion/9780195369151/toc.html>  
[accessed 11 Dec 2009]

Creswell, J W (2009) *Research Design: Qualitative, Quantitative and Mixed Methods Approaches*, 3<sup>rd</sup> edition, London, Sage Publications

de Wolfe, P (2002) *Private Tragedy in Social Context? Reflections on disability, illness and suffering* **Disability and Society**, Vol. 17, No. 3, pp. 255-267

Dearnley, C (2005) *A reflection on the use of semi-structured interviews* **Nurse Researcher**, Vol. 13, No. 1, pp. 19-28

Deland, J (1999) *Images of God Through the Lens of Disability* **Journal of Religion, Disability and Health**, Vol. 3, No. 2, pp. 47-81

Department of Health (2005) *Research Governance Framework for Health and Social Care* 2<sup>nd</sup> ed  
([http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4108962](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4108962)) [accessed 16<sup>th</sup> October 2009]

Eiesland, N (1994) *The Disabled God: Toward a liberation theology of disability*, Abingdon Press, Nashville, USA

- Epperly, B (2003) *Healing and Hospitality in Jesus' Ministry* **Journal of Religion, Disability and Health**, Vol. 7, No. 3, pp. 81-93
- Essien, K (2009) *Chapter 7: Identity Issues in Mental Health Research*; Sweeney, A; Beresford, P; Faulkner, A; Nettle, M; Rose, D (Eds; 2009) *This is Survivor Research* Ross-on-Wye, PCCS Books Ltd
- Faulkner, A and Tallis, D (2009) *Chapter 6: Survivor Research: Ethics Approval and Ethical Practice*; Sweeney, A; Beresford, P; Faulkner, A; Nettle, M; Rose, D (Eds; 2009) *This is Survivor Research* Ross-on-Wye, PCCS Books Ltd
- Finkelstein, V (1987) *Disabled People and Our Culture Development* **Disability Archive UK**, University of Leeds, <http://www.leeds.ac.uk/disability-studies/archiveuk/finkelstein/Cultural%20Development.pdf> [accessed 24 May 2009]
- Fox, M and Kim, K (2004) *Understanding Emerging Disabilities* **Disability and Society**, Vol. 19, No. 4, pp. 323-337
- French, S and Swain, J (2004) *Whose Tragedy? Towards a personal non-tragedy view of disability* **Disability Archive UK**, University of Leeds, <http://www.leeds.ac.uk/disability-studies/archiveuk/swain/affirmative%20chapter.pdf> [accessed 8 Jan 2010]
- Galvin, R (2003) *The Paradox of Disability Culture: The need to combine versus the imperative to let go* **Disability and Society**, Vol. 18, No.5, pp. 675-690
- Gockel, A (2009) *Spirituality and the Process of Healing: A narrative study* **International Journal for the Psychology of Religion**, Vol. 19, No. 4, pp. 217-230
- Goffman, E (1963) *Stigma* Prentice-Hall, Penguin Books, London
- Goodley, D (1996) *Tales of Hidden Lives: a critical examination of life history research with people who have learning difficulties* **Disability and Society**, Vol. 11, No. 3, pp. 333-348
- Gordon, J (2009) *Is a Sense of Self Essential to Spirituality?* **Journal of Religion, Disability and Health**, Vol. 13, No. 1, pp. 51-63
- Grinyer, A (2005) *Personal Agendas in Emotionally Demanding Research* **Social Research Update** (University of Surrey), Issue 46
- Guba, E (1990) *The Alternative Paradigm Dialogue*; Guba, E (1990, ed) *The Paradigm Dialogue* Newbury Park, California, Sage Publications Inc.
- Harren, J (2009) *Bones and Bread: Knowing God in our Bodies Through the Communion Table* **Journal of Religion, Disability and Health**, Vol. 13, No. 3, pp. 274-292

Healy, D (2009) *Rediscovering the Mysteries: Sacramental stories from persons with disabilities, their families and their faith communities* **Journal of Religion, Disability and Faith**, Vol. 13, No. 3, pp. 194-235

Hernandez, B (2005) *A Voice in the Chorus: Perspectives of young men of colour on their disabilities, identities and peer-mentors* **Disability and Society**, Vol. 20, No. 2, pp. 117-133

Hersh, E and Hughes, R S (2006) *The Role of Suffering and Disability* **Journal of Religion, Disability and Health**, Vol. 9, No. 3, pp. 85-92

Holy Bible, New International Version (printed 1998) Hodder and Stoughton, Great Britain

Hughes, P (undated) *Christian Trends in the United Kingdom* Christian Research Association <http://www.cra.org.au/pages/00000167.cgi> [accessed 7th May 2010]

Hunt, S (2000) *Dramatising the 'Health and Wealth Gospel': Belief and practice of a neo-Pentecostal 'faith' ministry* **Journal of Beliefs and Values**, Vol. 21, No. 1, pp. 73-86

Johnson-Straughan, H (2009) *Chapter 11: Influencing Change: User or researcher? Elitism in Research*; Sweeney, A; Beresford, P; Faulkner, A; Nettle, M; Rose, D (Eds; 2009) *This is Survivor Research* Ross-on-Wye, PCCS Books Ltd

Joseph Rowntree Foundation (undated) *Writing a JRF Report* Joseph Rowntree Foundation (<http://www.jrf.org.uk/sites/files/jrf/writing-a-JRF-report.pdf>) [accessed 14<sup>th</sup> November 2009]

Kvale, S (1983) *The Qualitative Research Interview: A Phenomenological and a Hermeneutical Mode of Understanding* **Journal of Phenomenological Psychology**, Vol. 14, No. 2, pp. 171-196

Ladd, K I and McIntosh, D N (2008) *Meaning, God and Prayer: Physical and metaphysical aspects of social support* **Mental Health, Religion and Culture**, Vol. 11, No. 1, pp. 23-38

Levine, M (2008) *Prayer as Coping: A psychological analysis* **Journal of Healthcare Chaplaincy**, Vol. 15, No. 2, pp. 80-98

Locker, D (2008) (*Chapter 6*) *Living with Chronic Illness*; Scambler, G (2008, Ed) *Sociology as Applied to Medicine*, 6<sup>th</sup> edition, Saunders Elsevier (no place of publication specified), pp. 83-96

MacNutt, F (1974) *Healing* Ave Maria Press, USA

Mason, M (1990) *Internalised Oppression* **Disability Archive UK**, University of Leeds, [http://www.disabilityarchive.leeds.ac.uk/authors\\_list.asp?AuthorID=110&author\\_name=Mason%2C+Micheline](http://www.disabilityarchive.leeds.ac.uk/authors_list.asp?AuthorID=110&author_name=Mason%2C+Micheline) [accessed 17<sup>th</sup> October 2008]

- Mason, J (1996) *Sorting, Organising and Indexing* [extract from] *Qualitative Researching* London, Sage  
[https://vlebb.leeds.ac.uk/webapps/portal/frameset.jsp?tab\\_id=\\_2\\_1&url=%2Fwebapps%2Fblackboard%2Fexecute%2Flauncher%3Ftype%3DCourse%26id%3D\\_68613\\_1%26url%3D](https://vlebb.leeds.ac.uk/webapps/portal/frameset.jsp?tab_id=_2_1&url=%2Fwebapps%2Fblackboard%2Fexecute%2Flauncher%3Ftype%3DCourse%26id%3D_68613_1%26url%3D) [accessed 7<sup>th</sup> November 2009]
- Mattison, M M (undated) *What is a Christian?*  
<http://www.auburn.edu/~allenkc/openhse/christian.html> [accessed 20th August 2010]
- McNair, J (2007) *Christian Social Constructions of Disability (Church attendees)* **Journal of Religion, Disability and Health**, Vol. 11, No. 3, pp. 51-64
- McNair, J and Sanchez, M (2007) *Christian Social Constructions of Disability (Church leaders)* **Journal of Religion, Disability and Health**, Vol. 11, No. 4, pp. 35-50
- Miles, M (1995) *Disability in an Eastern Religious Context: historical perspectives* **Disability and Society**, Vol. 10, No. 1, pp. 49-69
- Miller, W and Thoresen, C (2003) *Spirituality, Religion and Health: An Emerging Research Field* **American Psychologist**, Vol. 58, No. 1, pp. 24-35
- Merton Council (2009) *The Merton Observatory* [http://www.mertonpartnership.org/mp-home/information-library/merton\\_observatory\\_august\\_2009-7.pdf](http://www.mertonpartnership.org/mp-home/information-library/merton_observatory_august_2009-7.pdf) [accessed 30th April 2010]
- Naemiratch, B and Manderson, L (2009) *Pity and Pragmatism: Understandings of disability in northeast Thailand* **Disability and Society**, Vol. 24, No. 4, pp. 475-488
- O'Connor, T; Hoge, D; Alexander, E (2002) *The Relative Influence of Youth and Adult Experiences on Personal Spirituality and Church Involvement* **Journal for the Scientific Study of Religion**, Vol. 41, No. 4, pp. 723-732
- Office for National Statistics (2004) *Religion (KS07)*  
<http://neighbourhood.statistics.gov.uk/dissemination/LeadTableView.do?a=3&b=276766&c=S W19+1BB&d=13&e=14&g=342739&i=1001x1003x1004&m=0&r=0&s=1273234861484&enc=1&dsFamilyId=17> [accessed 7<sup>th</sup> May 2010]
- Oliver, M (1981) *A New Model of the Social Work Role in Relation to Disability*; Campbell, J (1981, Eds) *The Handicapped Person: A New Perspective for Social Workers?* RADAR, London
- Oliver, M (1992) *Changing the Social Relations of Research Production?* **Disability, Handicap and Society**, Vol. 17, No. 2, pp. 101-114

- Oliver, M (2002) *Emancipatory Research: a vehicle for social transformation or policy development* **Disability Archive UK**, University of Leeds, <http://www.leeds.ac.uk/disability-studies/archiveuk/Oliver/Mike's%20paper.pdf> [accessed 2<sup>nd</sup> October 2009]
- Ostrander, R M (2008) *When Identities Collide: Masculinity, disability and race* **Disability and Society**, Vol. 23, No. 6, pp. 585-597
- Pargament, K I; Ensing, D S; Falgout, K; Olsen, H; Reilly, B; Van Haitsma, K; Warren, R (1990) *God Help Me: (1) Religious coping efforts as predictors of the outcomes to significant negative life events* **American Journal of Community Psychology**, Vol. 18, No. 6, pp. 793-824
- Pope, C; Ziebland, S; Mays, N (2000) *Qualitative research in healthcare: Analysing qualitative data* **British Medical Journal**, Vol. 320, pp. 114-116
- Pursey, A (1996) *Chapter Four: Sociological Methods: Health services and nursing research*; Perry, A (1996, Ed) *Sociology: Insights in Health Care*, Arnold (Hodder Headline), London, UK
- Rappmann, S (2004) *The Disabled Body of Christ as a Critical Metaphor- Towards a Theory* **Journal of Religion, Disability and Health**, Vol. 7, No. 4, pp. 25-40
- Reeve, D (2004) *Psycho-emotional Dimensions of Disability and the Social Model* **Disability Archive UK**, University of Leeds, <http://www.leeds.ac.uk/disability-studies/archiveuk/Barnes/implementing%20the%20social%20model%20-%20chapter%206.pdf> [accessed 29 Nov 2009]
- Rhodes, P; Nocon, A; Small, N; Wright, J (2008) *Disability and Identity: The challenge of epilepsy* **Disability and Society**, Vol. 23, No.4, pp. 385-395
- Rich, T R (2009) *Who is a Jew? Judaism 101* <http://www.jewfaq.org/whoisjew.htm> [accessed 20th August 2010]
- Robinson, B A (2006) *Christian Identity Movement* [http://www.religioustolerance.org/cr\\_ident.htm](http://www.religioustolerance.org/cr_ident.htm) [accessed 20th August 2010]
- Rose, A (1997) *"Who Causes the Blind to See?": Disability and quality of religious life* **Disability and Society**, Vol. 12, No. 3, pp. 395-405
- Rosmarin, D; Pargament, K; Flannelly, K (2009) *Do Spiritual Struggles Predict Poorer Physical/ Mental Health Among Jews?* **International Journal for the Psychology of Religion**, Vol. 19, No. 4, pp. 244-258
- Rozario, S (2009) *Allah is the Scientist of the Scientists: Modern medicine and religious healing among British Bangladeshis* **Culture and Religion**, Vol. 10, No.2, pp. 177-199

Rush, W (2004) *Harvesters with Disabilities: A journey testimony* **Journal of Religion, Disability and Health**, Vol. 7, No. 4, pp. 65-71

Scambler, G and Hopkins, A (1986) *Being Epileptic: Coming to terms with stigma* **Sociology of Health and Illness**, Vol. 8, No. 1, pp. 26-41

Schumm, D and Stoltzfus, M (2007) *Chronic Illness and Disability: Narratives of suffering and healing in Buddhism and Christianity* **Journal of Religion, Disability and Health**, Vol. 11, No. 3, pp. 5-21

Selway, D and Ashman, A (1998) *Disability, Religion and Health: A literature review in search of the spiritual dimensions of disability* **Disability and Society**, Vol. 13, No. 3, pp. 429-439

Stainton, T (2008) *Reason, Grace and Charity: Augustine and the impact of church doctrine on the construction of intellectual disability* **Disability and Society**, Vol. 23, No. 5, pp. 485-496

Stolzenberg, R M; Blair-Joy, M; Waite, L J (1995) *Religious Participation in Early Adulthood: age and family life-cycle effects on church membership* **American Sociological Review**, Vol. 60, No. 1, pp. 84-103

Sutherland, A (1982) *Coming Out Disabled* **Disability Archive UK**, University of Leeds, <http://www.leeds.ac.uk/disability-studies/archiveuk/Sutherland/coming%20out%20disabled.pdf> [accessed 24 May 2009]

Swain, J and French, S (2000) *Towards an Affirmation Model of Disability* **Disability and Society**, Vol. 15, No. 4, pp. 569-582

Treloar, L (2000) *Spiritual Beliefs, Response to Disability, and the Church – Part 1* **Journal of Religion, Disability and Health**, Vol. 3, No. 4, pp. 5-32

Tuckett, A G (2005) *Part II: Rigour in qualitative research: complexities and solutions* **Nurse Researcher**, Vol. 13, No. 1, pp. 29-42

University of Sussex (undated) *Discourse and Communication Analysis: Lecture One: What is Discourse (Analysis)?* [http://www.sussex.ac.uk/linguistics/documents/806q1\\_lecture\\_01.pdf](http://www.sussex.ac.uk/linguistics/documents/806q1_lecture_01.pdf) [accessed 8<sup>th</sup> January 2010]

UPIAS (Union of the Physically Impaired Against Segregation, 1975) *Union of the Physically Impaired Against Segregation: comments on the discussion held between the Union and Disability Alliance on 22<sup>nd</sup> November, 1975* **Disability Archive UK**, University of Leeds, <http://www.leeds.ac.uk/disability-studies/archiveuk/finkelstein/UPIAS%20Principles%202.pdf> [accessed 8<sup>th</sup> January 2010]

Vasey, S (1989) *Disability Culture: It's a way of life* **Disability Archive UK**, University Of Leeds, <http://www.leeds.ac.uk/disability-studies/archiveuk/Vasey/Disability%20Culture.pdf> [accessed 24<sup>th</sup> May 2009]

Vasey, S (1991) *Disability Arts: A National Perspective* **Disability Archive UK**, University Of Leeds, <http://www.leeds.ac.uk/disability-studies/archiveuk/Vasey/Disability%20Arts.pdf> [accessed 24<sup>th</sup> May 2009]

Vernon, A (1999) *The Dialectics of Multiple Identities and the Disabled People's Movement* **Disability and Society**, Vol. 14, No. 3, pp. 383-398

Watson, N (2002) *Well, I Know This Is Going to Sound Very Strange to You, but I Don't See Myself as a Disabled Person: Identity and disability* **Disability and Society**, Vol. 17, No. 5, pp. 509-527

Webster, C M (2007) *Paradox in the Development of the Non-Disabled Church: Reflection on John 9:1-41* **Journal of Religion, Disability and Health**, Vol. 11, No. 3, pp. 23-49

Wolfensburger, W (1983, reprinted 2001) *The Most Urgent Issues Facing Us as Christians Concerned with Handicapped Persons Today* **Journal of Religion, Disability and Health**, Vol. 4, No. 2, pp. 91-102

Zarb, G (1992) *On the Road to Damascus: first steps towards changing the relations of disability research production* **Disability, Handicap and Society**, Vol. 7, No. 2, pp. 125-138

Zinnbauer, B; Pargament, K; Cole, B; Rye, M; Butter, E; Belavich, T; Hipp, K; Scott, A; Kadar, J (1997) *Religion and Spirituality: Unfuzzing the fuzzy* **Journal for the Scientific Study of Religion**, Vol. 36, No. 4, pp. 549-564

## Appendix One

### Participant Information

This table summarises information about the nine interview participants, listed in order the interviews took place.

<b>Pseudonym</b>	<b>Sex</b>	<b>Age</b>	<b>Type of Impairment(s)</b>
Ms G	Female	52	<ul style="list-style-type: none"><li>• Physical (mobility)</li><li>• Sensory (visual)</li><li>• Mental health</li></ul>
Ms T	Female	36	<ul style="list-style-type: none"><li>• Sensory (deaf)</li></ul>
Ms J	Female	67	<ul style="list-style-type: none"><li>• Physical (neurological)</li></ul>
Ms M	Female	66	<ul style="list-style-type: none"><li>• Physical (mobility)</li></ul>
Ms R	Female	52	<ul style="list-style-type: none"><li>• Physical (cerebral palsy)</li><li>• Physical (blood disorder)</li></ul>
Ms P	Female	52	<ul style="list-style-type: none"><li>• Physical (cerebral palsy)</li></ul>
Ms C	Female	29	<ul style="list-style-type: none"><li>• Physical (cerebral palsy)</li></ul>
Ms W	Female	64	<ul style="list-style-type: none"><li>• Physical (neurological)</li></ul>
Mr X	Male	63	<ul style="list-style-type: none"><li>• Physical (cerebral palsy)</li><li>• Sensory (visual)</li></ul>

} Ms R and Ms P are twin sisters

## **Appendix Two**

### **Participant Pack**

The Participant Pack has been included in the following pages in its original form, as it was distributed during 'snowball sampling'.



Hello,

**Are you a Christian?**

**Are you a disabled person?**

**Then I would like to interview you!** My name is Rachel Allen and I am studying for a Masters in Disability Studies at Leeds University. It is my second year and I am required to complete a research project (dissertation).

I have decided to research Christian faith and disability for my project. I became a Christian when I was in my teens, and shortly afterwards became ill with ME. This is an illness that makes you very tired and achey, and doctors do not really understand what causes it or how it gets better. I am interested in learning about other people's experiences of Christian faith and being a disabled person.

I felt it was very important to interview Christians who are disabled people because there seems to be a lot written by people about disability and Christianity, but not so much from disabled people who are Christians themselves.

The interview will not be formal, like a job interview, it will be more of a chat about your feelings and experiences. It will probably last for one to one and a half hours and we can agree a time and day that is most convenient for you. The interviews will take place in Morden town centre. Car parking, tube, and bus routes are nearby and the facilities are accessible via lift or stairs.

With this letter, you will find attached a guide to the questions I may ask during the interview. Every interview will be different though and the exact questions will depend on how our chat goes. You will also find more information about the project and a copy of an agreement to sign if you decide to take part.

**If you would like to be interviewed, ask me any questions or need any further information, you are very welcome to contact me:**

**By text or phone to mobile number 07979 312 133**

**By email to [faith.disability@gmail.com](mailto:faith.disability@gmail.com)**

You can also ask my Supervisor at Leeds University questions. His name is Colin Barnes and his phone number is **0113 343 4414**, his email address is **[c.barnes@leeds.ac.uk](mailto:c.barnes@leeds.ac.uk)**. If you contact Colin or I to ask any questions this does not obligate you in any way.

Thank you very much, I look forward to hearing from you,

Rachel

## What is this Project About?

The purpose of my project is to answer the question “**How does the adoption of Christian faith influence the lives of people who identify as ‘disabled’ in Britain in the 21<sup>st</sup> century?**”

I have already started the *literature review*, which involves researching, reading and analysing what has already been written about faith and disability. I chose the question above because I felt this would add something new, something a bit different. I feel the results will be an important development in understanding the experiences of disabled people who are Christians. I hope people will find the results helpful and interesting.

I will record interviews because after the interview is finished, I will need to type it so there is a written copy. This is to make it easier for me to analyse what was said. I will then put my analysis with the literature review and other work to produce my *dissertation* or finished project. This is due in September 2010, so I need to interview people during March and April 2010 to give me enough time for typing and analysis.

I would like to interview people who *identify* themselves as Christians and also disabled people. ‘Identify’ means what you would call yourself or what you believe yourself to be. You do not need to belong to any particular denomination of Christianity or go to a particular church. You do not need to provide any proof of disability, like benefits, to be interviewed. I will ask you what the nature of your *impairment* is. Impairment is a word used to describe what is different about your body. So, for example, my impairment is ME. I need to ask you about your impairment because this will help put your experiences into context and help me to understand your answers and compare with others.

To be interviewed, you will need to have a *physical* or *sensory* impairment. You will also need to be over eighteen years old.

I hope this page has helped explain what this project is about. If anything is unclear or you would like to ask me any questions, you are very welcome to contact me.

## **About the Interview**



We will arrange a time and date for the interview that is convenient for you. The interview will take place in facilities in Morden town centre. Car parking is available close by. The tube station is on the northern line and there is step-free access from the platform to the street by lift. There are numerous bus routes with stops in Morden. The interview room is accessible by stairs or lift.

If you need anything during the interview, for example a hearing loop, please let me know beforehand so I can ensure this is arranged.

As the interview starts, we will agree your *pseudonym*. The pseudonym is the name you will be referred to in my project to protect your confidentiality. I will ask if you are male or female, and how old you are. I will then ask you to tell me about your impairment, for example what it is called and how long you have had the impairment for, and what affect you feel it has had on your life. I ask these questions because it is important to put your experiences into context and allow for comparison with others.

I will ask you about becoming a Christian, for example how your faith developed. I will ask about going to church and the impact your impairment may have on church life. I will ask about reading the bible, if there are any passages or verses you have found particularly helpful or difficult. I will ask about how you understand God's relationship to your impairment. I will ask about your understanding of Christian healing and what you think about this, and how your faith affects you living as a disabled person in the UK.

The interview will not be formal and there are no right or wrong answers. I am interested in hearing your perspective, understanding and feelings. You do not need to be really good at talking or have a 'special story' to take part. Your experiences are unique and really interesting.

I hope the interview will be a positive experience for you. This is an opportunity for you to share your understanding and insights. You may not have discussed these issues with anyone before. It may be that after the interview we have run out of time but you would like to carry on talking to someone. Faith and disability can be emotional subjects to talk about. You may want to discuss taking part in the interview with a close friend, faith leader or family member beforehand so that they can support you if you need it.

## Interview Agreement

I agree to undertake an interview with Rachel Allen about Christian faith and disability.

I agree that I have received a 'participant pack', which included a guide to the questions I may be asked during the interview.

I agree that I have been given opportunity to ask questions prior to signing this agreement.

I agree that the content of the interview is to be used towards Rachel Allen's dissertation project about faith and disability. I understand that this may include national and international publication.

I understand that my real name will not be used in any published material.

I understand the interview will be recorded to enable Rachel Allen to transcribe it in written form.

I understand that I can have opportunity to review the written transcript (for a minimum period of seven days).

I understand that the recording of the interview will be destroyed after I have been given opportunity to review the written transcript.

I understand that the transcript will be used 'as is' if my contact details are not correct or I do not respond within the time period given (a minimum of seven days).

I understand that I am able to withdraw from the research project at any stage, including during the interview, if I want to and I do not have to give a reason.

I understand that I will not be able to withdraw after the interview has been completed.

Signed:

Date:

I would like Rachel to send me the written transcript of the interview so that I can review it.

I would like Rachel to send me a copy of the dissertation / summary when it is finished.

I prefer to be contacted by post / email

Please use this contact address:

## **Appendix Three**

### **Interview Guide**

Explanation of social model/ language, use of pseudonyms, further contact discussed.

Name:

Sex:  Age:

#### **Can you tell me about your impairment?**

Prompts:     Medical diagnosis  
              Medical prognosis  
              Experience of disability/ effects of impairment  
              Onset of impairment

If onset during infancy/ childhood: **How do you think X has influenced who you are?**

If onset in adolescence/ adulthood: **Do you think X has changed you?**

Prompts:     How?  
              Character  
              Identity  
              Past experiences  
              Spiritual direction

#### **Do you feel X has influenced your spiritual life?**

Prompts:     How?  
              Influence of family  
              Past experiences  
              Becoming a Christian

#### **When did you become a Christian?**

Prompts:     Can you tell me how that came about?  
              Why then?  
              Did X affect that decision? How?

#### **Do you currently belong to a church?**

Prompts:     Disabling barriers or discrimination.  
              Why that particular place?  
              How long for?  
              Why not?

#### **In the bible, are there any particular passages or verses that have been helpful to you in respect of living with X?**

Prompts:     Old/ New testament  
              Psalms

**What about passages that have been confusing or difficult to understand?**

Prompts: Old/ New testament  
Jesus' healing stories

**How do you understand X and God?**

**Prompts:** *Why do you think you have X?*  
*Relationship between body and God*  
*Experience of prayer*  
*Perception of blessing/ curse?*  
*Purpose in impairment?*

**What is your understanding of healing?**

Prompts: Attending healing service  
Experience of prayer for healing  
Miracles  
Feelings about healing- part of Christian faith?

**How does your faith affect your everyday life as a disabled person?**

Prompts: Experience of discrimination/ disabling barriers  
Forgiveness  
God's presence  
Overcoming difficulties

**Is there anything else you would like to tell me before we end the interview?**

Prompts: Positive/ negative experiences  
Future aspirations  
Emotions/ feeling

**Thank you.**

Interview summary to follow.