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The Upside-down Kingdom of God:
A Disability Studies Perspective on Disabled People's Experiences in Churches and Theologies of Disability

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Abstract

This thesis argues that, in many churches, disabled people are conceptualised as objects of care. However, disabled Christians are capable of being active agents in churches, with service, ministry and theologies of their own to offer. In *Part A*, I explore the discourses that have historically functioned in churches to marginalise disabled Christians. Using a Foucauldian approach, I argue that the Christian pastoral model has a fundamental orientation towards individualism, addressing disability through frameworks of care and charity, rather than through a model of justice. I compare this approach with the liberatory theologies of critical disability theologians, whose socially located perspectives are often marginalised in mainstream theology in favour of universalist theological approaches. In *Part B*, using data from interviews with 30 Christians, I argue that their subjugated perspectives highlight a precarious normalcy in churches, where environments do not sustain the bodyminds of many disabled worshippers. Using theories of misfitting from disability studies, I argue the study's participants were often prevented from fitting in churches: in buildings, in worship contexts, in social interactions, and in their attempts to offer their own service and ministry to others. I theorise the concept of discipl(in)ing, where bodyminds are shaped towards norms as they participate in church life. Drawing on the Gospel parable of the banquet, I argue that, through the theological and ecclesial focus on hospitality, disabled people are offered a conditional welcome into churches, resulting in a power imbalance between non-disabled hosts and disabled permanent guests. In *Part C* I discuss the theological perspectives of participants, whose own theologies call for the churches to be the "Upside-down Kingdom of God." They explore an alternative: transformation of churches so that all may have access to worship and church culture. I argue that the fields of academic and ecclesial theology have a responsibility to enable disabled people's own socially contingent theologies and sharing of experience, if access to "all" for churches is to include disabled people as part of the "all."

List of Abbreviations and Acronyms

BSL	British Sign Language
CDA	Critical Discourse Analysis
CDS	Critical disability studies
PAR	Participatory action research
RAG	Research Advisory Group
WAVE (Church)	We’re All Valued Equally

Table of Contents

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For Shai

Part A: Theorising and Contextualising Disability and Christianity

Introduction

I took part in Naomi's research because [I] felt that there is a part of the body of Christ that is unseen and if we can make our voices heard then we might get our needs met by our fellow brothers and sisters in Christ. We may not be physically able but I believe we still have gifts to share with the rest of the church if they could only accommodate us!

Faith, post-interview correspondence on research message board

Disability—it's just part, for me, of the whole theology of the Church. That Jesus came to turn values upside down with the Beatitudes.

Rhona, focus group 1

In recent years, there has been a growing Christian interest, emerging from churches and theologies, in the topic of disability. It is increasingly recognised in Christian settings that, while disability is not a concept that would have been relevant to the earliest churches, it is now a useful social category defining neglected groups in society, whose members are also present in the pews. This growing engagement with disability can be seen in new fields of theology addressing the topic, and pastoral denominational structures which aim to consider the inclusion of disabled people. However, there is little resulting engagement with the experiences and opinions of disabled Christians, or their communities and movements, from either churches or theologians. As I will argue in this thesis, for the most part, churches are drawing on pre-existing, potentially marginalising models of disability and illness to shape their responses to disabled people in their congregations. Most commonly, a pastoral care approach shapes these churches' response to disability, reproducing a model of church service and theology *for* and *about* disabled Christians, rather than *with* or *by* these disabled people. This potentially conflicts with user-led and activist models of disability, which are increasingly common in wider society. I argue that, where a charitable and paternalistic model constructs disabled people as reliant on the welcome of churches, rather than as active and autonomous agents of service of their own, this impacts their access to and inclusion in churches. While usually unintentional, institutional exclusion follows for disabled people in churches, arising from pre-existing church structures, cultures and theologies which are designed only to sustain bodies and minds which fall within a normal range.

In this thesis, I argue that disabled people in churches are seen as objects, not agents, of ministry, service and care.[1] Churches' limiting paradigms of disability impact how far disabled people are enabled to be theological agents, sustaining the theological status quo where disabled people are more spoken about than allowed to speak for themselves. However, my thesis will also explore participants' concepts of how faith, God and disability are related, and their capacity to act as theological agents when enabled. I will consider what might be required for more disabled people to enter the theological conversation on disability. This thesis is based on interview research into the experiences of disabled Christians, taking a critical disability research approach in order to prioritise the voices of disabled people, and drawing on social and affirmative models of disability.

In this Introduction, I will introduce the key concepts and frameworks on which the thesis is based, including social and affirmative models of disability. I will argue that religious issues in disability studies have been neglected, and that in the field of religious studies there is a similar failure of critical engagement towards issues of disability in religious contexts. I will then outline the research context of churches and disability, including academic perspectives and the church context of Christian disability work. I do not provide a full literature review here; rather, the relevant literature is addressed throughout the thesis where it is relevant.

1. Structure of Thesis

This thesis is divided into three parts. In Part A, I introduce the research context, outlining the situation for disabled people in churches today. In Chapter 1 I discuss my methods, including an argument for the relevance of a critical disability research approach, which allows participants and other members of the researched community to guide and shape the research questions and methods. The interview research is supported by in two fieldwork contexts; in Chapter 1 I will discuss how this background contributed to research questions. In Chapter 2 I then explore relevant theologies of disability. First, I briefly examine socio-historical uses of the Bible to conceptualise disability in churches. I then consider several Christian discourses of disability that were relevant to participants. I divide recent theologies

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[1] I credit Fiona MacMillan from the St Martin-in-the-Fields Disability Advisory Group for this concept of disabled people as agents or objects in churches. Doreen Freeman (2002) uses a similar concept of theological agency for disabled people.

of disability into pastoral theologies of disability, which are often produced by theologians discussing disability from non-disabled perspectives, and critical disability theologies, which centre the experiences and agency of disabled people in churches; the latter is a minority approach among theologies of disability.

Part B presents and analyses the results of thirty interviews with disabled Christians. In Chapter 3, I examine research participants' experiences of the built environments and worship and social cultures of churches. I argue that many of the participants *misfit* in churches, theorising the concept of discipl(in)ing, used to examine ways in which participants' bodyminds were shaped towards the norms as they participated in church life. As such, their subjugated perspectives highlight a precarious normalcy in churches, where the bodyminds of many disabled worshippers are not sustained by environments and cultures. In Chapter 4, I consider manifestations of the pastoral model in participants' experiences of serving and being served in churches, arguing that disabled people in churches are primarily seen as objects, not agents, of ministry and care; I reprise this theme in Chapter 6, when I consider participants' theological agency. In Chapter 5's analysis I use the Gospel parable of the banquet, first referenced in Chapter 2, to shape an argument that, through a focus on hospitality, disabled people are only offered a conditional welcome into churches. The politics of welcome and hospitality creates an imbalance between non-disabled hosts and disabled permanent guests in churches; the usually non-disabled leadership of churches has power to determine how, and how far, disabled people will be welcome into those churches.

Part C brings many of these themes together to discuss the theological perspectives of participants. I discuss the barriers that participants encountered when attempting to access and interrogate theologies of disability, and to shaping and sharing their own disability theologies. I theorise that the pastoral model's conception of disabled people as objects of ministry was a particular barrier to their theological agency. However, despite these obstacles, many participants formed coherent, resistant theologies, rooted in their social locations as disabled people. Among these were theologies of privilege and marginality in churches and society, with a number of participants calling for churches to be the "Upside-down Kingdom of God," challenging social concepts of disability. Participants were often focused on the need for the transformation of churches for better access for all to worship and church cultures, rather than on rhetorical and affective welcome. However, for many participants, the barriers to engaging in the theological conversation about disability were significant. I will argue that the fields of academic and ecclesial theology have a responsibility to enable disabled people's own socially contingent theologies and sharing of experience, if access to "all" for churches is to include disabled people as part of the "all."

In my Conclusion, I return to the alternative models of church explored in the contextual fieldwork, asking whether user-led and other approaches which centre the experiences of disabled people might allow for their increased agency in churches, as agents of theology and service of their own, and what transformation this might involve for churches.

1.1 Research aims, objectives and questions

The primary aims of the research were inductive and exploratory, using a critical disability research framework. Given the lack of ethnographic research into the experiences of disabled Christians, as I discuss below, the research aimed to extend and deepen understanding of disability in Christian churches, particularly the relationship between the reception and inclusion of disabled Christians in churches, and the theologically- and socially-informed ideological approaches on which their churches drew in their understanding of disability.

There were two research objectives. The first was to investigate the practices of a sample of churches towards disabled Christians, in terms of physical access, institutional structures, and the biblically-, theologically- and socially-informed ideological approaches that they have experienced. The second objective was to explore the interpretative strategies of disabled Christians, in their uses of theology and biblical interpretation, in relation to issues of disability in Christian contexts.

As I discuss further in Chapter 1, the methods by which the research questions developed, based on these initial objectives, arose from the critical disability research approach of the thesis. Prioritising disabled Christians' voices, I encouraged them to shape the focus of the research and its questions. As a result, the following research questions emerged.

1. What are the experiences of the disabled Christians in this study with access to and inclusion in, or exclusion from, churches and church culture?
2. What practices and attitudes are apparent among Christian churches in their treatment of these disabled people?

I address these research questions in Part B of the thesis, in Chapters 3, 4 and 5, where I discuss participants' experiences of access to and inclusion in churches.

A further, two-part research question subsequently emerged:

> 3. a) How do the disabled Christians in this study understand their own social locations in their church and in wider Christian contexts, as disabled Christians?
> b) What theologies of disability have been encountered by these disabled Christians, and what theologies of disability do they profess themselves?

These research questions are primarily addressed in Chapter 6.

I consider a final, two-part research question in Part A, in the contextual chapters of the thesis:

> 4. a) What constitutes the current and historical context of these attitudes and practices towards disability in UK churches, socially, theologically and ecclesially?
> b) What activism is present and emerging among disabled Christians in the UK churches, and what concerns is it addressing?

These contextual research questions are considered in the Introduction and Chapters 1 and 2.

2. The Research Paradigm: Key Concepts and Frameworks

Sharon Snyder and David Mitchell's concept of cultural locations of disability will frame this Introduction. They describe a cultural location of disability as "a saturation point of content about disability that has been produced by those who share certain beliefs about disability as an aspect of human differences" (2006:3) They trace these beliefs back to models developed in the era of eugenics, in which disability was interpreted as a deviance from a norm. Cultural locations of disability, such as special schools and care centres, continue to construct and reproduce these discourses of disability. Furthermore, in cultural locations of disability, people who are *not disabled* continue to have control of discourses of disability. There is a long history behind the association of Christian churches and disability, explored in the following chapter, and Christian discourses have had influence over the development of many of these cultural locations of disability. This thesis will argue that the control of discourses of disability by churches in the UK is prevalent in church policies and practices, and that it is rare for disabled Christians to have input into these discourses.

2.1 Disability studies and emancipatory and critical disability research

The history of academic disability studies in the UK and the history of the disability rights movement in the UK are closely related. In this context, disability studies and its research paradigms are themselves linked to cultural locations of disability. In the mid-twentieth century, when a significant number of disabled people in the UK lived in care homes, the disabled residents of the Le Court Cheshire Home encouraged independent research into their situation, believing that it would reveal the socially oppressive and segregated conditions in which they lived. Researchers Eric Miller and Geraldine Gwynne were funded by the Department of Health to carry out a study of the care home. However, their research failed to support the claims of the residents that their civil and human rights were being curtailed. Instead they recommended an "enlightened guardianship" role of care, to support residents in what they considered the "social death" of disability for the "parasite" residents (Barnes et al., 1999:214). The residents denounced the researchers, and their research paradigms, as the real parasites, arguing that they were on the "side" of false objectivity, which replicated a pattern between researchers and residents of "exploiters and exploited" (Hunt, 1981:39). This incident was significant in the development, in disability studies, of what became known as the emancipatory or critical disability research paradigm. Among its aims, the emancipatory paradigm is critical of disabled people's social contexts, centres the viewpoints of disabled people, aims to be useful to disabled people, and requires researchers to confront their own epistemologies and ontologies while eschewing false objectivity (Stone and Priestley, 1996). It also aims to involve participants from the disabled community fully in research, to be committed to the amplification of disabled people's voices through research, and to challenge the inequitable social relations of research production (French and Swain, 1997; Mercer, 2004; Oliver, 1992; Zarb, 1992). The slogan "nothing about us without us," central to much disability activism (Charlton, 1998), is reflected in the aims of critical and emancipatory disability research.

Furthermore, emancipatory and critical disability research models are activist paradigms, rooted in the social model of disability. In common with other forms of activist research, they examine cultural locations of disability, and critique the social conditions that lead to disability oppression. These research paradigms are also distinguished by a commitment to the social model in its focus on society and oppression, rather than an individual focus on impairment. The social model, though widely debated and contextualised in disability studies, remains controversial in theologies of disability, as I explore further in Chapter 2. Given John Swinton’s contention (2012b) that disability may not be a relevant concept for Christian churches, it is important to outline the models of disability which frame this thesis, and why these are relevant to the research context of disability and churches.

The social model of disability was developed through disability activism and disability studies together. The term “social model” was coined by Mike Oliver in 1981 (Barnes, 2007a), based on an earlier distinction of impairment from disability, by a disability rights campaigning group:

> In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society.
> (UPIAS, 1976:14)

This approach contrasts with the dominant medical and individual models of disability, which conflate disability and impairment, and represent disability as lack, or distance from a norm (Barnes et al., 1999). In contrast, the social model is materialist (Barnes, 2007a; Oliver, 1990; Priestley, 1998),[2] allowing for the identification of social and material *barriers* which result in disablement, as a result of the material relations of capitalist and post-industrial societies. The social model was not intended to be a complete theory of disability (Oliver, 1996a), but a heuristic device to shift the focus onto society as the source of disability oppression (Barnes, 2007a). From a social-model viewpoint, disability is understood as “an oppressive social relationship imposed on top of our impairments—something *done* to us rather than something we *have*” (Cameron, 2011:10). For Barnes, the social model is thus “nothing more or less dramatic than a concerted shift *away* from an emphasis on individual impairments as the cause of disability, but rather *onto* the way in which physical, cultural and social environments exclude or disadvantage certain categories of people; namely, people labelled disabled” (Barnes, 2002:n.p.). The social model locates the source of disability oppression in society (Barnes, 1992; Kumari

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[2] Furthermore, the social model is specifically Marxist in its earliest statements (e.g. Oliver, 1990), although many later explorations of disability which take the social model as a starting point have de-emphasised its Marxist aspects.

Campbell, 2012), through exploration of such themes as normalcy (Davis, 1995),[3] and ableism (Goodley, 2014).[4] Social disability theory based on the social model has developed in a number of directions which inform this thesis.

Following its initial development, there have been significant debates about the social model in disability studies. Colin Barnes (2002) contends that the social model does not preclude exploration of impairment effects or disability experience. However, theory and research based on the social model is sometimes criticised, within disability studies, for its tendency to focus on societal structures to the exclusion of disabled people's experiences and narratives (Crow, 1996; Thomas, 2004), reifying impairment in ways that can marginalise its theorisation (Slater, 2013). From these critiques have developed alternative models and theories informed by the social model. I draw on the affirmative model of disability (Cameron, 2007, 2011; Swain and French, 2008; Swain et al., 2003) and social relational frameworks for understanding disability (Reeve, 2012; Thomas, 2007) in this thesis.

Both social relational and affirmative approaches centre the social location of disabled people, through their narratives and perspectives, as a basis for privileging their perspectives. Social relational definitions of disability are rooted in the social model, but they extend the concept of barriers into relational and psycho-emotional territories:

> Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being.
> (Thomas, 1999:60)

In this thesis, I explore participants' narratives of social relational encounters, which have psycho-emotional impacts, as part of their experience of disability in churches. Likewise, the affirmative model of disability also centres the social location of disabled people and communities of disabled people. However, its focus is affirmation, in resistance to social representations of disability as deficit or deviance.

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[3] Drawing on Foucauldian concepts, Lennard Davis coins the term *normalcy*, a late modern social construct rooted influence of statistical measurement for eugenics. Normalcy "is constructed to create the 'problem' of the disabled person" (Davis, 1997:9). He argues that "in a society where the concept of the norm is operative, then people with disabilities will be thought of as deviants" (1997:13) in comparison with a statistical average to which all members of society are expected to aspire.

[4] Goodley defines *ableism* as "the system from which forms of disablism, hetero/sexism and racism emanate, [which] has in mind a 'species-typical' human being" (Goodley, 2014:22), particularly in a neoliberal context. As a concept, it overlaps significantly with Davis's concept of normalcy; I refer to both in this thesis. See also Kumari Campbell (2012); Wolbring (2008).

The affirmative model, which has grown out of the disability arts movement, encourages "being different and thinking differently about being different, both individually and collectively" (Cameron, 2011:18). Through reflection on disabled people's narratives, it allows disabled people to challenge "presumptions about themselves and their lives in terms of not only how they differ from what is average or normal, but also about the assertion, on their own terms, of human embodiment, lifestyles, quality of life and identity" (Cameron, 2011:18; Swain and French, 2008). Drawing on a social model framework, it acknowledges that the struggle with social barriers can be demoralising for disabled people (Mason and Rieser, 1990), while also recognising the creative resistance of disabled people's own positive definitions of identity in community. In contrast with deficit models of disability, it does not seek to ameliorate impairment towards a fictional non-disabled norm, but affirms disabled people's existences as they are. This thesis aims for a similar balance, drawing on both the social and affirmative models of disability to underpin an examination of both the social oppression faced by participants and their creative resistance to it. Although models of disability were not always of particular interest to participants in this study, many nonetheless drew on frameworks encompassed by the social and affirmative models, to engage creatively, practically and theologically with church environment and disabled Christian identity.

Nonetheless, disability status cannot be taken for granted in disability research, not least because it is usually defined primarily by the researcher. The liminality of disability as a social status, and the definition of disabled communities, is strongly relevant to this study. My reflections on the liminality of disability begin with my participants, who had various ways of identifying as "disabled."[5] Disability status was often theorised by participants in ways that expressed their liminality in relation both to disabled communities, and to churches and Christian contexts. Such liminality and fluidity of disability is widely acknowledged in disability studies. Postmodern disability perspectives, for example, query the rigid, dualistic categories

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[5] In Appendix 2 I outline the variety of ways in which participants identified in relation to concepts of disability. Most identified as disabled, to varying extents, but many had multiple ways of defining their disability and health status, often including concepts of chronic illness. A few stated that they thought of themselves as ordinary people more than as disabled people, a position that is not uncommon among participants in disability research (Watson, 2002), while they also acknowledged disability as a unifying issue for the research that had relevance for Christian churches. Michalko's concept (2002) of disabled people being located on a spectrum of identity ranging from the "what" to the "who" of disability is relevant for the identity of many participants.

of “disabled” and “non-disabled” (Corker, 1999; Shildrick, 2009; Tremain, 2002; Wendell, 2010). Shildrick (2009) and Slater (2013) take postconventionalist approaches to disability, rejecting definitions and emphasising that our frames for disability are constructed by society, while also not denying “the significance disability plays in the lives of disabled people” (Slater, 2013:18), nor that disability identity is often part of that significance.

However, other disability theorists retain the strategic importance of definitions as tools for creating disability identity and community. As Rosemarie Garland-Thomson argues, both “strategic essentialism” and “strategic constructionism” (1997:23) are necessary theoretical strategies for framing the body in the debate about disabled identity. They are strategies for specific, different ends, such as “facilitating imagined communities from which positive identities can emerge” among people whose impaired bodies are often positioned negatively in society (ibid.). Garland-Thomson recognises what Slater terms the pre-existing “heavily loaded frames” (2013:18) of disability: social constructs of discourse and culture which construct and label disability before it is encountered. However, she recognises these frames as essential to experiences of disability oppression and identity, engaging with them rather than ignoring them. Similarly, Rod Michalko (2002) notes that it is society that reinforces a disabled/non-disabled binary, through oppression of impaired bodies, and Robert McRuer recognises “that the question ‘aren’t we all queer/disabled?’ can be an attempt at containment and…I resist that containment” (2006:157).[6] Bill Hughes argues that an “epistemological crisis” can result from rigid adherence to models of disability which leave other aspects neglected or untheorised (Hughes, 1999:160). Such a definitional crisis can be seen in some Christian and theological contexts where these reject disability as a classification. To return to the affirmative model of disability, Colin Cameron argues that affirmation of disabled people’s own perspectives requires “not an avoidance of the term ‘disability’ or an uncomfortable, unconvincing pretence that everyone is the same, but an acceptance and equal variation of difference and a recognition of and determination to address the barriers inherent in social environments” (2007:508). Instead, echoing Garland-Thomson’s strategies, Hughes recommends a theoretical

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[6] McRuer nonetheless embraces moments in which this may be perceived to be true, embracing Garland-Thomson’s fluid position of multiple strategies towards disability identity.

approach of "epistemological pragmatism" towards definitions of disability, drawing on various perspectives to illuminate oppression in disabled people's lives (Hughes, 1999:156). This thesis takes such a pragmatic and strategically constructionist and essentialist approach to definitions of disability. Throughout this study, I have aimed to respect and represent participants' range of ways of identifying with, or rejecting, disability, while also maintaining a social model and affirmative model approach to my own definitions of disability, noting that these thereby shape the research. Such reflection on disabled identity leads into considerations of disabled *community*, and disabled Christian community in particular, to which I now turn.

2.2 Defining "Christian" and "disabled Christian community": Identity and liminality

There is significant critique of the social model and disability rights discourses from theologians who consider issues of disability in churches. Related criticisms from theology are aimed at the disability movement or disability activists. As I explore below, this position has often been part of a mutual rejection of disability theory by religious discourses and religion by disability theorists. In particular, a number of theologians express concern about the original Marxist roots of the social model, and situate equality movements in the liberal Enlightenment project, which they represent as distinct from Christian approaches (Creamer, 2009; Swinton, 2011; Weiss Block, 2002). Frances MacKenney-Jeffs summarises these theologians' anxieties about the social model when she argues for the need for alternative Christian models of disability:

> Judaeo-Christian thinking does not foreground difference but celebrates the diversity of those made in the divine image, and for that reason we must seek an alternative view.
>
> (2013:53)[7]

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[7] MacKenney-Jeffs' argument is based on an assumed diversity approach within what she represents as a unified Christian and even "Judaeo-Christian" approach to disability. However, as Chapter 2 explores, there is no such unified tradition towards disability in Christian theologies. Such calls for alternative models of disability in Christian contexts are often based on a redemptionist claim (see below) that Christianity itself is inherently positive towards disability. Furthermore, as I argue in later chapters, while diversity approaches can be useful as one aspect of disability models, those which erase difference often overlook disability oppression. I will go on to explore the effects of this erasure of difference and oppression, and potential alternative Christian approaches to disability oppression which do not leave important aspects of difference unnoticed.

However, MacKenney-Jeffs simultaneously acknowledges discrimination in churches, and accordingly the usefulness of secular equality law in churches, where disabled people are often under-represented in congregations. Such uneasy alliances, between aspects of the disability rights movement's frameworks and Christian discourses of disability, are often found in theology. As I explore in Chapter 2, there is significant discussion in theologies of disability about the exclusion of disabled people from churches, the existence of which is rarely disputed. Nonetheless, where disability rights discourses are often overtly rejected by theologies of disability, this often goes hand-in-hand with a rejection of the activist communities of disabled people with which these discourses are associated. MacKenney-Jeffs uses the concept of the disabled people's movement, creating a dichotomy between this movement, reified and represented as a secular campaign, and churches and Christianity. Activist and cultural movements of disabled people exist, and have had input into the social model and disability theory (Riddell and Watson, 2014); the concept of an activist disability movement has been central to the history of disability studies (Campbell and Oliver, 1996; Finkelstein, 2007; Oliver, 1990). However, the concept of a unified disability movement has been debated in disability studies. Scholars have argued that, while many disabled people do feel that they are part of a community or minority of people like them (Peters, 2006), not all do (Watson, 2002). Such movements are likely fluid, in parallel with equally nebulous concepts of disability identity (Asch and Fine, 1992; Beckett, 2006; Gilson et al., 1997). Theologians who depict this dualism of a secular disability movement outside of and opposed to the churches, are in fact criticising discourses more than communities.[8] However, this thesis will argue that disability activists and those involved in disability rights movements are in the churches, and make up part of the population of disabled Christians. The disability movement does not exist completely apart from the churches: many of its members are in the pews.

I argue throughout this thesis that an imagined community of disabled Christians was relevant to many participants.[9] I allowed participants to self-define as

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[8] Where a similarly strategic essentialist approach (see below) is relevant, in this thesis I sometimes refer to a disability (rights) movement, but minimally and with the caveat that not all disabled people share rights-based perspectives, or do so to varying extents, as reflected in the diverse views of research participants.

[9] In this use of terminology I follow Garland-Thomson's (1997) use of Benedict Anderson's (1991) concept of imagined communities, a broad interpretation of his category used to highlight ways in which strategic concepts of community can be formed through an understanding of shared experience.

Christians: to be a disabled Christian in the UK was the only initial prerequisite for participating in the research. Participants outlined a range of views about their faith and relationships with churches in their initial sampling forms; they ranged from clergy to people no longer attending churches. To varying extents, an imagined community of disabled Christians was important to many of them, and they were often involved with physical (or virtual) communities of disabled Christians as part of such a broader imagined community. As I emphasise throughout this thesis, there is no homogeneity of disability, and no single cohesive model of disability was shared by all participants. Nonetheless, in this thesis I take a pragmatic and strategic essentialist approach to Christian disability community. In this approach, I draw on Nasa Begum's assertion about disabled women that, while they cannot be assumed to be "a unitary group," they are nonetheless often united by shared oppression: "the experiences of disabled women must be seen as an integral part of the social, economic and political structures which serve to control our daily lives" (1992:70).

Beginning with this pragmatic approach, I recognise criticisms of concepts of disabled identity, disabled community and disability movements. However, I note also that non-disabled identity is rarely interrogated to the same degree as disabled identity. McRuer's concept of compulsory able-bodiedness[10] begins not with disabled identity, but non-disabled identity. "Able-bodiedness," he argues, "even more than heterosexuality, still largely masquerades as a nonidentity, as the natural order of things" (2006:1). Here McRuer participates in a broader effort, in disability studies, to make the invisible visible by turning a critical lens on the social structures which construct disability oppression. As I argue in Chapter 2, academic and ecclesial theological discourses have widely criticised concepts of disability identity, but have less often considered their own constructions of normalcy and ableism. In contrast, this thesis begins with the argument, based on interview data, that disabled participants often shared similar experiences of oppression in churches and other Christian contexts.

In a Christian context, the concept of imagined community resonates with Stanley Fish's (1980) theory of interpretive communities. No theological reading of a biblical text is without social context (McGowan, 1999); the question of who is

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[10] I use instead the term "compulsory non-disability," rather than "able-bodiedness," because disability and normalcy are broader than traditional concepts of the body, as this study's range of participants demonstrates.

reading Christian texts, and what they bring to those texts, is always relevant in their interpretation (Saye, 1996), and biblical reading is always situated in communities (McClintock Fulkerson, 1998). Participants' resistant theologies and creative readings of biblical texts were often framed around concepts of an imagined disabled community, whether more or less implicitly. Participants' interest in finding disability theologies and other resources for understanding the Bible *as disabled people* emphasised this need, for many, for an interpretive community of other disabled people with whom to read the Bible and develop theologies, if only an imagined community. Nonetheless, as much as disability identity is fluid, disabled Christian identity may be even more so. Participants began from a range of starting points in their views of disability and impairment, and its relationship to their Christian theologies, and I discuss this range of positions in the following chapter.[11]

Two key markers of Christian disability identity among participants were liminality and isolation. Participants in this study are often Christians in liminal positions, "living on the edge" of their churches (Inclusive Church, 2018). Disabled Christians' social and physical liminality within the churches has been recognised by one disabled Christian community, where it has been reflected in the biblical image of the prophet speaking from the edge of society, as I discuss in the following chapter. Relatedly, many participants experienced isolation, with many aware that this was shared by others in an imagined community of disabled Christians. While many participants had some awareness of a broader imagined community of disabled Christians located in other churches, for many, due to their isolation in churches, this community remained simply that—imagined.

2.3 The pastoral model

In addition to the concepts derived from critical disability studies (hereafter, CDS), a central concept of this thesis is that of the pastoral model, and pastoral power, as it operates in churches. Foucault (1982) describes pastoral power as a form of governmentality that is focused on the conscience and inner life of an individual.

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[11] While my research is framed by the social model, given the research context in which participants' voices had rarely been heard, I sought a balance between framing participants' experiences critically, and choosing not to speak over their own models. I neither "correct" participants' own models of disability arising from their experience, nor rename their theological perspectives with academic terminology. In this I draw on Hughes' concept (1999) of the "epistemocracy" of the social model, and the academic elitism of its use.

Foucault argues that a Christian model of pastoral power is at the root of modern state power, and that this pastoral model has been transformed into a "modern matrix of individualization or a new form of pastoral power" (1982:783). Thus pastoral power has shaped the way in which society now manages those who are constructed as vulnerable, those who experience mental health problems and those in receipt of medical treatment. This state pastoral power is enacted through institutions such as schools and hospitals (1982:787), which Snyder and Mitchell call cultural locations of disability. Foucauldian disability scholars argue that bodily deviance is policed through systems of surveillance and self-surveillance (Shildrick, 2009), where an external social control of the body is shaped by society's professional services, and is then reinforced by disabled service users' own internal discipline in their efforts to meet socially constructed standards of normalcy (Begum, 1996; French and Swain, 2001; Sutherland, 1981). The result is a powerful "disability business" (Albrecht, 1992), characterised by disempowering and unequal power relationships between disabled people and professionals (Swain et al., 2003) who have definitional—discursive—power over disability.

Despite the secularisation of the pastoral model, churches are not exempt from professionalised and disempowering power relations between disabled people and service providers. Churches draw on centuries of history of a Christian pastoral care discourse of dependency in their relations with disabled people (Black, 1996; Eiesland, 1994; Freeman, 2002; Lewis, 2007). Furthermore, churches are also likely to be influenced by developments in the secular disability industry, as service providers on behalf of the state.[12] As I explore in later chapters, the professionalising of religious knowledge and theology is an aspect of the divide between disabled objects of care and charity, and their non-disabled ministers. As I will argue there, spiritual capital is concentrated in the hands of the clergy and ministers, denying disabled people the resources to empower themselves; this is reflective of the broader social divide of disabled service users from professional service providers.

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[12] Churches have been widely involved in the expansion of the voluntary sector to meet social needs in response to cuts to state services, beginning in the 1990s with "Big Society" initiatives (Caplan, 2016).

3. The Research Context

3.1 Academic perspectives: Christianity and disability

While religion is "an empty signifier in the sense that it is historically, socially and culturally constructed and negotiated in various situations" (Taira, 2013:26), as a social construction it has material effects in people's lives (Beckford, 2003). For Teemu Taira, "discourses are historical and can only be understood in relation to their context as a form of practice" (2013: 28); accordingly, a discursive study of religion can identify hegemonic discourses which become dominant in religious thought, examining shared premises behind these discourses.[13] This thesis takes a discursive methodological approach, further described in Chapter 1. Beginning with theologies of disability, which I explore in Chapter 2, I have focused on those discursive practices which most impacted participants and their Christian and church lives, based on interview data. The approaches of disability studies towards discourses of religion, and religious studies towards discourses of disability, are important context for my examination of theological and ecclesial discourses of disability.

As a field, disability studies has explored a broad range of socio-cultural matters. However, disability studies has rarely—and only poorly—explored the subject of religions (Grech, 2012; Hutchinson, 2006). Ahistorical approaches to the subject of religion are not uncommon in disability studies (Hutchinson, 2006; Moss and Schipper, 2011). Nonetheless, there is some awareness in disability studies that churches in the UK and beyond had significant early social dominance over the institutional sphere of disability. However, disability scholars tend to conceptualise a historical split between a monolithic pre-Enlightenment religious age, and a modern, industrialised and secularised "Judeo-Christian" age, in which religion no longer has relevance to concepts of disability (e.g. Borsay, 2005; Stiker, 1999). Perhaps most significant here is the extent to which disability studies ignores religions, sometimes preceded by a dismissal of "religion" as a discourse that is inherently oppressive of disabled people (e.g. Barnes, 1997; Bredberg, 1999; Fairchild, 2002; Gleeson, 1997). Such approaches to religions are reductionist, representing a homogeneity of different religions' varying historical, social and cultural approaches to disability,

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[13] Taira argues that "discourses are embedded in a social and cultural context in which they function in constructing and maintaining collective identities" (2013: 37); disability is one example.

their texts and practices (Moss and Schipper, 2011:7). Disability studies generally fails to engage with sociological approaches to religion, approaching religion as an increasingly irrelevant aspect of a secularising society, rather than acknowledging religious growth, change, and continued observance in late modern societies such as the UK. It also often fails to engage effectively with religious contexts when it considers the majority world, which Shaun Grech (2012) attributes in part to disability studies' materialist and Marxist history.

The neglect of religion by disability studies can be seen in the dearth of research on the experiences of disabled people in churches. The ethnographic research of several theologians, drawing on some disability theory, are exceptions (MacKenney-Jeffs, 2013; Treloar, 2000a, b; Wallman, 2001; Webb-Mitchell, 1988). However, all nonetheless locate and prioritise their conclusions within confessional, theological frameworks. Because of the absence of research using disability perspectives into disability and churches, it has been left to critical disability theologians to examine churches' disability praxis and discourse (e.g. Betcher, 2007; Hull, 2003b; Lewis, 2007), as I discuss further in Chapter 2. That there is a lack of interdisciplinary work on religion in disability studies, particularly in the UK, may also relate to this scarcity of research and theory about disability in religious studies.[14]

The neglect of religion by disability studies is thus not one-sided; there is a mutual neglect of disability in religious studies and sociology of religion, despite churches' situation as influential cultural locations for disability discourse and praxis. Christian churches' historical interactions with illness, healing and impairment have been examined in a range of historical and textual-analytical work (e.g. Baer, 2001; Bowler, 2011; Daughton-Fear, 2009; Ferngren, 2009; Porterfield, 2005; Robinson, 2014), while church healing ritual has been the focus of much ethnography from anthropological perspectives (e.g. Csordas, 1994; Kennedy, 1998; Klassen, 2005; McGuire, 1988; Scheff, 1979). There is also research on religious "coping," examining whether religious attendance is positive for the well-being of

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[14] A significant exception is the growth of disability biblical studies, primarily in North American contexts, which is distinct from theologies of disability and, in common with much biblical studies, is usually of a "post-confessional" nature (Legaspi, 2011:viii). This draws on disability perspectives via the American academic tradition of engagement between cultural studies and disability studies; this tradition is lacking in European contexts. See Moss and Schipper (2011). However, such cultural and textual analysis does not usually engage directly with the voices of disabled Christians.

disabled people, primarily in the field of psychology, in which disability is often framed using individual, medical and pastoral models (e.g. Bergin, 1983; Ellison and Levin, 1998; Gartner et al., 1991; Pargament et al., 2001). However, these subjects are rarely written about in relation to the modern social constructs of disability, nor do they often take into account discourses of normalcy/ableism or social oppression. Hannah Lewis (2007) notes that this lack of engagement with disability and Deaf studies is a significant oversight, when many other academic fields are drawing on critical theories of disability in interdisciplinary theory and research.

The fields of academic and church theology have engaged with disability in more detail. However, as I explore in Chapter 2, these theologies of disability often begin from a pastoral perspective, and tend to reject disability studies' models. Gregor Wolbring (2007), one of the only theologians to examine churches and ableism,[15] argues that significant social issues and discourses relating to health and ableism have been left untheorised by churches and theologies. While pastoral and practical theology's relatively frequent engagement with this topic, in comparison with religious studies, may be seen as positive, the work of pastoral theologians on disability is often framed by a pastoral model which rarely includes the input of disabled people.[16] Echoing Grech (2012), a number of theologians have implicated the Marxist bias of the social model in theology's disregarding of disability studies and its models (Creamer, 2009; MacKenney-Jeffs, 2013; Swinton, 2011), as discussed above. However, this does not fully account for the minimal voices of disabled people heard in theologies of disability, nor for its lack of engagement with disability theories from perspectives outside theology. A few lone theologians, such as Wolbring, argue for the need to include the voices of those affected by ableism in

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[15] Wolbring (2008) provided an early definition of "ableism" in the context of medical technologies and transhumanism. In common with Goodley, Wolbring's definition of ableism situates it in a social context where values around the body, related to the capitalist requirement for bodies to be productive, give rise to embodied forms of discrimination. Examining church and theological interest in transhumanism, medical technologies and the concept of health, he argues that, whether church leaders and theologians reject or embrace transhumanism, they rarely scrutinise its social context. Considering the influence of eugenic ideologies in transhumanism, he identifies parallel eugenic ideologies in Christian hermeneutical and theological traditions (2007). I explore such Christian theological ideologies of normalcy further in Chapter 2.

[16] This thesis does not look in detail at popular pastoral theology of disability, such as the ministry and writing of Joni Eareckson Tada (2010). This is because my participants rarely expressed interest in such writing that emerges from ministry, although one had read Eareckson Tada. Church ministries on disability tend to have pastoral approaches in common with academic disability theologies, as I outline further below. In contrast, as later chapters explore, many participants were seeking theological discourses of disability that made sense of the full range of their experience, including social oppression, and had not found these in pastoral church ministry contexts.

theological reflection on the social issues which affect them, calling for theological engagement which is not merely a conversation between “academic ‘experts’ and the ‘experts’ from religions, theologies, faiths, denominations and churches, but a…broad bottom-up discourse” (Wolbring, 2007:n.p.). However, as we will see in Chapter 2, the majority of discussion from theologians about disability is indeed led by non-disabled academic and church “experts.”

Furthermore, even those theological studies which draw on some disability theory or use disability studies methodologies (e.g. Morris, 2010; Webb-Mitchell, 1988) are often framed by pre-existing theological assumptions about disability. For example, Treloar (2000a) advocates pastoral care methods as the best way to meet disabled people’s needs in churches, while MacKenney-Jeffs’s research (2013) into segregated provision in churches is generally supportive of their pastoral model and pastoral theological approaches. What little ethnographic research there is on disabled people in churches generally fails to engage with the underlying discourses of disability in churches and theologies. Instead, theology often focuses on what the disability movement, or societal discourses of disability, might gain from theologies of disability (e.g. MacKenney-Jeffs, 2013; Morris, 2010; Schumm and Stoltzfus, 2016; Swinton, 2012b). In confessional contexts, theology is the primary field where disability is discussed, with little critical input from other fields examining its common underlying discourses of disability.

Theology is defined in Chapter 2, where I explore theological discourses of disability in more detail. However, it is relevant here to introduce some of the key theological concepts on which I draw throughout the thesis. The first is Wells and Quash’s (2010) typology of *universal, subversive* and *ecclesial ethics*, which are three approaches to theology. They broadly divide Christian ethics “into three approaches: universal (ethics for anyone), subversive (ethics for the excluded), and ecclesial (ethics for the church)” (2010:vii). In Chapter 2 I explore what they would call subversive theologies of disability, which I term *critical disability theologies*. I refer particularly in this thesis to universal ethics, which posit that theology must be applicable to all the people of God; as we will see in Chapter 2, this universal ethical approach is frequently found in pastoral theologies of disability, especially where these reject theologies of and for disabled people.

In this thesis I also draw on the work of disability biblical scholar Hector Avalos (2007b), who argues that the Bible can be read in three ways on the subject of disability: *redemptionism*, *rejectionism* and *historicism.* Redemptionist readings argue that the Bible itself does not represent disability negatively, but that interpretation has done so, and aim "to rescue the text from the misinterpretations of modern scholars with normate views" (2007b:91). As I argue in Chapter 2, this is the position often taken on the Bible by pastoral theologians of disability, and many participants had encountered redemptionist readings of the Bible from preachers and church leaders. In contrast, rejectionism argues "that the Bible has negative portrayals of disability that should be rejected in modern society. The aim of such an approach is not to recontextualize, but to repudiate" (ibid.). Historicism is more interested in surveying histories of disability in relation to the Bible than exploring more recent social consequences of these histories in churches or society. While, as we will see in Chapter 2, rejectionism is an approach taken by some critical disability theologians, in practice most theologians employ a mixture of these approaches when considering issues of disability.

The Bible has had an impact on social constructions of disability, exercising profound effects on the lives and worship of disabled Christians. Just as biblical texts have emerged from socio-political contexts, the biblical texts themselves have been iteratively constructed by the social contexts in which they have been employed (Berger, 1967; Esler, 1994; Exum and Moore, 1998; Rhoades, 2008). Foucauldian studies of texts' ideological work in the service of power ask questions about the social origins of texts and whose interests they are used in (Taira, 2013). The Bible's normative and legitimising power in relation to disability has recently been examined in disability-focused biblical studies (Avalos et al., 2007; Olyan, 2008; Raphael, 2008) and theology (Eiesland, 1994; Epperly, 2003; Grant, 1998). Disability is a late modern social construction which would not have been shared by biblical writers and audiences (Hogan, 1999; see also Raphael, 2008),[17] but it is salient to the way the Bible is now read and received. Many of the participants in the research commented on the Bible, its interpretation, and its effects on their lives as

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[17] Raphael argues that the biblical text reflects some degree of social construction of disability, but that this involves entirely different conceptual groupings of impairments from our own, and does not include the overarching concept "disability" (2008:14-15). Disability studies considers disability to be a late modern phenomenon (Finkelstein, 1980). Nonetheless, social paradigms of disability are both constructed and affected by readings of the Bible, and modern concepts of disability are read back into the Bible, in churches and theologies, despite the very different social contexts of the biblical worlds from late modern society.

disabled Christians. Their responses to biblical interpretation and constructions of disability are explored in Chapter 6.

3.2 The role of disability studies and religious studies for representations of disability in churches and theology

Despite my engagement in future chapters with theology, where it pertains to churches' representations of disability, this thesis is not located in the field of theology. Rather, this is disability studies research, influenced by research and theory from the fields of religious studies and sociology of religion, which engages with theologies as they relate to disabled Christians' experiences. My research is largely unprecedented in its focus on the narratives of disabled people in churches, particularly in its ambition of centring their perspectives in research and discussion about their experiences (see Chapter 1).

As I explore in Chapter 1, I was asked on more than one occasion whether research into disability and churches should be conducted by Christians. This is a question that draws on the insider/outsider debate in religious studies, which has often constructed a binary opposition between "insiders" to faith communities, researching them from "emic" perspectives, and "outsiders" who generally use "etic" methods and take a position of methodological atheism (Chryssides and Graves, 2007; Knott, 2009; 1998). However, the ambiguity of boundaries between insider and outsider perspectives is now increasingly acknowledged (Ergun and Erdemir, 2009; Hayfield and Huxley, 2015; Sherif, 2001), and I explore my own ambiguous insider/outsider position in Chapter 1. However, this research draws on the non-confessional traditions of religious studies, including Russell McCutcheon's premise (2001) of the public study of religion. He argues that scholars of religion should critique discourse, rather than taking for granted that religion is divinely inspired. Given the public impact of religion on society, McCutcheon argues, religious studies has a role to play in examining the social effects of religious discourses. Disability studies' focus on the structures of normalcy and ableism, in its turning of a lens on ways in which society constructs and creates disability (Priestley, 1998), intersects closely with this critical religious studies tradition.

The field of theology has a different, confessional role, and uses different analytical tools, accordingly. Theologian Stephen Pattison summarises the position of Liberation Theology (see Chapter 2) when he states that "Christian theology in and of itself has no cognitive or analytical tools for understanding contemporary social reality" (1994:48), and that social research is therefore useful for theology that seeks such understanding. Here there is a parallel with the aim of critical disability research to be a useful tool for disabled people. However, as Chapter 1 discusses in the context of this research, any aim to produce research that is useful for both disabled Christians and churches will not always be a straightforward endeavour; the aims of churches and critical social researchers will not always overlap. Given the dearth of research into disabled people's experiences of churches, this research aims to prioritise the voices and narratives of disabled people over any potential usefulness of the research to churches. Nevertheless, in highlighting the experiences of disabled Christians and critiquing the discourses and practices which they encounter in churches, both oppressive and emancipatory, there is likely to be much that churches will find useful in the conclusions of this research.

3.3 Church contexts for disabled people

As I discuss in later chapters in relation to participants' experiences, many church organisations for disabled Christians are exactly that—charitable organisations *for*, rather than *by* or *of*, disabled people. Although a few have moved towards user-led models (defined below), the majority continue to be organised and controlled by non-disabled people, taking pastoral approaches to disability. Examples include Livability (2017), a registered charity which runs Christian care homes and other services for disabled people and directs much of the disability inclusion work in UK churches; they organised a recent, widely-reported Church of England conference about disability with Archbishop Justin Welby (Mbakwe, 2018). There are also several impairment-specific charitable church services such as the Torch Trust (2018), of which some participants had experience. WAVE Church, one of the groups I discuss in the following chapter as forming part of my research background, is itself part of Causeway Prospects, another charitable organisation. There are few alternatives to pastoral organisations, for those who seek resources for including disabled people in their churches. Other disability church ministries are denomination specific, such as the Church of England's Committee for Ministry of and among Deaf and Disabled People, on which clergy and laypeople sit. Hannah Lewis (2007) has examined the segregated and charitable landscape of church history and practice today for Deaf Christians; there is no comparable critical survey of church ministries for disabled people more generally, nor examination of pastoral groups' effectiveness for the inclusion of disabled people in churches. However, MacKenney-Jeffs has outlined a recent history of reports and policy initiatives from the Church of England, noting that "even though there has been talk of the importance of inclusion in the church for nearly three decades, little has been done" (2013:56), with many reports written from the perspectives of non-disabled church leaders. She notes in this context Avi Rose (1997) and David Potter's (2002) concerns that cultural exclusion persists in largely well-meaning churches.

Segregated church ministries are often well-regarded by theologians of disability, but the limited ethnographic research undertaken with these groups has reached mixed conclusions on their effectiveness. Brett Webb-Mitchell (1988) carried out research with L'Arche, a movement for people with learning difficulties with its roots in Roman Catholic churches.[18] L'Arche is often represented as a counter-cultural Christian alternative to segregated cultural locations of disability, drawing on concepts of welcome (see Chapter 2). In contrast, Webb-Mitchell's analysis suggests that the branch of L'Arche he visited is, in practice, another segregated institution.[19] MacKenney-Jeffs' ethnographic case studies in church groups for people with learning difficulties found mixed evidence of inclusion: some but not all of the groups she observed aimed also to include disabled people in mainstream church activities. This thesis places segregated church groups for disabled people in the context of the pastoral model, particularly in Chapter 4, as my part of my interrogation of practices towards disabled people in churches which are rooted in the pastoral model. However, my background contextual visits to WAVE Church, discussed further in Chapter 1, showed that such groups are useful for some disabled people and may be able to form the basis for alternative models of church. However, pastoral segregated groups were not my primary focus in this thesis.[20]

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[18] While theological discussions of L'Arche often represent it positively, such discourse often draws on the churches' longstanding inheritance of *graciosi* theology, as I describe further in Chapter 2, which represents disabled people—especially those with intellectual impairments—as in receipt of special grace for the benefit of non-disabled people (Cusack, 1997).

[19] While this is a single critique among many positive theologically-focused descriptions of L'Arche, Webb-Mitchell's work is an ethnographic study of a specific L'Arche community, whereas more positive representations are often based on personal impressions by theologians (e.g. Nouwen, 2012; Reinders, 2010).

[20] Further research on segregated services in churches, especially from disability studies perspectives, is recommended in the Conclusion.

User-led and user-involved church and parachurch group models

The concept of user-led groups is central to disability studies, defined as activist groups which, in contrast with self-help or pastoral groups,

> emphasize indigenous organization and self-reliance, and a political, rather than therapeutic, orientation. The central aim is not to modify their own behaviour in conformity with traditional expectations of disabled people, but to influence the behaviour of groups, organizations and institutions.
> (Barnes et al., 1999:167)

The concept of "user" comes from the disability movement's term "service user" and originally referred to those who use state disability services. The term "disabled-led" could be substituted, but in this thesis I use the term known in disability studies. In practice, as I discuss in Chapter 1, there are few of these groups and organisations in UK churches. However, there are church pastoral groups with a range of levels of input from users (members). In Chapter 1 I describe how I initially set out to find groups such as these, but was able to identify very few.

More recently, a number of loose, informal activist and user-led networks of disabled Christians are emerging. However, these activist networks tend to be fringe and minority groups, on the edges of the churches. A few disabled experts have become known in particular denominations, although they too are a minority in church disability work. Ann Memmott (2018) is one such disabled expert. She is autistic, is the author of the Autism Guidelines for the Church of England, and is currently co-authoring a book on autism and theology. She has a prominent presence online, and has expressed her concerns through her blog and Twitter when she has encountered discriminatory practice towards autistic people in churches and theology. In common with Memmott, many activist disabled Christians do most of their work informally and outside the churches, with examples including the network *Disability and Jesus* (2018), which has organised in-person events but mainly networks with disabled Christians through Twitter and its blog. They, along with other alternative models of disability and church, have sometimes found it difficult to find recognition for their work in mainstream church contexts. The St Martin-in-the-Fields Disability Advisory Group, discussed in Chapter 1, organises an annual disability conference; it is widely attended by an increasing number of disabled Christians from across denominations, but it has not always received as much church publicity as pastoral groups and conferences. Similarly, my visits to WAVE Church, a church group for people with learning disabilities, and my encounters and interviews with leaders and members there, presented a contrast between their engaged practical work and their difficulties obtaining funding and church recognition for it.

In the following chapter, I outline my methods and the methodological research paradigms which shape the thesis, which prioritise the voices of disabled Christians, setting their experiences within a critical examination of the churches they attended, their access to those churches, the roles they were enabled to engage in there, and their theological perspectives about disability in church contexts.

Chapter 1. Methods and Methodology

As described in the Introduction, an activist and critical research strategy (Mercer, 2004; Oliver, 1992) framed this project from the start. My research methods were informed by principles of the emancipatory research paradigm, with participatory aspects, aiming to strive for involvement and direction from disabled Christians. As outlined in the Introduction, the context of this research is an environment in which little priority is placed on the views and experiences of disabled people, when discussing disability; it was therefore important that this project centred the situated, subjugated knowledge of disabled Christians. While there is no one set of methods associated with the emancipatory research paradigm, this study has been influenced by many of its aims, most importantly the principle that the research should be responsible and useful to the groups and individuals with whom I worked, and others from the researched community who may be impacted by the results. As I will outline, the shape and focus of the research was responsive to the interests of participants and other disabled Christians, and strongly influenced by their views.

Researchers in the field of disability studies have condemned research into disability that "reinforc[es] the dominant idea of disability as an individual problem" (Oliver, 1992:105). Responses to these concerns have emerged through the development of an emancipatory paradigm in disability research (Mercer, 2002), as described above. Central to such a paradigm are concepts of "reciprocity, gain and empowerment" (Oliver, 1992:111). A single disabled PhD researcher working alone, with limited funding, cannot hope to meet all the methodological requirements of the emancipatory research paradigm, which have been defined and codified by a number of scholars (Barnes and Mercer, 1997b; Oliver, 1992; Stone and Priestley, 1996; Zarb, 1997). Furthermore, the participatory action research (PAR) strategy recommended in much writing on emancipatory research is not suitable for all research questions and aims (Watson, 2012). This is not a PAR project. However, it can be described as an accessible, critical disability research study, which from the start has aimed to work within the framework of the emancipatory paradigm, as I will outline below.

While codification of the emancipatory research paradigm has made important contributions to the academic conversation on research with disabled people, codification also has drawbacks. Debates on this paradigm have helped to ensure that not all research can simply call itself “emancipatory” without aiming in any way to be socially transformative (Oliver, 1992; Stone and Priestley, 1996). However, the codification of the paradigm may potentially discourage researchers from working within the principles of emancipatory research. The emancipatory paradigm has a broad scope of aims, which may not all be achievable in single research projects (Watson, 2012). Meeting these extensive aims may cause difficulty for those who wish to undertake potentially socially transformative research but do not have access to adequate resources, including funding and, ideally, teams of researchers to engage effectively with stakeholders. Stone and Priestley address this concern, citing further issues that arise in the context of emancipatory research (1996:22). These may include the risk of assuming the homogeneity of a disabled community; potential conflicts where the social model is a guiding principle of research but the participants do not themselves have a social model understanding of disability; and, as already noted, potential tensions between “surrendering control” to disabled people and the academic agenda.

Furthermore, there are specific issues with some of the codified principles of the paradigm in the specific context of my research field. In particular, it is sometimes proposed that disability research should only be located in user-led disability organisations (Stone and Priestley, 1996). There are very few user-led groups in UK churches; disability work in churches is dominated by charities and denominational pastoral work, as I discussed in the Introduction and will outline further in Chapter 2. The appropriateness of working only with user-led groups is questionable in church contexts, as a result. The user-led model is a secular model; while it has application in a few church groups, including one of the groups with which I conducted initial observational fieldwork (discussed below), most disabled Christians are not found in such groups. I have taken these and other limitations of the paradigm in this context as a challenge. As Zarb (1992) and Oliver (1992) describe, the emancipatory disability research paradigm is a philosophy of the long-term change of the relations of research production: it is a process, not a single research project (Barnes, 2002).

Activist research can take many forms, and there are many ways to prioritise the concept of reaching and serving researched communities. Nonetheless, in a research project influenced by the emancipatory paradigm’s aims of reciprocity and empowerment, the question of *which* disabled people should be empowered by research is raised, and how this can be enabled in a project with inductive, exploratory research questions. During the course of this research, I have sometimes been asked whether it is the place of a non-Christian to emancipate or liberate disabled Christians.[1] Although I address this issue in detail below, the question highlights some important principles of critical disability research paradigms. Activist critical disability research may aim to contribute to the struggle of disabled people towards equality and justice in society in a variety of ways (Stone and Priestley, 1996; Watson, 2012). Active and immediate participation of a community in the research is only one way in which a study may contribute to the enfranchisement—or, to use a Christian theological term, the *liberation*—of that community. Another important way in which such research may contribute is in providing a better understanding of the landscapes of inequality in which those disabled people move, and making efforts to ensure that this understanding reaches those who could and should benefit from it. This may be especially relevant in under-researched contexts, where little is known about the ways in which disablement manifests for a specific community of disabled people. Such understanding is the primary aim of this study.

Furthermore, in the critical research tradition of disability studies, my thesis is an unapologetically activist study. Disability studies research often begins from a critical, social model approach to society. This study is framed by a critical realist understanding of the social model; this approach can answer exploratory research questions without the attendant "danger that disability research stops looking at what people are saying and looks instead for evidence that supports the social model" (Watson, 2012:98). This study was designed with the intention of inviting disabled people to speak about their own experiences of churches—an aim which is largely unprecedented in sociological research on disability and Christianity, as already noted. It was important to balance my social model framework with the voices and opinions of participants. Nonetheless, my philosophies, social location and commitments, including a commitment to the social model of disability, are the bedrock of the study and cannot be overlooked. I explore my own positionality below.

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[1] I was asked this question by a small number of church leaders and other researchers, but never by participants or members of the groups where I conducted fieldwork observations, who on the whole were far more interested in the significance of the research itself.

A principle of accessibility was central to my research, allowing people who may be silenced by other forms of research to take part. The study's accessible methods, discussed below, were designed to foreground the voices of disabled people, making prominent their own commentary on the experiences of disabled people in churches. The strong focus of the thesis on disability exclusion and disability activism in the churches emerged from an inductive analysis of interview data, supported by fieldwork observations of church inclusion work by and with disabled people in churches. Interview data analysis identified not only the exclusion from churches that many of the disabled participants faced, but also possible solutions to this exclusion which disabled Christians themselves proposed and, in some cases, had begun to establish. Indeed, the themes that emerged from the interviews echoed many of the principles of critical disability research: in later chapters I argue that my participants were themselves often interested in disabled Christians' voices and experiences as a potential means of change in churches.

1.1.1 Locating myself in the research: Whose side am I on?

The question of whose "side" the researcher is on, an aspect of their positionality, is relevant in any research that draws on principles of the emancipatory paradigm (Barnes and Mercer, 1997a; Zarb, 1992). My commitment to the perspectives of disabled Christians, and the shaping of this project through reflection on the principles of emancipatory research, all emerge in part from my social location. There are two important factors of positionality that have impacted on the research: my disability status, including my involvement with disabled communities, and my religious background. I explore these below.

I have experienced a number of impairments since childhood, and I have been a part-time wheelchair user for over ten years. I have a congenital physical chronic health condition, an autistic spectrum condition, and am a long-term user of mental health services. Perhaps more importantly for the background of this research project, I am a disability rights activist, and have been involved in various manifestations of disabled community and disability rights movements. The initial impetus for this project was my past experiences as a disabled Christian. While I was developing the initial plans for this study, my "insider" status in some disabled communities gave me initial access to disabled Christians and other disabled people who had come into contact with churches. This allowed me to ask disabled people informally, before the study began, about whether a study on disability and churches seemed relevant and useful to them; I was encouraged by the level of response and engagement in the idea.

I consider that, for the most part, my social location as a disabled person had largely positive impacts for the research, as explored further below. However, the concept of "being disabled" is complex, and so is the concept of a researcher with an insider status in a disabled community. Disabled people are not a homogenous community; the concept of a disabled community is contested within disability studies and among disabled people (Deal, 2003; Watson, 2002), though there is some evidence to suggest that many disabled people do consider themselves part of a group with shared experiences (Peters, 2006). As I argued in the Introduction, many of my participants drew, to a greater or lesser extent, on concepts of an imagined community of disabled people and/or disabled Christians. In common with all disabled people, I can only ever be perceived as a partial insider to most disabled communities. This is particularly the case where I do not share an impairment in common with others. Nonetheless, it was obvious during interviews that I used visible aids and adaptations, and I made use of a support worker throughout the research. I also considered it important to identify myself overtly to participants as a disabled person, and this was generally received positively. As a result, interviews often demonstrated a perception, on the part of participants, that I was an insider to the disabled community, or otherwise in a comparable situation to them. This often led to more openness from participants in interviews. The effects on interviews of my status as a disabled person will not all have been positive, as I discuss below, but for many participants it allowed a shared background knowledge to frame interviews.[2]

It is also important to reflect upon the challenges of carrying out a research project as a disabled PhD researcher, and how these have impacted the project. Much discussion of the role of disabled people in disability studies research is framed by an implicit assumption that the researcher will be non-disabled while the participants will be disabled (Goodley, 2011; Stone and Priestley, 1996). On the part of disabled researchers, there has been recent discussion about whether revealing disability

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[2] Fairclough's concept of background knowledge (1995) describes interaction enabled through varying levels of shared understanding and experience, which may be dissociated from its specific social context into assumed shared beliefs, or ideological-discursive formation.

status in research is advisable, and its impact on a normative concept of "professionalism" (Andrews, 2005; Brown and Boardman, 2010), sometimes framed in a comparison with non-disabled researchers as the implied unmarked ideal. Yet, this thesis queries the association of normalcy with professionalism for clergy and ministers in churches (see particularly Chapters 4 and 6); parallel questioning of the assumptions of professionalism for academic researchers is relevant here. There is no doubt that, in comparison with many non-disabled researchers, my impairments have impacted my research, not least in the time it took to complete. However, while disability was sometimes a barrier in the research process, I do not believe it negatively impacted research participation or results, for the most part. The study's participants were overwhelmingly positive when I asked them to communicate via my support worker, requested breaks during interviews, or informed them about delays to research publication. Many expressed a sense of shared experiences, where disability has impacted their own work and life in similar ways. The tangible effects of my impairments on the research most often served to strengthen, rather than threaten, research relationships. Most importantly, without my social location as a disabled person, this project would likely look very different, and so to deny disability's impact on the research would be disingenuous.

My religious background is no less complex than my disability status, in terms of insider/outsider perspectives. I grew up in charismatic and Pentecostal churches, and I am a confirmed Anglican with about thirty years' involvement in churches, as a disabled member. The impetus for this study was rooted in this personal, insider perspective: the study was first conceived of during a visit to the Greenbelt Christian arts festival, where a number of disabled friends and I faced access and inclusion difficulties, and began discussing the state of disability theology and disabled people's inclusion in churches. During the early stages of my PhD studies, I stopped attending churches for a number of reasons, including access issues. I now attend Anglican churches semi-regularly; for some years more recently, I have also been involved in the Neopagan movement. My own religious perspective is now difficult to define. However, I continue to have an involvement in the community of disabled Christians, partly maintained through my research in this study, an aspect of reciprocity that I will explore shortly.

These multiple factors complicate the question of whether I am an "insider" or an "outsider" to the field of my research. Insider and outsider status in relation to religious community has been widely discussed within in religious studies, as I outlined in the Introduction to the thesis. However, given the ambiguity of this division, I consider that I am neither simply an insider nor fully an outsider to the religious field that I am studying, that of Protestant Christianity and its institutions in the UK.

Before undertaking fieldwork, realising that I had not attended church for some years, I spent six months visiting a different local church every week, primarily to re-familiarise myself with church contexts. This involved a process of becoming familiar with attending church while using ethnographic methodologies. I went on to take a participant-observer position (Chryssides and Graves, 2007; Hammersley and Atkinson, 1983) in three church settings which I observed more closely as part of background research, as I describe further below.

Representing myself to participants as either an outsider or an insider, in terms of Christian faith, was more complex. It was my intention to be clear about my situation. I decided to wait and outline my position in person, unless participants had questions about this in advance. While I did briefly explain my religious background at all interviews, there was not always time to describe it in detail, while in other situations I was concerned about interrupting the flow of interviews to do so. In some interviews, I was able to discuss my situation in relation to church in detail, sometimes assisted by participants' questions.

Occasionally, especially outside of participant settings, assumptions may have been made that I was a Christian, and I am not sure I always contradicted these clearly enough. A general understanding that I was an insider to the *disability* world may have been generalised to an assumption that I was straightforwardly an insider to the *Christian* world. During the early dissemination stage of the research project, I took part in a radio interview about my research for Premier Christian Radio, where at no point was I asked whether I was a Christian. When the interview was uploaded to the station's website, I found that they had described me as a committed Christian. I immediately contacted them, and asked for this information to be corrected, as it suggested a deeper involvement with Christianity than is true in my current situation. My familiarity with many church contexts, in part based on my previous insider experience, may have created confusion, for example through my comfortable use of Anglican terminology, which created a sense of shared background knowledge. While I did what I could to address assumptions that I was an insider, I acknowledge that I may not have made this clear enough, likely based on a not-entirely-conscious concern that a research relationship—such as with a gatekeeper—might be negatively affected if I were to position myself more clearly as an outsider.[3]

Indeed, in situations where I was perceived as an outsider to the Christian context, this sometimes led to my exclusion from potential research contexts. During a meeting with a denominational leader in disability pastoral care, it was strongly suggested to me that non-Christians should not research the topic of disability and the church. This may reflect the negative responses of many theologians to secular disability studies, as discussed further in Chapter 2. Although I have offered a counter-argument to this position below, perceived insider/outsider status can certainly impact relationships with the communities that a researcher is studying (Hayfield and Huxley, 2015; Merriam et al., 2001); this was, to some extent, in evidence in my interactions with communities during this study. I expect my social location to have further impacts on the reception of my work during dissemination among churches and Christians. Nonetheless, my religious position appeared to have far less of a negative impact on my research relationships with participants, who were more focused on the importance of the research itself.

One way to summarise my ambiguous insider/outsider position to Christian churches is to use concepts that have emerged from one community of disabled Christians. In 2015 the St Martin-in-the-Fields/Inclusive Church conference on disability and Christianity took *Living on the Edge* as its theme. This theme resurfaced at subsequent conferences, and in their book celebrating five years of the conference (Inclusive Church, 2018). The experience of liminality in relation to churches was also a recurrent one among many of my participants. My own position of similarly liminal relationships and blurred insider/outsider boundaries in a Christian context gave me much in common with a number of them.

It is relevant here, too, to relate my status in relation to Christianity to the principles of the emancipatory research paradigm. I consider that the most relevant question is not whether or not a non-Christian should conduct research into the situation of disabled Christians. Rather, where research results may be potential

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[3] It can be difficult in a church context to negotiate the effects of participant-observer positioning. I chose not to sit separately from the congregation during services and events, for example, as this would have distanced me from the fieldwork setting. My model for this form of researcher participation drew on the concept of the actor-researcher (Torbert, 1981), where interactions with the researcher in the field are analysed as part of collected data.

resources for disabled communities, the emancipatory paradigm would suggest that it is important that these resources emerge from research that amplifies the voices of disabled Christians. In parallel terms, some critical disability research commentators have argued that it is unimportant whether researchers themselves are disabled, but rather that research should be controlled by, and empowering to disabled people (Stone and Priestley, 1996). While the extent to which this control and empowerment is possible may vary, as discussed above, I did not want my research to lose sight of the aim of centering the voices of disabled Christians. I now explore this in relation to the concepts of reciprocity and accountability in research.

1.1.2 Reciprocity: My responsibilities to disabled Christian community/ies

Reciprocity is central to the emancipatory research paradigm, and I was keen to give back to the churches and groups that hosted me for fieldwork. This was possible when working with some of the fieldwork settings where I conducted more in-depth observation. I was asked to sit on the planning committee of the annual user-led conference on disability and churches, organised by the St Martin-in-the-Fields Disability Advisory Group; I took on this role for two years of the conference. I was asked to offer informal disability inclusion advice to a church leader in one of the initial observational contexts, which I was able to do as part of an interview. In WAVE Church, another of the observational contexts, which I discuss below, I have also spoken informally with leaders about assisting with action research with them in the future, so that their approaches to doing church with people with learning difficulties can be shared. Reciprocity is also about offering the results of the research back to the community of stakeholders for whom the results may be useful. I have presented the research in settings attended by disabled and other Christians: at three of the Inclusive Church/St Martin-in-the-Fields conferences on disability and churches, where I presented via accessible posters and talks, at a conference on autism and churches, and on Premier Christian Radio. I discuss the project's accessible dissemination methods further below.

1.1.3 The research advisory group

Focusing on the importance of accountability for this research, at the start of the study I established a research advisory group (hereafter, RAG) comprised of three members who identify as disabled Christians. The concept of accountability in disability research can be interpreted in a number of ways. For Stone and Priestley it is envisaged as "control over research production to ensure full accountability to disabled people and their organizations" (1996:706). Often, this is translated in research projects into a PAR strategy focused on consultation with participants and stakeholders. However, as I have argued above, a PAR strategy is not suitable for all studies, and was not appropriate for the research aims and questions here. Nonetheless, accountability was a central principle of my study. Direct accountability to participants is important, as discussed below, but accountability is also relevant to a wider community of disabled stakeholders—in this case, disabled Christians. I established the RAG to help meet the aim of accountability to the second group, the wider disabled Christian communities.

Consultative research groups are a participatory method for allowing some measure of control of the research by stakeholders, recommended by a number of researchers in disability studies (Barnes, 2002; Kitchin, 2000; Stone and Priestley, 1996). I identified potential members of the RAG through networking in disabled Christian contexts and online advertising. Purposive sampling was used here: I considered that it would be useful to include RAG members with user-led DPO[4] experience, theological interest, and academic research backgrounds. I met with each member of the RAG at least seven times: we met as a group throughout the research process, and I met with individual members on several other occasions. The group discussed the research design, its aims and questions, methods, themes that emerged in data analysis, and findings. They emphasised the importance of including in the research those who might not traditionally refer to themselves as disabled, such as older people, those with mental health problems, and those with chronic illnesses. They further stressed the need to ensure accessible and inclusive dissemination of results, nonetheless recognising the possibility of competing demands between academic and community expectations for the research. They were particularly interested in the structures and cultures of churches, and how these can marginalise disabled church members, and this consequently became a major focus of the study. Group members were not particularly concerned about whether the study should

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[4] Disabled People's Organisations (DPOs) are user-led organisations of disabled people, with participatory and activist aims of societal change for disabled people, especially in the area of service provision. These organisations "came into being against existing charities and pressure groups which worked for disabled people" rather than with them (Shakespeare, 1993:254). They are central to the history of the disabled people's activist movement, as it has been defined in disability studies.

have any denominational focus, echoing the disinterest towards denomination shown by many interview participants, as I discuss below. The group's input helped to shape the research questions and methods.

Although I have argued that research into Christianity does not have to be undertaken solely by Christian researchers, it is a central concept of critical disability research that disabled people should have meaningful input into studies about them (Barnes, 2002; Oliver, 1992); I considered it important, therefore, to ensure involvement of disabled Christians in the design and analysis stages of the study. However, I make no claim that the group represented the whole disabled Christian community. They were additional voices from the community on which the research was focused, who were able to have input into the research. Nind and Seale's description is relevant here: "None of the participants could be said to be speaking for the whole of their group or profession but gave insights from within their different worlds" (2009:275). Nonetheless, all members of the RAG felt that their input was important to the study. For example, during one RAG meeting I discussed how a small number of (non-disabled) Christians had expressed concern that the study was not being conducted by a Christian researcher. The group asked me to emphasise their position as disabled Christians involved in the research, if the concern arose in future.

I prioritised three principles in the operation of the RAG: 1) accessibility for all members to the group and its discussions; 2) paying participants for their time;[5] and 3) meeting regularly with members of the group. Due to disability-related needs, the group could not always meet *as a group*; providing alternative times and methods of meeting, including meeting one-to-one with some members, allowed the continued involvement of members. While some commentators stress the importance of group-based discussions for participatory theory development (Kitchin, 2000; Stone and Priestley, 1996), it has been my experience during this research project that traditional focus groups are not always accessible to disabled people, as I discuss further below. Furthermore, the RAG was not the only source of input from disabled people into the research design, aims and questions. I actively took my cue for areas of focus from the disabled Christians' groups I observed prior to the

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[5] RAG participants were paid at the same rate as participants, of an amount above the minimum wage, for which I budgeted from research funding by the St Luke's College Foundation.

interview stage of the research, and from interview participants, taking on board their views about what they felt needed to be researched in relation to churches and disability. I now outline this research design process.

1.2 Designing Accessible Research: The Story of a Research Project

Throughout the research project, my methods were iteratively developed. They were refined by the research context, through discussions with participants and with the RAG. As a result, a number of methods which I had initially proposed for the study proved unsuitable.

1.2.1 Research methods I did not use: Gatekeeping and clashing models of disability

My initial two-part research design planned to undertake church case studies in which to base focus group discussions, ideally identifying groups with strong control by, and involvement of, disabled Christians following the principles of emancipatory disability studies research. However, as already noted, there are few user-led groups across the UK church landscape. It also became clear in my early fieldwork observations that there were questions to be explored about the experiences of disabled Christians, which I needed to investigate with those outside church-based groups. Furthermore, the case-study model proved unsuitable as result of power relations between disabled people and churches, which became apparent as the research progressed. There were a number of other changes to the research design as a result of my experiences in the field. Experiences with participants and churches led me to consider questions of power, user-led control, and models of disability in church contexts, and to reshape my research design in response.

First, as I explored the ways in which methods could be accessible to participants, I made changes to the research design as a result of input from disabled Christians. Accordingly, where I had begun participant observation in church and parachurch groups of disabled people, initially intended as case studies, these observational contexts were reworked into my new research design. I continued to be involved with these groups, but they primarily became locations in which I refined my research questions, through observation and informal discussion, before interviewing individual disabled Christians. I describe these groups and my observational fieldwork further below.

Second, my earliest research designs anticipated that I would conduct expert interviews with people who are influential in the field of churches and disability, such as members of denominational pastoral committees for disabled people. However, early discussions and interviews with disabled Christians changed my position on this aspect of the research design. Some interview participants, and others in the groups which I was observing, believed that the work of disabled people themselves is marginalised in churches, sidelined in favour of pastoral care in churches, which is often conducted by non-disabled people. Indeed, this pastoral care approach towards disabled people in churches became a strong focus of the research. These early discussions clarified for me that disabled Christians often wish to speak for themselves about their situations in churches, while many of the voices already heard in churches on the subject of disability are those of usually non-disabled theologians and ministers. As a result, my final research design returned to the principles of the emancipatory paradigm's centring of disabled people's voices, rather than interviewing church pastoral leaders.[6]

My early experiences with churches also shaped changes in research design. At the early stages of the research, I attempted to identify potential participants through churches. However, I encountered a clash of models of disability between the historical pastoral care model of the churches and ostensibly secular disability rights models, often leading to misunderstandings about my research. A number of churches were only willing to offer limited access to participants on their own terms, often working within a pastoral model that ascribed vulnerability to disabled members.

One email exchange between myself and a Church of England minister illustrated this difference of approach to disability. I asked if she was willing to advertise the research in her church's newsletter. Although I made no presumption that any minister would wish to do this, I was surprised by her response, which was that she could not share confidential information about disability among her congregants with me. I explained further that I did not expect to be put directly in touch with potential participants, but was simply asking whether ministers would make the study generally known to church members. I received no reply. Similar

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[6] That I have focused on disabled Christians rather than denominational leaders does not mean that no influential or important voices were heard in the interviews. A number of participants are activists in disability and churches in the UK, although often on the margins of church institutions.

comments were made by a number of other ministers and church pastoral committees. There were other examples of ministers and church leaders misunderstanding the concepts on which the research was based. Some wrote back to me to say that they had no disabled members; one minister said that he led a church made up of young families and therefore that no one in their congregation was likely to be disabled. However, 37% of Church of England congregants are disabled and every congregation includes at least one disabled person (The Archbishops' Council, 2015). This and similar assumptions were revealing about attitudes towards disability among these church leaders, particularly in terms of stereotypes about what disability involves or looks like.[7]

At the extreme end of this clash of models, my involvement in one church observational context had to be suspended entirely, due to a conflict between church leaders' pastoral model approach to disabled people and my research study's contrasting approach of centring disabled people's agency and expertise. I was contacted by members of the church, who ran a pre-service social event before Sunday services which was attended by a number of disabled people, some together with their families and supporters. A number of potential participants were interested in the research and took part in informal pre-sampling interviews. However, leaders of the church seemed uncertain about the research. I was asked to interview people at the front of the church, surrounded by non-participants having refreshments, and next to the stage where the worship band was rehearsing. When I expressed concern about the confidentiality issues this raised, the minister told me that he was concerned about allowing me to have contact with disabled members of the church, and that I was not allowed to interview them in private, for reasons of safeguarding. The resulting constraints placed on the research had such severe ethical and practical impacts that my engagement in this observational context had to be abandoned.[8] Another church would only pass on information about the research to members after scrutiny of the research by the pastoral care team.

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[7] This issue of expectations about disability from church ministers and staff was raised by a number of participants: the next chapters will include discussion of participants' experiences with church leadership and the ways in which they were impacted by church leaders' attitudes towards disability.

[8] This was unfortunate in terms of sampling and representation, as this church's membership included people with learning difficulties and others who are under-represented in the interviews. I decided not to follow up with interviews outside the church context, despite the willingness of the individuals to be interviewed again, as the church was opposed to this. I am grateful to these participants for attempting to take part in interviews despite the conditions imposed on our interactions.

In part as a result of these early experiences, I aimed to ensure that no participant took part in research directly through a church, even where ministers acted as gatekeepers. In a few cases, participants found out about the research through their churches, after my initial contact with churches asking if they would advertise the research. In one case I interviewed a participant in a private room in her church, at her request, for her convenience of access. In two other cases, church representatives passed on participants' details directly to me, though I would have preferred individuals to make their own contact with me without churches' mediation. However, I assured all participants that they were interviewed as individuals, and potentially identifying information about churches would be anonymised. In fact, few participants disclosed details of their churches.[9]

Such situations raised the issue of vulnerability and safeguarding of church members, cited by several church leaders as the reason why they needed to mediate between me and potential participants. To some extent, this is a legal issue with which churches must comply. Potentially, disabled people can be considered "vulnerable adults" under the Safeguarding Vulnerable Groups Act (2006). However, the law does not mean that all disabled adults are necessarily vulnerable (Roulstone and Sadique, 2013), though it is often interpreted this way. Disability scholars have expressed concern over legal concepts of vulnerability for disabled people (Morris, 1991; Roulstone and Sadique, 2013), some arguing that the legal concept of vulnerability further disempowers disabled people by creating socio-political contexts in which they are treated paternalistically, their right to make decisions removed (Hollomotz, 2011; Warner, 2008). With this in mind, and as discussed further below, this study's ethical framework is based on the critical disability research principle of the "dignity of risk" (Nind and Seale, 2009:283).[10]

Nonetheless, an assumption of vulnerability was not made in all church settings. The starkest contrast involved my observations in WAVE Church, a church group for people with learning difficulties where I conducted initial observation. Leaders of the group informally suggested potential interview participants, but

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[9] In all interviews, participants were shown what was written about them and asked whether they were comfortable with their anonymisation. However, in the case of interviews that arose from churches in this way, I have made extra efforts to ensure that participants cannot be identified by churches. This is why interview transcripts are not published in the appendix to this thesis.

[10] This phrase was coined by Dora Bjarnason (2005), who argues disabled people have the right to experience risk, together with the benefits that it brings, rather than consistently being shielded from it in a construction of vulnerability.

allowed these members to make their own decisions about whether they wished to talk to me. WAVE Church's values and practices suggested that a partly pastoral model approach was not necessarily incompatible with a rights-based emancipatory research model.

1.2.2 Research stage one: Fieldwork observational contexts

As discussed above, the initial case study design for the research proved unsuitable for a number of reasons. A key experience here was the church which became a failed fieldwork context, where gatekeeping prevented full engagement with potential participants. Furthermore, when disabled Christians began to hear about the research, many people wished to be interviewed who were located outside the groups where I was conducting initial observation. All the data referred to in the following chapters was collected through the interviews in the second stage of research, rather than in the observational fieldwork contexts. Nonetheless, the church-based groups were of vital importance for establishing and refining research questions, and I will thus briefly outline these observational contexts.

The first of these was WAVE Church, a parachurch organisation for people with learning disabilities.[11] It is not a user-led group, instead a pastoral group established by parents of people with learning disabilities, although there is a high level of involvement of people with learning difficulties in all their activities. Other, similar church groups for those with learning difficulties exist, although it is unclear whether all have a similar high involvement of disabled Christians.[12] WAVE Church runs several activities for people with learning difficulties and those without, including an accessible church-style service once a month on Sunday afternoons. This involves songs with Makaton signing, and Bible teaching through very short talks, drama, crafts and other active engagement, along with social time. They aim to provide a small, accessible church service to support members' parallel attendance at

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[11] In consultation with group members and leaders, I made the decision not to pseudonymise these groups. Both the groups wished to be recognised for their innovative and useful work with and among disabled Christians. It would also be practically very difficult to anonymise these groups, particularly the St Martin-in-the-Fields group, because of its connection with the conferences on disability and churches which I discuss in this chapter. No interview data from members of these groups or other potentially identifying information about individual members is used in the thesis, with the exception of one interview participant who had some involvement with one of the groups; this participant has been pseudonymised and has not been linked with the group in any data presented here.

[12] Most church groups for people with learning difficulties are operated through Prospects, a Christian organisation which recently became part of the Livability organisation for disabled Christians (Livability, 2017). They operate more than 200 groups; WAVE Church is part of this network.

mainstream churches. I was a participant observer at their services over the course of eight months, while also carrying out short joint interviews with members of the groups and their family members,[13] and interviewing the group's founder. These interviews were aimed at finding out more about the group and members' experiences of it, in order to contribute to my understanding of the social contexts of disabled Christians, and to help shape research questions for the second stage of the study.

The second group in which I conducted fieldwork observations was the user-led Disability Advisory Group at St Martin-in-the-Fields church, a large Anglican church in the centre of London. This group was also established by individuals who had faced difficulties with access at their church. Group members are involved in training staff and clergy, consulting on disability policy and practice, and organising events around issues that impact disabled people in churches more generally, often attended by interested visitors from other churches. For the past five years, the group has been organising an annual conference on disability and churches, which has been well attended by disabled Christians from around the country. The group holds regular meetings, which incorporate both consultation on disability issues in the church, and spiritual and social activities. As a user-led group, it is not a segregated pastoral group, but it does engage in some pastoral activities during its meetings. In this fieldwork context I observed group meetings and training delivered to the rest of the church by the group. I also carried out interviews with members and the chair of the group. Again, the primary aim of the interviews was to learn more about the group and its impacts on members, to help refine research questions for the next stage of the study. I was also a regular participant observer at the annual conference and sat on its organising committee, as I have described above.

These fieldwork contexts helped me to shape the aims, research questions and methods for the primary stage of the study: the interviews with disabled Christians. Through my observations of these two groups' activities and discussions

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[13] Goodley (1996) recommends joint interviews with people with learning difficulties and their carers, to allow participants to be supported. In the cases of the interviews with members of WAVE Church, both of the interviewees with learning difficulties requested that their mothers be present to help with interviews. The parents, who did not have learning difficulties, were also members of WAVE Church.

with their members, I gained a fuller understanding of the church landscape for disabled Christians, including the barriers that face many when accessing churches.[14]

1.2.3 Research stage two: Interviews

Thirty interviews with disabled Christians comprise the primary data sources for this thesis. As I will describe below, the methods used to interview participants were flexible, focusing on accessibility so that as many disabled people as possible were able to participate.

Sampling

In my initial research design, I intended to recruit interview participants from a variety of sources, including churches, using snowball sampling to reach potential interviewees through under-explored networks of disabled Christians. However, two issues emerged regarding the use of churches in sampling and identifying participants. Firstly, as discussed above, it became clear that recruiting through churches would not always be in keeping with the study's methodology. It was possible that some participants would feel unable to criticise their churches if they believed I was representing the church leadership in any way. Given the specific criticisms that many interviewees had of their churches' practices, this decision was appropriate—ethical dilemmas would have resulted if their churches had asked for feedback and this had affected members' willingness to raise criticism of their churches. The importance of empowering networks and individuals from the researched community (disabled Christians)—a key aim of critical disability research—also made it inappropriate to work through institutions and thereby suggest that I was allying myself with them, rather than with disabled people.

Nonetheless, needing points from which to start the snowballing strategy, I asked churches if they would consider contacting their parishioners/members of my behalf, or help me to make contact with them. This revealed further issues with sampling methods that involved churches. From February to April I contacted 151

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[14] Leaders and members of both the St Martin-in-the-Fields Disability Advisory Group and WAVE Church, described in Chapter 1, were keen to be involved in the project, given their difficulties achieving recognition for their work. The leader of one of the groups was frustrated that much of the disability work in churches is undertaken primarily by service providers who use a charity model approach, rather than a user-led model, while the work of smaller groups with more user involvement is less celebrated in churches. It is therefore a priority for future research outputs to highlight my research with these groups.

churches, mainly in the London and south-east areas, asking them to advertise in their newsletters or ask members if they were interested in participating in the research. I received 14 replies, with only 3 willing to advertise in their newsletters, for the reasons of safeguarding or lack of disabled members, as outlined above. Thus, with few interviewees identified through churches, I advertised more broadly for potential participants, using a mix of print advertising and internet publicity. I was aware that the "digital divide" for disabled people means that many have limited access to the internet and social media for socio-economic, impairment and age reasons (Kent and Ellis, 2015, 2018; Macdonald and Clayton, 2013). However, research also suggests that many disabled people find the internet and online communication to be transformative for accessing the social world (Anderberg and Jönsson, 2005; Bundon and Hurd Clarke, 2015; Pearson and Trevisan, 2015; Seymour and Lupton, 2004). Accordingly, I provided a mailing address for people to reply to, along with email contact details. Some participants made use of the traditional mailing facility, and sent letters replying to my advertisements. However, most of the participants contacted me through email. I then pre-sampled participants using sampling questionnaires, establishing that participants met the research participation criteria, and looking for participants from a range of church, impairment, and social backgrounds.

I set up a blog (https://naomijacobs.wordpress.com/) and Facebook page for the research project, to share issues arising from the research with disabled Christians, and to encourage research engagement. I used these forums iteratively to find groups which were under-represented among research participants. For example, part-way through the fieldwork, I realised that I had few expressions of interest from potential participants who experienced mental distress.[15] I wrote a blog post about the churches and mental health, noting that I would be keen to speak to anyone affected by the issues. This post was directly responded to by several people, some of whom became research participants.

Sampling criteria for research participation were theoretically driven, as were post-sampling decisions about whose interview data to include in the thesis, made as

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[15] The emerging field of mad studies increasingly uses the terms *mental distress* or *madness*, rather than older terms such as "mental illness" (LeFrancois et al., 2013) as these are terms that allow a focus on personal experience and issues of societal oppression, i.e. encompass a social model framework for mental illness. However, I have not "corrected" participants' own uses of the similar terms "mental health problems" or "mental illness."

the research developed. I chose not to sample for any single impairment group, focusing instead on a broad imagined community of disabled people, as discussed in the Introduction. I also did not use solely social model terms to recruit participants. While research that draws on the principles of the emancipatory research paradigm generally defines disability in terms of social oppression, not all disabled people use social model definitions of disability to represent themselves or their experiences. Given the current dearth of research into the experiences of disabled Christians in the UK, I wanted to ensure that the research could include any Christians who considered themselves disabled or as having a long-term impairment, mental health condition or learning difficulty, as well as people in those categories who no longer attended churches. In the end, I used the definition of disability employed by the Equality Act (2010).[16] In my advertising and research publicity, I clearly signalled the range of impairments that this definition might include.

While the concept of disability used in disability studies is a secular one, and has been resisted by some theologians as a result, as I discuss in Chapter 2, a large number of potential participants identified with this broader definition of disability. Over a hundred people expressed interest in participating in interviews, coming from a range of backgrounds and church contexts. They included people with long-term illnesses, autism spectrum conditions, learning difficulties, mobility impairments and sensory impairments, among others. Although a majority of these potential participants considered themselves disabled people, some used other terms to define themselves, and a small number signalled that they did not identify with the activist disabled community. However, they all had an understanding of a general concept of disability that they felt was relevant to them. Many also had a sense that the issue of disability was under-researched or not often considered by churches, with some saying that they thought that the research study was unprecedented and would be useful to churches.

I acknowledge that, even though it is usefully inclusive, there are limitations to taking this broad approach to disability. There are good reasons why research on this topic might want focus on people from specific impairment groups in churches.

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[16] A person is considered disabled under the Equality Act (2010) if they have a “physical or mental impairment” that has a “substantial” and “long-term” negative effect on their daily activities. I allowed participants to self-define under this definition, rather than questioning their impairment effects in detail.

For example, there are between 100 and 125 Deaf churches in the UK (Lewis, 2007), while there is evidence that churches find it difficult to include Christians with learning difficulties (Swinton, 2002). However, as already noted, little previous research has focused on the general situation of disabled Christians in UK churches. As a result, I consider that it is currently important to focus primarily on analysis of the structural barriers facing a range of disabled people and groups, framed broadly by a social model perspective on disability in society. Later research can then build on theories developed here, including work with people from specific impairment groups, for which I make recommendations in the thesis Conclusion.

Sampling criteria were also not limited to particular denominations. There may have been advantages to focusing on particular church denominations. The Church of England, for example, has an established structure of ministry towards its disabled members, which could be explored in research. However, I again considered that at this early stage of research into experiences of disabled Christians, it was useful to consider a broad range of experiences of participants from across denominations. My priority was to explore the experiences of those who wished to take part in the research, regardless of denominational background. Additionally, the RAG was interested primarily in issues other than the denominational background of participants. Furthermore, early discussions and sampling forms used with participants showed that many placed a low priority on denomination, and this finding shaped the early focus of the research. This reflects some recent findings in sociology of religion, which suggest that denomination may no longer be a leading concern among many UK Christians (Breen and Hayes, 1996), leading to a scholarly focus on other descriptions of Christianities (Ammerman, 1997), including lived religion (McGuire, 2008) and extra-institutional practices among modern Christians (Cornelio, 2014). The related phenomenon of increasing church mobility or "church-shopping" also has a number of potential effects for this study, where the tendency of people to look for a church that meets their needs seems to be growing (Roof, 1994). Low levels of denominational loyalty were relevant to my project because many participants had moved churches when seeking a more disability-inclusive church environment, often after experiences of exclusion. To these participants, denomination was less important than accessible, accepting church environments.

Relatedly, it is difficult to establish single church backgrounds for many of the participants. Participants' church and denominational backgrounds are outlined in detail in Appendix 2, and included Church of England, ranging from liturgical to charismatic, Methodist, Baptist, Pentecostal denominations, and independent/New Church evangelical. Many were involved in multiple denominations, either serially or concurrently. Almost a third of participants (9) come from mixed denominational backgrounds, with several (5) describing attendance at three or more denominations over the past few years. 2 attend more than one church concurrently. One participant wrote in her pre-sampling form: “I tend just [to] identify as ‘Christian’ as I attend the church I feel is the best fit rather than refer to denomination or type” (Susanna, initial sampling form). This was a common sentiment among participants. However, all interview participants were from Protestant church backgrounds.[17]

I advertised the research broadly in publications that would be seen by potential participants from across a number of denominations. However, with a limited advertising budget, some denominations’ publications were prioritised due to circulation. This may be one reason why some denominations were more represented than others. I advertised in *Church Times*, a Church of England newspaper, *Third Way*, a socially-focused Christian magazine, *Direction* magazine and website, which reach Pentecostal Christians, and *Keep The Faith* magazine and website, aimed at women in Black majority churches. I also advertised in secular venues, aiming to reach Christians from a range of church backgrounds and those not currently attending churches, including the *Disability Now* magazine and website. I also promoted the research online, as described above. While both online and offline advertising resulted in some convenience sampling, I used this together with snowball sampling to reach members of already-existing informal networks of disabled Christians.[18] A number of participants said that they had found out about the research through friends and contacts who had previously been interviewed.

A number of trends emerged among potential and actual participants. Significantly more women than men applied to participate, and many more women took part in the interviews than men. The data used for the thesis compromises interviews from 5 men and 25 women. In part I addressed this imbalance through post-sampling decisions: interviews with a further 6 women were carried out but not

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[17] It was not a sampling criterion that participants be from Protestant church backgrounds. However, as a result of numbers of potential participants from Protestant church backgrounds, with very few from non-Protestant denominations, a decision was made to focus on those from Protestant churches.

[18] Snowball sampling is often recommended when a community is hard to reach or little known about, where as a result there is no sampling frame available (see Becker, 1963; Bryman, 2012).

used. I also attempted to identify more men for interviews, but was unable to find them. There was a more representative gender balance in the observational contexts—WAVE Church and the St Martin-in-the-Fields Church disability advisory group. It is difficult to establish reasons for the under-representation of men in applications to the research and final interest in participating, but it may be affected by the higher number of women than men actively involved in Christian churches in the global North (Walter and Davie, 1998), including in the UK churches, to varying degrees across denominations (Bruce et al., 2006; Foster, 1992; The Archbishops' Council, 2015).

There was little interest in the study from people who no longer attend churches. The final interviews included 4 participants who are Christians but no longer actively attend churches, for a range of reasons. There was initial interest from a small number of former Christians, but all eventually decided that they did not wish to explore that part of their lives any further. Again, I made further efforts to identify potential participants who are no longer Christians, which were not successful. A study focusing entirely on disabled non-Christians and former Christians might have more success in locating participants from this group; such a study is recommended in the Conclusion to the thesis.

I was surprised by the number of potential participants who are ministers, both lay and ordained, or who otherwise had an interest in theology and church leadership. My initial research design did not focus on leadership in churches, but participation from this group, as well as narratives from others with an interest in church leadership and ministry, moved the research focus in this direction. Final participants included Church of England ordained and lay ministers, a Methodist local minister, Franciscan Tertiaries and a spiritual director. Many more participants expressed an interest in future church leadership or ordained ministry, or had considered this in the past. Participants' experiences with church leadership are discussed further in Chapters 4 and 6.

As people from Black and minority ethnic backgrounds are severely under-represented among participants, I made attempts to recruit members of Black majority churches and other Christians from minority ethnic backgrounds, including visiting Black majority churches and attempting to develop networking relationships there. However, I was able to recruit few participants through these methods. This is perhaps not surprising, as I was a sole white researcher approaching these communities without links to evangelical churches or other shared background contexts. There may also have been cultural clashes between the way these religious contexts would conceptualise disability and my own definitions. As a result, the study's participants have come primarily from white British ethnic backgrounds, with the exceptions of one British Asian and one white European participant. A single member of a Black majority church was interviewed. However, it became clear that, while she too shared many experiences in common with other participants, her denominational background was very different from that of other participants, and to account for this background fully would require changing the research focus. Additionally, this was my only participant who was a carer rather than a disabled person herself. I therefore decided to exclude this participant from analysis. However, the excluded Black participant had much to contribute on the topic of disability in the specific context of Black majority churches, and I hope to follow up with future research with her. Disability in Black majority churches is an area where I would recommend further research to focus, especially given that much of the expansion in UK church membership is in these churches (Goodhew, 2016).

Another group not well-represented in the interviews are those with more profound learning difficulties, though some participants had more moderate learning difficulties. This in part relates to the particular needs of this group, for whom interviews are not always ideal forms of communication. Multiple methods were employed to compensate for this across the full research project, particularly in my observational fieldwork with the WAVE Church group for people with learning disabilities.[19] In the Conclusion I have made a recommendation for further research with Christians with learning difficulties, particularly that which is led by them and centres their voices and experiences.

Finally, it was not possible for this research to focus comprehensively on Deaf Christians or Deaf churches.[20] This would have required an entirely separate

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[19] One mother of a person with learning difficulties, interviewed together with her daughter as part of the fieldwork with WAVE Church, was keen to see research focused on people with learning difficulties. Although this was the voice of a parent, rather than of a person with learning difficulties, I nonetheless took this group member's perspective into account; it contributed to a sense that, while observations in the background research contexts were useful for shaping the research aims and questions, I could not do these groups full justice within the scope of the thesis. Accordingly, interviews from these groups are not used as sources of data in later chapters.

[20] Work in the field of deaf studies has recently challenged the traditional academic division between *Deaf*, representing a minority linguistic and cultural community, and *deaf*, representing those with hearing impairments who do not use British Sign Language (hereafter, BSL), nor consider themselves

approach, looking at the specific linguistic, cultural and access needs of Deaf people. Research has begun to investigate Deaf Christian communities, primarily from a theological perspective (Lawrence, 2009; Lewis, 2007; Lewis and VanGilder, 2017; Morris, 2008). While much more research with Deaf people in relation to churches and theology is needed, this could not fit within the scope of this study. Nonetheless, the two deaf participants in this study were strongly aware of the audiocentric bias in churches and its effects for D/deaf people, as I explore in later chapters.

1.2.4 Accessible and flexible research methods and data analysis

The relations between researchers and participants are explored in work on the emancipatory research paradigm, whose broad aim is to "shift the balance of power" in research towards participants (Barnes, 1992:123). While this aim is unlikely to be achieved in any single research project (Barnes, 1992, 2002; Freedman, 2006; Oliver, 1997; Zarb, 1992), steps can be taken to increase the meaningful involvement of participants in the research process. In this research project, I used an iterative research design approach based on the input of participants throughout the study, as I describe below, to allow participants' interests and concerns to shape the research. This required the use of accessible, flexible and responsive methods, so that as many disabled participants as possible could be involved in the research in ways that worked for them.

A range of interview methods were used, depending on the access needs of each participant. There is significant precedent for accessible research methods in the field of disability studies (Atkins, 2013; Goodley and Moore, 2000; MacLeod, 2010). Many of these studies problematise positivist data collection and analysis methods. Describing their research with people with learning difficulties involved in theatre arts, Goodley and Moore emphasise that they rejected "pseudo-scientific ambitions in favour of critical engagement with participatory, qualitative research" which led them to reflect that the division between "abstracted versus accessible findings" in the academy threatens "disconnection" (Goodley and Moore, 2000:862) between the realities of disabled people's lives and the requirements of academic research. Studies such as these demonstrate that these realities are more effectively

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part of a cultural minority (Kusters et al., 2017). However, my participants continued to use these terms distinctly, and I reflect their use in this thesis. I refer to "Deaf and disabled theologies" where both are encompassed, given that there is a cultural distinction between the Deaf people's movement and the disabled people's movement, although I primarily discuss disability theologies.

represented through more accessible methods, rather than by prioritising positivist methods. It is from these precedents that I took my cue for flexible methods. I offered participants a range of ways to be interviewed. Concern is sometimes expressed in social research about using interview methods other than the standard face-to-face interview (Novick, 2008), with some social scientists reluctant to use online interviewing because of data quality concerns (Farrell and Petersen, 2010; Illingworth, 2001). However, accessible methods do not necessarily mean less effective data collection or analysis (Farrell and Petersen, 2010). In fact, the opposite may be true, in cases where more disabled participants are able to participate in a study who would otherwise not be reached.

I initially intended to conduct interviews in focus groups. A number of researchers suggest focus groups as ways to shift the balance of power in research, with the potential to allow people from marginalised groups to take more control over the agenda of the research (Beazley and Ennew, 2006; Stone and Priestley, 1996). In practice, however, focus groups would have excluded many of this study's participants for disability access reasons. Some had mobility impairments that caused travel difficulties, preventing attendance at in-person focus groups. Some were on the autistic spectrum, or experienced anxiety, or hearing difficulties, or other impairment effects which impacted their ability to engage in in group settings. Others faced social barriers: for example, they were not able to arrange enough help from personal assistants or supporters to be able to commit to coming to an in-person group meeting. Instead, I offered a variety of participation methods, in groups, pairs or individually, to encourage people to take part in any way that best allowed them to participate, established in discussion with each participant (see Appendix 2 for details).

In light of the difficulty that in-person focus groups presented for many participants, I offered individual, remote and online methods for participation. While some focus groups did meet in person, I also offered the options of individual in-person interviews, email exchanges, Skype interviews either individually or in pairs, and text-based interview. Internet-based methods can form one part of a research strategy aiming for more accessible interview methods, and can be useful where participants are already using the internet to meet their own access needs (Anderberg and Jönsson, 2005). However, Illingworth argues that the internet should not be used as an "easy option" in social research (2001:n.p.), but instead used when it is appropriate, with consideration of issues raised by internet communication in interviews.[21] I concluded that the benefits of access for those many participants who could not meet with me face-to-face outweighed the issues that can arise with remote interviewing, although I address specific ethical concerns of online interviewing and research recruitment below. Given that, as already noted, not all disabled people find the internet more accessible or have access to the internet, I also offered other alternative interview options to participants.

The creation of a password-protected secure internet message board also allowed for participants' non-verbal and remote participation outside of interviews. While the message board was not intended to replace interviewing, it allowed participants an additional, non-verbal way to add further comments after interviews. For confidentiality and consent reasons, I only invited participants to join the message board after they had signed their confidentiality agreements and were accepted as research participants, and participants chose pseudonyms. However, the message board was not as widely used as I had hoped. The high level of engagement in the Facebook information group about the research suggests that it would have been convenient for participants if I could have created a research discussion group on Facebook. However, security concerns precluded this. It is clear, however, that many disabled Christians are beginning to use online networking,[22] and a number of the participants told me that the most positive aspect of taking part in the research was the chance to connect with other disabled Christians. The message board allowed several participants to share experiences with other disabled Christians, finding that they had issues in common.

Paying participants was an important principle of the study's accessibility, so that financial barriers did not prevent anyone from taking part. Participants were paid £10 per hour for their time, along with full travel and other expenses. I clarified that, if benefits or other financial issues precluded this, the money could go to a charity of the participant's choice: several participants accepted this option. A few refused the

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[21] Most of these issues are in fact the same as those posed by telephone interviewing. I also offered the option of telephone interviews, and conducted one, with older participant Jean. She would also have found it difficult to meet with me for impairment reasons, but did not use the internet.

[22] Purposes of such networking range from the activist, such as the use of Twitter by the *Disability and Jesus* group (@DisabilityJ) to connect and campaign, to personal and spiritual support. The use of user-led internet networking among disabled Christians would be a potentially fruitful avenue for future research to explore.

payment for other reasons. Some particularly valued the principle of payment for participation.

Allowing participants to set the agenda: Iterative methods and analysis

The concept of shifting the balance of power in interviews, and allowing disabled Christians to set the research agenda, also impacted the style of interviewing I chose to use. I considered that semi-structured interviews would impose too much of my own agenda on interview structure and subjects of discussion, potentially restricting participants' contributions. I therefore conducted largely unstructured interviews with participants, which have been recommended as part of research processes that examine power relations in research and encourage disabled people to set the agenda for interviews (Gilburt et al., 2008; Low, 2013; Stone and Priestley, 1996). However, I prepared an interview guide with subject headings for discussion, given to participants in advance of interviews, with the aim of assisting those whose access needs meant that they required a clearer structure and guidance.[23]

Interview questions and subject headings were refined iteratively as interviews went on, in response to subjects raised by multiple participants. In interviews and focus groups, participants developed ideas and theories together with me, in a "collaborative learning" partnership (Peters and Armstrong, 1998:76). Thematic analysis then allowed me to organise data discussion under subject areas that participants had prioritised, using an iterative data analytic process influenced by that used in analytic induction (Hammersley, 2003).[24] Iterative research design and analysis are often recommended when researchers aim to allow participants to define the issues to be considered (Barbour and Barbour, 2003; Cornwall and Jewkes, 1995; Stone and Priestley, 1996). However, a side effect of unstructured interviewing was that interviews were often long, even though interview length was

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[23] No qualitative research interview is completely unstructured, but while semi-structured interviews have strong topic areas to be followed, it is possible for interviews to be very loosely structured with the participants' interests deciding on the direction of topic areas within a general framework (Mason, 1996). This loose structure shaped the interviews here.

[24] Analytic induction recognises the need to develop analytical categories in and through the research process, seeing change in research questions not as weaknesses, but as an intended process of the research. To employ analytic induction rigidly would have been inappropriate for this study, since it usually relies on the testing of hypotheses. However, my approach followed the general process of the initial definition of a phenomenon for research, examining a few cases—in observations in church contexts—and then iteratively refining concepts through the focus groups and interviews.

led by participants' need for rest and ability to contribute. There is, therefore, a significant quantity of data that could not be included in the thesis.[25]

Participants were offered the opportunity to be interviewed a second time, or otherwise to discuss questions and issues further, after their first interviews. Two-part interviews are recommended by Barnes (1992) as one method that can help to shift the balance of power between researcher and participant. This method offers participants a chance to reflect further on questions and to offer additional information or clarification. A few participants took up the option of follow-up discussion through email exchanges with me, following their initial interview. Only one participant asked for a second interview, which was conducted over a Skype text call. It was often clear that the time and energy involved in making further contributions was prohibitive for many of the disabled participants. This is an indication that emancipatory and participatory methods can sometimes be a burden for participants, as much as they can be empowering (Stone and Priestley, 1996). I decided that repeated contributions to the research should only be encouraged to the extent that they did not cause difficulty for participants.

Further focus groups would have been very useful during research analysis, as recommended for refining theories and analysis together with participants (Stone and Priestley, 1996; Touraine, 1981). However, the success of this would be dependent on participants' ability to participate in further stages of research, which in many cases was limited. Instead, research findings and analytical methods were discussed with the RAG throughout the analysis process, and participants were invited to comment on everything that was written about them in the thesis.[26] This allowed for some level of shared analytical refining, primarily via email discussion, although this was much less in-depth than Stone and Priestley's method would have allowed. These reminder discussions were particularly important as significant time

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[25] This unused data will be the focus of future publications on participants' experiences of healing practices, and on user-led disabled Christian groups. I have also published a book chapter on the history and current practices of healing in charismatic Christian movements, influenced by the research (Lawson Jacobs, 2016).

[26] I offered all participants the option of further contact and discussion before the thesis was completed, to ensure that any who had rethought any of their contributions or had further thoughts could discuss them. This is recommended by Priestley and Stone (1996) as a method of accountability between researcher and participants. I sent participants copies of the interview data that would be used about them, together with my discussion relating to them; I did not send full transcripts to participants. The British Sociological Association's *Statement of Ethical Practice* (2017b) emphasises that, after focus groups and pair interviewing, transcripts should be treated sensitively. They were especially sensitive here, given small networks of disabled Christians in churches.

had passed since interviews, due to my part-time researcher status. Additionally, all participants were kept informed on the progress of the research throughout the span of the project, through research newsletters written in accessible English and with text-only versions available. While the ideal of sharing the analytical frameworks and approach of a research project with participants (Stone and Priestley, 1996) was not practically possible in this study, I was as open as possible with participants about the ways in which their data would be analysed and discussed.

Furthermore, while the research aims were inductive and exploratory, they were still framed by a critical disability research approach. Thus, while the framework for data analysis was abductive (Blaikie, 2000), I also took a critical approach, rather than a purely phenomenological one, which aimed not collapse into "mere 'storytelling'" (Stone and Priestley, 1996:20). My analysis drew on Critical Discourse Analysis (hereafter, CDA) (Fairclough, 1995) and thematic analysis to work with the categories and topics that were most important to participants. CDA allowed for the analysis of power relations for these disabled people in their churches. There will, as a result, be places where my analysis diverges from that of participants. This is always a difficult balance to maintain in critical disability research, which critiques society but still endeavours to take the voices of disabled people seriously. Disabled people are not a homogeneous group, and the views of disabled Christians towards churches will be equally diverse. Nonetheless, Stone and Priestley argue that "where the researcher has expertise in research skills, this should not be taken as a green light to assume knowledge of the needs, feelings and conceptualizations of other research participants" (1996:713), which emphasises the importance of consulting with participants on interpretations of their interview data and showing where researchers' interpretations diverge from participants' own, as I have done where relevant.

1.2.5 Dissemination: Sharing useful and accessible research results

A range of dissemination outputs are planned from the study, with some already in process. These will include more accessible outputs with a range of intended audiences, in keeping with the principle of this study that its results should be useful to disabled Christians. I conceive of research dissemination not as a separate product that begins when the research ends, but as part of a spectrum of reciprocal activities in the wider research community, which in this research project have ranged from early networking in the community to later sharing of initial results. For example, my involvement on the planning committee of the Inclusive Church/St Martin-in-the-Fields disability and church conferences led to interest in the project and its results from disabled Christians, even at conferences where I did not formally present on the research. More formally, to date I have carried out the following community-based dissemination activities:

- 2015/2017, St Martin-in-the-Fields Church/Inclusive Church annual conference on disability and churches. 2015: Presented a talk and a research poster on the process and initial results of the research. 2017: Presented a series of posters on the initial results of the research, written in accessible language.
- 2015: I presented the research to autistic people and interested members of churches at the *Autism and the Church* conference organised by London autism charity *A2ndVoice*.
- 2016: Interview for the Premier Radio show *Reflections* about the research.
- 2016: Short article for a book commemorating five years of the St Martin-in-the-Fields/Inclusive Church conference on disability and churches (Inclusive Church, 2018).
- Ongoing: Throughout the research project, a public-facing research blog has shared concepts and issues arising from the research.[27] Together with a Facebook group dedicated to the research, this has informed the wider Christian disabled community about the research.
- Ongoing: email newsletters have been sent out throughout the project, informing participants and other interested stakeholders on the progress of the research.

I have also presented at multiple academic conferences since the beginning of the research, with a research results focus from 2016 onwards.

Future dissemination, it is hoped, will include the following activities:

- The research results poster series initially created for St Martin-in-the Fields disability and church conference (2017) will be expanded and shared through online networks created through the research, and other networks of disabled Christians.
- The research blog will feature research summaries and discussions, including the poster series.

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[27] To date no research results which refer to participants' stories have been shared online, as it was important for participants to agree everything written about them before data was shared publicly. In the few cases where participants' stories were presented at research conferences, pseudonyms were used for all participants.

- A research report will be published for churches and other interested stakeholders, based on the Conclusion to the thesis, available in a range of accessible formats.
- A talk and training workshops, based on the results of the research, will be made available to churches. Distinct talks/workshops will be available to groups of disabled Christians, with a focus on making the research useful to them.
- Short articles about the research for Christian magazines.
- Two academic journal articles, on the observational fieldwork contexts and on findings from the interviews on healing.[28]
- A non-academic book aimed at disabled Christians.
- An academic book on disability and Christian churches.

I am keen to share the research results with churches, through talks and workshops. In the Church of England context, I have been asked to do this only through its Committee of and Among Deaf and Disabled People; as a result, access to individual Anglican churches for dissemination of research results will depend on their mediation, although contacts have been made throughout the fieldwork and initial dissemination that are likely to continue regardless.

1.3 Practical Ethical Research Methods

While ethics are inseparable from the framework of my research, and have been discussed in detail above, it is also important to outline the specific, practical ways in which professional research codes of ethics have been met in the research. This research project passed two separate university processes of ethical review. It was approved by the University of Sheffield University Research Ethics Committee in 2012 and by the Department of the Study of Religions at SOAS, University of London in 2015, and is compliant with the ethics policies of those universities, and of the British Sociological Association (2017b).

1.3.1 Consent and access to information

University ethical codes often represent disabled people as particularly vulnerable. While it is certainly important to follow laws on informed consent in research, these are sometimes represented in university guidance in ways which may conflict with the social model or the emancipatory paradigm. I discuss the legal framework of the

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[28] Although healing is discussed in Chapter 6, there was no space to discuss significant material from the interviews on the subject of Christian healing practices. These will be explored in a journal article.

potential vulnerability of disabled people below. While no research participant is necessarily vulnerable, issues of vulnerability and risk in relation to consent for disabled people can be reduced, especially by using more accessible information about the research.

Informed consent to the research was given formally by all participants, accompanied by an information sheet (see Appendix 3). Participants who were being remotely interviewed completed this form by email, using a typed signature. One participant who could not write by hand also used a typed signature. One visually impaired participant gave verbal consent after the form had been read aloud to her, as did one older participant interviewed by telephone who did not have access to the internet. No participant in this study would be considered unable to consent under UK law. To assist members of the WAVE Church group with informed consent, a modified consent form and information sheet was created using a "simple words and pictures" format (see Appendix 3), and I explained the research to participants together with parents or carers. This simplified consent form was also useful for several of the second-stage interview participants.[29]

1.3.2 Anonymity, confidentiality and ownership of data

Power dynamics for disabled people within church contexts were a key driver for requests for anonymity. A number of participants expressed concern over confidentiality and anonymising, particularly in relation to any criticisms they had of their churches. This was especially the case as many participants perceived that they were the only disabled people in their churches or their wider networks of Christians, or one of very few disabled ministers.[30] Furthermore, the potential for some participants to be identified is high: some disabled Christians in the UK are beginning to form loose networks and communities, and some prominent members of these communities have been interviewed. This was a driver in the decision not to include full transcripts with the thesis and other additional anonymisation measures.

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[29] Several of the second-stage interview participants had moderate learning difficulties, including some of those with autistic spectrum conditions. See Appendix 2, showing participants' backgrounds.

[30] This perception is not borne out by data, which suggests that there are significant numbers of disabled Christians in churches, yet several participants felt that they were identifiable and that there were few other disabled Christians. This may suggest that not many participants were meeting Christians who identified as disabled, despite meeting legal criteria, or it may reveal something of participants' own concepts of disability.

However, this contextually-driven need for anonymity was balanced with a desire from some participants to own their data and experiences. Reflecting this right to ownership of data, many asked for their first names to be used. Prioritising the right of disabled research participants to have control over how their data is used and presented, I have honoured this request, and I consider that participants should have the right to ownership and agency over data. I would have liked to have been able to offer to cite the full names of the participants in this project whose theologies are shared here, especially in the light of discussions in later chapters about disabled people and access to theology. However, this concept of ownership of ideas was difficult to balance with the need for confidentiality as outlined in research ethics guidance. I prioritised the requirements of the Data Protection Act (1998), given that sensitive data required enhanced ethical confidentiality procedures. In future books or articles arising from this study, I will be able to return to the participants and ask whether anyone would like to be cited with their full name in conjunction with the theologies and concepts which they shared during the interviews, after transformation and detailed reconsideration of the data.

1.3.3 Use of digital and online research methods

As outlined above, a mix of digital and offline methods were used to reach and engage with participants at all stages of the study. In addition to debates about the quality of data obtained using online methods, discussed above, there are particular ethical discussions around the use of internet-based social research methods. Internet-based social research involves no higher risk than other forms of research, but the risks of research conducted online are different from those in other research settings (British Sociological Association, 2017a; Kraut et al., 2004; Trevisan and Reilly, 2014; Zimmer, 2010).

Consent is a key issue of risk where internet-based research takes place. No internet data collection methods were used without full consent of participants, using standard consent procedures, which mitigated some of these risks. However, consent issues precluded research into other data available online. As discussed in the Introduction, there is increasing networking between disabled Christians using the internet, including blogs and Twitter. However, the BSA considers that personal data available on the internet should be treated with caution because of potential issues of consent (British Sociological Association, 2017a). I therefore did not use online materials by disabled Christians, other than the blogs of a small number of disabled church leaders on the subject of disability, which were used as part of the literature review and following ethical citational practices.[31]

Further risks of internet-based interviewing included interactional differences between face-to-face and remote interviews (Illingworth, 2001), and acknowledged academic risks of the stigma of internet-based methods (Farrell and Petersen, 2010) which may affect how the results are received. These were mitigated, for example in my careful consideration of how to use the open Facebook group versus the password-protected message board. Where some risks of using internet-based methods remained, I again chose to afford the "dignity of risk" to participants, weighing the risks against improved access for relevant participants. Trevisan and Reilly (2014) argue that there is no reason why disabled people should necessarily be considered more vulnerable than other users of social media in research. However, I considered that the use of data from social media might nonetheless affect the enhanced confidentiality procedures required for this project. For this reason, no interviewing or sharing of data took place via public social media. However, as described above, it was a central principle of the research that interviewing methods should be as accessible as possible to all, and for many participants, online methods allowed better access to the research.

I also gave thought to the ways in which I wrote about and marketed the research online. No names, pseudonyms or individual cases were discussed in the blog or Facebook group. Instead, general issues and findings were reflected upon there. After publication of the thesis, when reports and materials for churches will be shared via the research blog, participants will again have the opportunity to confirm that they are happy with their anonymisation there.

Given new General Data Protection Regulations (2018), in 2018 I asked recipients of the research newsletter if they wished to continue to receive it. However, participants had already given consent to be contacted directly about the research, through the research consent forms, which complied with new regulations.

As already discussed, this study's activist and critical disability research methodology are particularly relevant to the research context of churches and

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[31] In the case of Ann Memmott's blog posts, I obtained the consent of the author before referencing them in the literature review, since her blog shares a mix of personal and professional reflections.

theology and their approaches to disability. The theme of centring disabled people's experiences and voices will recur throughout the thesis, as I explore how disabled people are represented in churches as objects of care and ministry, rather than as active agents of theology and service. To contextualise this theme, the next chapter examines some of the historical and current theological discourses of disability that were most relevant to my participants' experiences.

Chapter 2. Theological and Ecclesial Perspectives on Disability

In this chapter I examine a number of frameworks used to understand disability in church contexts, in order to contextualise the issues and topics raised by my participants in later chapters. First, I examine some trends in theologies of disability today, and consider how mainstream theology of disability is distinct from disability theologies which centre the experiences of disabled Christians. Second, I consider how the Bible has been read as representing disability: I raise the question of whether the Bible represents disability at all, and consider how it has been interpreted as speaking about, or to, disabled people. Finally, I briefly examine two historical Christian discourses of disability which were relevant for my participants: the wholeness paradigm and the pastoral care model. Here I begin to explore the impact of these discourses for disabled people in churches today; in later chapters, discussions of these themes focus on my participants' experiences.

Here I do not offer a full history of Christian theologies of and practices towards disabled people, as this has already been undertaken from a number of perspectives (Avalos, 1998; Covey, 2005; Cusack, 1997; Goodey, 2011; Kelley, 2007, 2011; Lewis, 2007; MacKenney-Jeffs, 2013; Walls, 2007), in addition to more general histories of illness and healing in Christianity (Daughton-Fear, 2009; Ferngren, 2009; Porterfield, 2005; Robinson, 2011; Sheils, 1982). Rather, with reference to these histories, I outline the major Christian theological discourses of disability relevant to the participants in my study, focusing on two prominent approaches to disability that they encountered. I then consider pastoral theology, as a theological tradition that was relevant to the experiences of many of the participants, looking at the ways that the pastoral care model has impacted disabled people and the reception of disability theology.

2.1 Theologies of Disability: Definitions and Contexts

With the rising influence of disability studies across various academic fields, social and theological research has investigated ways in which, for disabled people, theology has an influence over participation, often leading to their exclusion (Betcher, 2007; Black, 1996; Clapton, 1997; Creamer, 2009; Eiesland, 1994; Lewis, 2007; McColl and Ascough, 2009; Morris, 2010; Treloar, 2000b). A number of theologians examining disability have entered this debate. Deborah Creamer argues that “While many people with disabilities have found welcome in the church, others may still wait outside the gates” (2009:36), linking this in part to under-theorisation of the impact of theologies on disabled people. Using a similarly biblically-derived image, Nancy Eiesland links accessibility to social and theological attitudes suggesting that “For many disabled persons, the church has been a city on a hill—physically inaccessible and socially inhospitable” (1994:20).

Furthermore, churches have not always been reflexive about this theological and interpretive process towards disability, or its impacts on disabled Christians (Clapton, 1997; Cusack, 1997). Churches’ processes of developing theology about disability are unclear; Christians draw on biblical and theological models for beliefs about issues relating to disability, such as miraculous healing (Village, 2005), but these responses to disability are often pieced together without sufficient reflection on their ideological implications (Creamer, 2009; Long, 2015; Treloar, 2000b).

Theology is located within Christian discourse and practice. It therefore tends to assume “the givenness of faith” (Boff, 1996:2).[1] It also usually assumes a church context for faith. Tyron Inbody locates theology, and its close relationship to personal Christian faith, within the context of churches: “If we are Christians…our faith is derived from and measured by the faith of the Christian church….Christian faith involves thinking about faith. This is what Christians call ‘theology’” (2005:2-3). For John MacQuarrie, theology “has become problematical in the modern world” (1967:11), where we face not only the Nietzschean “‘death of God’” but also the growing irrelevance of mythological and religious language in late modern society. He argues, however, that there is a “close connection between theology and the living faith out of which it comes by a process of reflection” (1967:19). He calls for theology which is rooted in questions of God and situated in church communities, rather than focused on detached questions of ethics, asserting that without this context, theology disintegrates into “empty debate” (1967:13). Similarly, Rebecca Chopp asks “How did theology ever get separated from the congregation?” (1987:124) and critiques the way that much academic theology fails to speak to community and wider society (see also Kelsey, 1980). However, socio-historical,

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[1] Boff refers here to the particular context of Liberation Theology, described below, which is focused on the religious and social experiences of those who are oppressed. However, faith’s “givenness” is generally assumed throughout the field of theology.

contextual and sociological issues have been a growing influence on theological thought since the 1970s (Gill, 1998), particularly in the adjacent field of biblical studies, a discipline which includes non-confessional approaches (Davies, 1995).

There are many disabled members of churches who, faced with a lack of access to church communities, argue that they have been excluded from the very process of "doing theology" that is so central to religious life (Black, 1996; Eiesland, 1994; Hull, 2003b; Lewis, 2007; Wallman, 2001). This theme, of abstract theology at the expense of the practical, has been explored by a number of theologians. Walter Lowe argues that in recent years, Christian theology has provided no alternative as society has sought a "ready-made enlightenment" (Lowe, 1993:3) through esoteric, non-institutional spirituality. Lowe contends that this commodified cult of the "bourgeois subject" (1993:5) is not addressed by Christian theology, which instead tends to look inward. As a result, Christianity risks "affirming the prevalent ideology" (Lowe, 1993:5), in much the way that Eiesland describes the churches' support of societal ideologies of disability.

In contrast, in recent decades a number of theologians have developed theologies of disability from a socially-located perspective. Some have argued that, for disabled people, theology has indeed become mere rhetoric. For disabled people in the churches, theology's primarily theoretical focus has led to exclusion, social injustice, and paternalism (Eiesland, 1994; Lewis, 2007; Long, 2015), especially where theology is focused on abstract, internal concepts, rather than on the material contexts of oppressed people within and outside the churches. Eiesland, whose influential work *The Disabled God* (1994) was one of the first examples of a social justice-focused approach to disability in Christian theology, argues that churches have long supported the structures and institutions that oppress and disempower disabled people.

The call, by Eiesland and subsequent scholars, for disabled people's access to churches and theology so that they can call for justice not just in the hereafter but also in today's churches, is strongly influenced by liberatory theologies.[2] A distinction is often drawn between Liberation Theology—capitalised to indicate its specific context of Roman Catholic Latin American communities—and other

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[2] See, for example, Black (1996); Boff (1996); Cone (1975); Gutiérrez (2001); Lewis (2007); Segovia (2000); Sugirtharajah (2002); Williams (1993).

liberatory or liberationist theologies. The latter draw on the principles established in Liberation Theology; these situate praxis and concepts of justice at the heart of theology, calling for a “preferential option” for oppressed groups and centring their perspectives. Liberation Theology argues that “God’s justice is a universal project whose first clients should be the poor and the marginalized” (Aquino, 2010:430), inviting those in positions of wealth and power to conversion in support of the oppressed (Althaus-Reid, 2010; Boff, 1996; Gutiérrez, 2001 [1971]).[3]

Liberatory and other disability-focused theologies have been emerging at least since Eiesland’s work was published, driven in part by disabled people themselves, and to some extent rooted in the field of disability studies (Metzger, 2011). In this thesis I also term this approach *critical disability theology*, following the development of critical disability studies, to allow for the inclusion of socially-located and critical theological perspectives that do not draw directly on liberatory theologies, whose features I explore below.[4] This critical theological approach is driven by theologians and sociologists of religion with an interest in the intersections of disability studies and disability in the churches, often centring the perspectives of disabled and Deaf people in theology (e.g. Betcher, 2007; Black, 1996; Creamer, 2003; Freeman, 2002; Hull, 2003b; Lewis, 2007; Weiss Block, 2002). In using the term critical disability theology for this socially-located theological approach, I particularly draw on critiques from CDS of those disciplines and professions which “conceive, discuss and treat disability within a diagnostic perspective that emphasises individual deficiency” (Meekosha and Shuttleworth, 2009:51).

There has also been a recent parallel growth in mainstream theology’s interest in issues of disability, in part in reply to the theology of Eiesland and other critical disability theologians. Such mainstream theology of disability often has a pastoral focus, with much in common with the individualistic and diagnostic discourses critiqued by CDS; it has a focus on ministries to support disabled people in churches, rather than on reshaping theology around disability perspectives (e.g. Edmonds, 2011; McCloughry and Morris, 2002; Swinton, 1997). For the purpose of this

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[3] Hereafter I follow this capitalisation convention to distinguish between contexts of liberatory theologies.

[4] This term also echoes Mike Oliver’s concept of “critical social research,” as described in Chapter 1, linking these disability theological approaches to critical disability research’s “[facilitation] of a politics of the possible by confronting social oppression” (1992:110). These critical disability theologies often have similar emancipatory aims of confronting oppression in theological, ecclesial and other Christian contexts.

chapter, I include these mainstream pastoral theological perspectives under the umbrella term "theologies of disability," explored in more detail below.

There are several distinct approaches to disability in these new critical disability theologies. Some take overtly liberatory approaches (Betcher, 2007; Eiesland, 1994; Hull, 2003b; Lewis, 2007; Weiss Block, 2002), arguing for a preferential option for, or prioritisation of, disabled people. However, disability liberatory theology remains a minority approach.[5] Other concerns of recent theologians of disability have included the representations of embodiment and suffering in Christian theology (Inahara, 2009; Moltmann-Wendel, 1994) and the physical barriers preventing disabled people's access to church buildings (Cunningham et al., 2009; Gourgey, 1995; Herzog, 2004; Weiss Block, 2002). A number of disability theologians have critiqued historical Christian theological discourses which create environments that encourage disability exclusion in the churches (Betcher, 2007; Eiesland, 1994; Hull, 2003b), as explored further below. Others apply the social model to the Bible, in resistant readings (Exum, 1993) of biblical material that relates to disability (e.g. Hull, 2013; Lawrence, 2009; Lewis, 2007; Melcher, 2004).

Perhaps most controversially, some disability theologians call for the widening of mainstream Christian discursive and theological traditions to include disabled people, not as the cared-for objects of pastoral theology and the Christian charity model, but in a new collaborative model of creating *theology with*, rather than *services for*, disabled Christians (e.g. Black, 1996; Eiesland and Saliers, 1998; Lewis, 2007; Wallman, 2001). A key theme in critical and liberatory disability theologies is the necessity of centring disabled experience and concepts of disability as oppression and injustice, rather than as deficit, in Christian discourse and practice. Social location is important in all liberatory theologies, from Black theology's critique of the Bible's role in oppressive societal paradigms (Cone, 1975) to feminist theology's resistant readings of hegemonic narratives (Christ, 1997; Exum, 1993; Plaskow, 2005). In these critical discourses, as in disability studies, although the social location of the reader is not always interrogated, the social location of the *reading* is

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[5] Betcher (2007) suggests reasons for the relative dearth of disability liberatory theologies, arguing that there may not be room for disability issues in liberation theology, given the importance, in late modern secular discourse and Christian theology alike, of wholeness and remediation of impairment as a higher priority than social justice.

(Shildrick, 2009; Thompson, 2007). Speaking from this tradition, Lewis argues that the experience of Deaf people should be placed at the centre of Deaf theology; she calls for a Deaf liberation hermeneutic and culturally-appropriate Christian praxis that emerges from Deaf culture, in order to challenge Deaf people's history of social oppression through Christianity (2007:140) in ways that are relevant for disabled people more generally:

> [T]heologies of liberation give us a methodology for challenging the discourse of "deaf" in traditional western theology. First we need to deconstruct that discourse and show how the way Deaf people have been constructed in the church is actively oppressive, and then we need to reconstruct theology from the perspective of our engagement in the struggle for Deaf liberation.
>
> (2007:12)

Responsibility for focusing Deaf theology on the experience of Deaf Christians lies with both liberatory theologians and mainstream theologians, Lewis argues, calling for new sources for theologians which centre experience. Disability theologians have similarly argued that a re-centring of disabled experience in theology will have significant practical implications, shifting the focus to the history and culture of disabled people, inclusive and anti-oppressive worship and church practices, and the interrogation of approaches to the Bible that marginalise disabled Christians.[6]

The embodied theological perspectives of disabled people, many disability theologians argue, are crucial to the re-centring of disability theologies on the perspectives of disabled people. Eiesland argues that disabled people need theology to be made more accessible to them before their full inclusion in Christian churches is possible. She highlights the oppression inherent for disabled people in theology, not just in relation to theological concepts, but also in terms of the theological method itself. Arguing that there is a need for an "accessible theological method" to allow disabled people full participation in practical and theological church contexts (1994:20), she draws on Chopp's critical praxis correlation[7] to call for theology "that encompasses difference, specificity, embodiment, solidarity, anticipation, and transformation" (1994:21). Here she and Chopp draw on a more practical and socio-

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[6] See, for example, Black (1996); Clapton (1997); Eiesland and Saliers (1998); Hull (2003b, 2013); Koosed and Schumm (2005); Lewis (2007); Melcher (1998); Metzger (2010); Schipper (2006); Schumm and Stoltzfus (2011); Treloar (2002); Webb-Mitchell (1994); Weiss Block (2002).

[7] Chopp's method (1987) is emancipatory, corporeal and transformative; as a method it has much in common with disability studies methodologies. It has influenced Eiesland's theology of disability and, accordingly, critical disability theology more widely.

historical understanding of theology, comparable to Inbody's "embedded theology" (2005), in which theology is about the relationship between God and humanity, rather than merely being descriptive of God. Similar theological approaches are sometimes called practical theology or applied theology (Chopp, 1987; Swinton et al., 2011), but these terms imply a hierarchy between theoretical and applied approaches, exemplifying Lowe's critique of the theological privileging of inwardness (1993). In contrast, for many disabled people, theology is not divided into theoretical and practical aspects, but is materially present in all church practices, from the words of hymns (Hull, 2001a) to the ideologies exemplified in church design that does not promote disability access (Black, 1996; Creamer, 1995; Eiesland, 1994; Webb-Mitchell, 1994). Such corporeal and material theology was evident in the contributions of many of the participants in this study, as I explore in subsequent chapters.

However, there is disagreement over the character of the new disability theology, and, from some theologians, over whether it is necessary at all. Creamer (2006) identifies three models of disability theology: that of the Accessible God, the Inclusive God and the Disabled God, all of which, she argues, fulfil Eiesland's call for new theological models to supersede those that have failed disabled people. Describing a complementary approach, Metzger (2011) identifies four strands to disability theology: a social model approach to disability, a politicised epistemological standpoint, a critical and resistant approach to biblical texts, and a shared view of God. However, Metzger's summary is primarily relevant to critical disability theologies, with other theologies of disability diverging from these principles. For example, much theology of disability explicitly rejects the social model, as noted, while there are at least three ways in which disability theologians and disability biblical scholars approach the Bible, some of which are confessional rather than critical (Avalos, 2007b). Furthermore, there are varying strands of critical disability theology, and disability theologians draw on different Christian and sociological discourses. Some are focused on access and social justice for disabled members of churches (Weiss Block, 2002; Yong, 2011b); others are more social-relational in their theologies (Black, 1996; Creamer, 2003; Epperly, 2003). Although not all these disability theologians draw overtly on liberatory theologies, they are often informed by the social model and other approaches from disability studies and the disability movement. Hans Reinders identifies two primary approaches to current theological work on disability: one with a focus on universal, “existential questions” (2012:440) that arise in the context of disability, and another which takes a more political and practical approach. This typology has influenced my own division between theologies of disability and critical disability theologies. However, while there are a number of writers on disability and theology who take a politically-engaged, social model-based approach, they remain the minority when compared with the number of theologians writing about disability from other perspectives (Metzger, 2011), and Reinders does not discuss this difference in emphasis. Many discussions of disability in modern theology remain rooted in pastoral care discourse; there has also been some candid objection from mainstream theologians to the new critical disability theology, particularly its social model and political influences, as I discuss below.

2.1.1 The Bible and disability: Resistant biblical readings

Biblical interpretive traditions of the body have been examined in biblical studies, including through feminist and post-colonial approaches. These biblical readings of resistance draw on liberatory theologies and secular emancipatory theory, offering alternatives to the textual-cultural process of marginalisation that disempowered groups have experienced in relation to their construction within and through biblical readings (Segovia, 2000; Sugirtharajah, 2002). For example, Schüssler Fiorenza’s feminist “hermeneutic of suspicion” (1998:81) takes an emancipatory approach to the Bible and the ways its interpretation has contributed to social discourses of oppression for women. Similarly, the Black theology of James Cone acknowledges the socio-political context not only of the biblical texts but also of their contextual uses in and by society, for both emancipation and oppression (1975; see also the postcolonial biblical scholarship of Rukundwa and Van Aarde, 2009; Sugirtharajah, 2002). Such unashamedly socio-political readings of biblical texts have their critics, who argue in favour of objectivity. However, in common with much disability theory, writers from these perspectives have argued that both theology and biblical interpretation are subjective, and that there is no reading of the Bible that does not have a political interest (Chopp, 1989; Gorringe, 1998; Schüssler Fiorenza, 1988); Cone argues that a reader’s “social and historical context decides not only the questions we address to God but also the mode or form of the answers given to the questions” (Cone, 1975:15).

In recent years, the field of disability biblical studies has developed similarly "interested" approaches to biblical interpretive constructions of disability. Disability biblical studies draws on sociological biblical perspectives, as well as wider sociological theory of disability, in responses to the Bible (Avalos et al., 2007; Eiesland and Saliers, 1998; Olyan, 2008; Raphael, 2008). In common with feminist and postcolonial theory, disability biblical studies addresses multiple simultaneous representations of disability and related concepts in the Bible, exploring how social concepts of disability both construct and are constructed by the Bible and its reception. Rather than replicating their historical work, I draw here on these liberatory and emancipatory readings of selected historical Christian discourses of disability to establish the background of representations of disability in churches and theology, particularly where these impacted the study's participants.

Disability biblical studies has explored the ways that disabled people are used for spiritual and social purposes in biblical material (Douglas, 1966; Melcher, 2004; Raphael, 2008; Toensing, 2007). Sharon Betcher argues that disability has been used as a Christian "metaphor to think with," to represent spiritual insufficiency or a situation in need of redemption: a "spiritual diagnostic" (2007:59). As such, she argues, in Christian contexts disability is implicitly associated with a deficit model, seen as a problem in need of remediation. In disability theory, Mitchell and Snyder refer to this use of disability for metaphorical purposes as a "narrative prosthesis" (2000:4). Such symbolic uses of the disabled or disfigured body, they argue, both draw on and produce the outer form reflecting the inner being or soul. They ascribe this material metaphor of the body in part to the nineteenth-century field of physiognomy, in which, "by 'reasoning from the interior to the exterior,' the trained physiognomist extracted the meaning of the soul without the participation of the interpreted" (2000:58-9). However, the concept that the appearance of the body reveals the content of the soul pre-dates physiognomy and other modern discourses of the body. It is reflected in interpretations of the Bible throughout Christian history (Ferngren, 2009).

For a number of biblical scholars and theologians, the enduring influence of the concept of the revelation of the soul by the body in Christian theologies has been the root of a number of historical discourses of the body that continue to impact disabled people today. For biblical scholars Grant (1998) and Webster (2007), this use of metaphors of disability for spiritual limitations in biblical texts is marginalising, exploiting disabled people as little more than moral narrative devices; the resulting spiritualising of disability makes real disabled subjectivities invisible (Webster, 2007). Such spiritualised use of disability as a symbol of an individual's lack of spiritual insight, as in the Gospel narratives of blindness (e.g. John 9:1-12), or in the healing of all disabled people as a sign of eschatology, positions a dehumanising paradigm of disability at the centre of Christians' holiest texts (Freeman, 2002; Hull, 2003b; Melcher, 2004). This is characteristic of the liminality created by negative ontologies of disability in many social contexts, especially where disabled people represent a threat to society (Kumari Campbell, 2005).

Such use of disability as no more than a metaphor, with its connotations of deficit, has difficult, if unintended consequences for disabled people in churches today (Black, 1996; Hull, 2003b; Schumm and Stoltzfus, 2011). Warren Carter (2011) argues that real disability is erased and made invisible as a consequence. For African womanist biblical scholar Renita Weems (1995), metaphors shape our reality and are our first lessons in marginalising others. Jennifer Koosed and Darla Schumm apply Weems' arguments to biblical metaphors of blindness in the Gospels, arguing that, as a result of the authority of the biblical text in churches, these metaphors "justify & reinforce the oppression of marginalized members of a community" (2005:88). Examples of this use of metaphors include the biblical and hermeneutical association of blindness with disobedience and ignorance (Black, 1996; Hull, 2013), and the similar connection of physical health to spiritual wholeness (Eiesland, 1994; Koosed and Schumm, 2005; Pattison, 1989). A normate hermeneutic (Wynn, 2007) arises from such use of narrative prosthesis and its attendant use of language in the Bible and theology (Eiesland, 1994; Hull, 2003b; Lewis, 2007). For example, discussing the association of blindness with sin and ignorance in hymns, Hull identifies precedents for these linguistic and metaphorical connotations in the Bible:

> The thought is based upon Revelation 3.17: "For you say, 'I am rich, I have prospered, and I need nothing.' You do not realize that you are wretched, pitiable, poor, blind, and naked." The verse, like the hymn, attacks the complacency and self-deception of the Church or of those who have not responded to Christ, and blindness is associated with poverty, nakedness and wretchedness.
>
> (2002:334)

Hull argues that the language of blindness as deficiency permeates throughout Christian traditions, as a result of this frequent emphasis in the Bible (2002:338).

Lewis (2007) has argued similarly for uses of language of deafness in Christian contexts, proposing the alternative of emancipatory language that does not associate disability with deficit. Mitchell and Snyder argue that narrative prosthesis draws on normalcy in its desire to separate people into groupings of "narrative fantasies of difference," used "as a means of managing biological deviancies and their attendant metaphorical monstrosities" (2000:65-66). In Christian contexts, such "managing" of the appearance of impairment in the Bible using narrative prosthesis reinforces a normal/abnormal dualism, marginalising and dehumanising those associated with the abnormal side of the binary (Black, 1996).

One particular consequence of the use of spiritualised metaphors of disability can be seen in what Eiesland calls the "sin-disability conflation" (1994:72). Biblical and classical scholars have argued that there is no singular form of "Jewish thought" or "ancient thought" towards disability (Moss and Schipper, 2011). However, there are potential associations between sin and physical or mental impairment in some biblical texts and their later reception. In the first-century Jewish religious context of the Gospels, scholars have argued, there is a strong connection made between disability and punishment, based in oblique rather than specific references (Grant, 1998; Hardie, 1966; Melcher, 1998). Rebecca Raphael's work (2008) on the concept of Israel's god as physically perfect and empowered, in contrast to deaf, mute and disempowered idols, identifies socio-historical contexts for the connection between holiness, sin and sickness (or impairment) in other biblical texts. While forms of sin-sickness link can be found throughout the ancient near eastern world, the strength of the connection varied in different contexts (Kelley, 2007; Walls, 2007). This link may have been influenced by Levitical laws which excluded people with some disfigurements and chronic illnesses from the Jewish Temple (Avalos, 1998; Melcher, 1998).[8] Love (2008) connects this Levitical purity system to concepts of disability as punishment, in a number of biblical texts, where it relates to a belief in divine will that gives order to the cosmos (see also Raphael, 2008).

Nonetheless, this contextual understanding of potential reasons for the development of a "sin-disability conflation" has not always been reflected in the uses

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[8] Each of the Gospels takes a slightly different approach to these Levitical purity codes, suggesting that their interpretation and social impact varied according to context (Avalos, 1998; Melcher, 1998). While they excluded those affected only from the Temple (Klawans, 2006), their stigmatising effect may nonetheless have acted in practice as an exclusionary force outside the Temple, in wider society.

of these texts and their impact on society. The societal impact of the Levitical purity laws, and other Jewish scriptures which relate disability to punishment, has been widely debated in disability biblical studies. The discussion has included reflections on divine ideals of beauty and wholeness and the impact of these on societal norms (Olyan, 2008), the removal of speech and agency from disabled people (Raphael, 2008), and the role of the non-disabled gaze in the Torah and Talmud (Watts Belser, 2011). The link between disability and punishment has also been explored in histories of illness in Christian contexts where the biblical sin-sickness conflation has had influence (Ferngren, 2009; Kelley, 2011; Porterfield, 2005).

While the sin-sickness link is by no means the only construct of disability in biblical texts (Lewis, 2007), it is a significant paradigm that remains a dominant way of understanding disability today. The immediate effects of this conflation have been significant for those disabled people considered candidates for healing or deliverance[9] ministries in churches: for example, Kathy Black (1996) and Nicole Kelley (2011) both describe situations in which healing ministries led to the deaths of disabled people. While some theologians and biblical scholars argue that associations between ancient models of disability and its aetiology with late modern disability are reductionist (e.g. Strecker, 2002), the link between disability and sin or punishment is still made in recent theology and other Christian writing, as discussed by the disability theologians, biblical scholars and sociologists who have begun to explore the broader societal effects of this and other persistent biblical discourses of disability for disabled people (Creamer, 1995; Eiesland, 1994; Lewis, 2007; Long, 2015; Treloar, 2002; Yong, 2011b). However, in more recent theologies the sin-sickness link often appears in less direct forms, such as the association of disability more generally with the Fall and a Fallen world in need of remediation (MacNutt, 1995; Maddocks et al., 1976), or an aetiology of some impairments where the cause is demonic forces (Twelftree, 1985). It was particularly in these more indirect forms that participants in my study encountered the theological conflation of disability with sin and punishment.

The concepts of ableist bias in the biblical text, including audio- and visiocentricity, have been explored by a number of theologians and biblical scholars.

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[9] Hunt defines deliverance ministry as "a 'low level' means of expelling evil spirits (demons)" (1998:215), which often encompasses healing from illnesses believed to be caused by demons, a growing form of ministry in neo-Pentecostal and charismatic churches.

Hector Avalos (2007a) has proposed a "sensory criticism" approach to the biblical text, while John Hull (2001b, 2013) has discussed the ways in which the Bible, theology and church practice can all exclude blind people, embedded in and emerging from a sighted world as they often are. The Deaf churches have inspired examination of audiocentricity in the Bible and churches, from theological and biblical studies perspectives (Lawrence, 2011; Lewis, 2007; Morris, 2008).

Disability theologians have taken a number of perspectives towards the use of disability as spiritual metaphor and related marginalising discourses, for disabled people, in the Bible. Many have developed redemptionist approaches to the Bible. For Creamer (2009), the Bible was never meant to be a book about disability and should not be read as such. Yet, this and similar arguments in theology of disability sometimes overlook the reality that biblical texts both contain and shape discourses of disability (Hull, 2014). Instead of purely redemptionist approaches that represent the Bible as entirely positive or neutral on the subject of disability (Webb-Mitchell, 1994; Yong, 2011a), Hull argues instead for candid analysis of the normate hermeneutic present in the biblical text. He considers that this allows the Bible to move from "dictatorial master" to "conversational partner" (2014:636) with respect to disability in many Christian contexts.

Disability theology and disability biblical studies have also offered alternative possibilities in approaching biblical texts whose frameworks of disability are not always read as positive or benevolent. Colleen Grant, neither attempting a completely redemptionist reading of the text nor acquiescing to its ideology, acknowledges the difficulties presented for disabled readers by some biblical texts: "I must also admit that an easy reconciliation between the Gospel healing stories and a vision of full and open participation for persons with disabilities is not readily at hand….However, I am also not ready to argue that the stories are devoid of any usefulness to us" (1998:78). Grant's perspective both recognises the negative effects of theological or ideological positions affirmed by biblical narratives, and acknowledges the more useful elements of the stories. Such approaches, drawing on liberatory theology, may allow for new perspectives on biblical narratives and their frameworks of disability. Moreover, it may be useful both for disabled and non-disabled Christians to recognise that biblical texts present a theological framework of sin and disability that modern Christians may, or may not, share. Nonetheless, redemptionist perspectives may allow for shifts in interpretive focus towards the disabled objects of biblical texts. Both redemptionist and other approaches were taken by this study's participants towards biblical texts (explored in Chapter 6); they engaged in interpretive methods that restored subjectivity to disabled people, where this subjectivity has been erased in much hermeneutical analysis of the Bible.

There are a number of other significant hermeneutical and theological traditions, encompassing health and the body, that may impact disabled people who encounter the Bible and Christian theology. These include the theological concept of the *Imago Dei*, the image of God in humanity, and how disability has led to reflection on this (Ferngren, 2009; Goodey, 2011; Porterfield, 2005); the concept of the suffering person who is blessed by God, or *graciosi* (Cusack, 1997; Ferngren, 2009); the Fall and the incorruptible heavenly body (Betcher, 2007; Goodey, 2011; Lewis, 2007; Upson-Saia, 2011). There has also been a significant quantity of writing and research on illness and healing in Christian contexts, in various fields,[10] although only a small percentage of this reflection on healing comes from a critical or disability theology perspective (Eiesland, 1994; Grant, 1998; Kelley, 2011; Moltmann-Wendel, 1994; Pattison, 1989).[11] There is not scope here to explore all these discourses in detail. Instead, in the remainder of this chapter, I examine one of the key discourses that was relevant to my participants' experiences. The discourse of pastoral care has been used as a framework for disability in theology and the churches, and has been critiqued by some disability theologians as a vehicle for oppression. I also consider the rejection of critical disability theology from mainstream theology and churches, in favour of this less radical discourse.

2.2 Pastoral Care Discourses and Disability in Churches

On the whole, mainstream theology does not engage with disability studies, the social model of disability, or the disabled people's movement. Instead, most theology focusing on disability remains rooted in pastoral theology. Christian pastoral theology has generally taken a charitable, rather than justice-focused, approach. With its history of charitable work and outreach to those in need, pastoral care is rooted in discourses connected to early church practice (Graham, 2000). Historically, pastoral care has been strongly influenced by a missional context, in

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[10] See, for example, Ferngren (2009); Maddocks (1981); McGuire (1988); Porterfield (2005); Sheils (1982); Stolz (2011); Twelftree (1985); Vellenga (2008); Village (2005); Watts (2011).

[11] I have written elsewhere on the socio-historical contexts of healing paradigms in Christianity and churches (Lawson Jacobs, 2016).

contexts ranging from the educational focus of Jesuism to Anglican inner-city missions among people living in poverty in the twentieth century (Dunstan, 2000; O'Malley, 2000). There has traditionally been a strong emphasis on healing in pastoral care, including an awareness of the historical link between sin and illness in Christian traditions (Bennett, 1994; Berinyuu, 2005; Black, 1996; Bronheim, 1994; Epperly, 2003; Evans, 2000; Jones, 2009; Swinton, 2000). The Christian pastoral care approach to disability is often sustained despite knowledge of objections, from elements of the disability movement and disability studies, to care and dependency paradigms (Barnes et al., 1999; Eiesland, 1999; Morris, 1991). For example, pastoral theologians Roy McCloughry and Wayne Morris are aware of the disability movement's resistance to the concept of care; however, they explicitly dismiss this, because of personal preference over terminology:

> Recently there has been a change in the language and the term "personal assistant" is being used instead of Carer. This is because the word "Carer" is said to be patronizing towards the person with a disability. Though we acknowledge this change, we are still committed to using the terms "pastoral care" and Carer in this chapter.
>
> (2002:84)

While not all pastoral theologians use a primarily care-focused approach, many do, and the care discourse is not widely deconstructed in pastoral theology.

One potential result of the charitable focus of the pastoral care discourse is the Othering of those receiving ministry and charity—generally the poorest and most oppressed in society—which can create and sustain power differentials (Betcher, 2007; Lewis, 2007). Black identifies the discourse of dependency that has divided non-disabled minister from lay disabled person, creating a paradigm based on *ministry to* disabled people rather than *with* or *by* disabled people, as a key reason for the location of much theology of disability in the fields of pastoral care and pastoral theology (Black, 1996; Eiesland, 1994). This denies the agency of disabled people, and reduces their ability to self-govern (Freeman, 2002; Lewis, 2007). Furthermore, pastoral theology encourages an individual model approach to disability, precluding a focus on justice. To draw on Lewis's terminology (2007), inclusion, rather than transformation, can become the standard in churches with a pastoral focus towards disability. This has a number of unintended effects for disabled people in churches.

First, the pastoral model and pastoral care can silence the voices of those it intends to serve. Stories of exclusion shared in theology of disability are often focused around the pastoral care that churches provide, showing both subtle and overt discrimination often arising as a result of decisions made for disabled people and without their input. Such experiences are widely cited in critical disability and Deaf theology (Black, 1996; Creamer, 2009; Eiesland, 1994; Hull, 2014; Lewis, 2007); critiques of such exclusion occasionally also come from within pastoral theology itself (e.g. Calder, 2004). The pastoral care model has not only failed to address such problems, it has contributed to them, by establishing a segregated environment in churches where pastoral staff and ministers, rather than disabled people themselves, have control over disability access. I focus on this issue in Chapter 4.

Another potential effect of the *ministry to* paradigm is the segregation of disabled people within the Christian churches. Some disability theologians argue that segregation is an example of one effect of the irrelevance of the church to disabled people, and of its inability to include disabled people fully. For example, although Lewis (2007) celebrates the Deaf church movement, she shows that it was initially established as an Anglican mission to Deaf people by hearing people, noting the political issues of control and self-definition that arose in many Deaf churches as a result. Deaf people, she argues, have been constructed as "objects of charitable giving" (2007:85) in the Deaf church movement ever since. The majority of Deaf churches still operate as charities that construct Deaf people as dependent upon, rather than responsible for, church ministry. In contrast, mainstream theologians have expressed varying responses to segregation, with many appearing unaware of the related issue of the segregation faced by disabled people in the secular world. So, while Mary McClintock Fulkerson (2007) is ambivalent about the segregation of disabled members into a congregation-within-a-congregation that she finds in a North Carolina church, she discusses the implications of segregation in this ministry only as an afterthought, while Wayne Morris (2010) celebrates Deaf churches uncritically and suggests segregated practice as a desirable model for disabled people in churches. Similarly, there is currently a focus on inclusion and welcome for disabled people in mainstream theology, but many of these calls for inclusion continue to operate from within a charitable and paternalistic model that constructs disabled people as reliant on the welcome of churches (e.g. Edmonds, 2011; McCloughry and Morris, 2002; Swinton, 2000), as I explore further in Chapter 5.

Furthermore, an additional result of the pastoral care *ministry to* approach is its effect on the ordination and church leadership of disabled people. Many critical disability theologians have commented on disabled people's exclusion from ordination and leadership (Black, 1996; Eiesland, 1999; Hull, 2001b; Robitscher, 1998; Wallman, 2001; Weiss Block, 2002). Lewis (2007) places this exclusion in the context of pastoral models, discussing stories of Deaf people's struggles to be ordained to the priesthood, primarily in the Church of England, the denomination that hosts most Deaf churches, where Deaf ordinands have faced barriers to ordination despite positive statements on the subject from denominational leadership. She gives the example of an ordinand who had to use his wife as a sign language interpreter during the entirety of his training, because both his diocese and home church refused to fund a professional interpreter (2007:88). Although this might be considered indirect discrimination, some church denominations have demonstrated more directly exclusionary policy towards disabled people wishing to train for priesthood or ministry. Eiesland examined the American Lutheran Church access policy which warned that not all disabled people would be suitable ordinands because of the potential for "distraction and congregational discomfort" and disruption to ritual where ministers are disabled (1994:86), recalling Levitical prohibitions on disabled priests. Similarly, Hull (2001b) relates the rejection of Jane Wallman from ministry, specifically because of her impairments, until an appeal to the Archbishop of Canterbury was finally successful in 2000. Wallman's own research (2001) suggested that little had changed since Eiesland's research twenty years before, with many disabled ordination candidates in the Church of England reporting barriers to ministry, including unmet support needs and a concern from denominations about potential lack of confidence in disabled ministers from congregations. Lewis considers the "power dynamics" (2007:89) behind such systematic exclusion, using the example of the tendency of many churches to provide wheelchair ramps to congregational areas but not up to the altar. Such architecture is a visible reinforcement of disabled and Deaf people's construction as passive recipients of ministry, rather than active participants in its delivery (see also Creamer, 2009; Deland, 1994; Stookey, 2003). Other critical disability theologians have also located the roots of the issue of exclusion from church leadership in the pastoral care model, and the discursive limits it places on disabled people's inclusion in churches (Black, 1996; Weiss Block, 2002). Such ongoing exclusion of disabled people from leadership positions in churches may suggest that the focus on inclusion in recent theology of disability fails to engage with issues of systemic ableism, in favour of a charitable and paternalistic focus on welcome. Where pastoral care discourses represent disabled people primarily as recipients of charity and care, it is difficult for churches to see them simultaneously as potential leaders, whose barriers to leadership involve systemic exclusion. I discuss access to and exclusion from ordination further in Chapter 4.

Pastoral theologians are sometimes aware of the exclusion of disabled people in churches described by Hull, Lewis and other disability theologians. However, in the pastoral model's context of care and dependency, church-based answers to issues of disability are often located in the existing practices of churches and Christian communities (Blair and Blair, 1996; Gourgey, 1995; Knight and Knight, 2009; Paterson, 2015; Reinders, 2008). Sometimes these church-based answers are proposed uncritically, without reflecting on the oppression inherent in Christian traditions. Expansions of the church pastoral care system are often seen as a way forward for disabled people: for example, Treloar (2002) believes that the answer to disability exclusion will be found in increased support from church pastoral care programmes. Some critical disability theologians also seek answers to disability exclusion within churches: Black (1996) locates the solution to exclusion in the communities of evangelical churches, which she assumes will be supportive of disabled people. In denominations where the Bible is particularly central, the theological answer to issues raised by disability is often rooted in biblical redemptionism, proposing the rediscovery a biblical truth that is assumed to be positive towards disability. In this vein, a recently widely-cited solution to disability exclusion, particularly among pastoral theologians, is that of friendship or welcome for disabled people in churches.[12] However, this proposal raises its own issues around the concept of friendship and how it is imagined by theology, to which I will return in below in relation to disability theology's critiques of concepts of welcome.

The pastoral history of the churches in healing and charity is difficult to make compatible with a social oppression or social model concept of disability. A number of critical disability theologians have criticised the pastoral care model for its orientation towards evangelism and salvation, which have, historically, been among

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[12] See, for example, Edmonds (2011); Hallahan (2008); Reinders (2011); Reynolds (2008); Swinton (2000); Vanier (1999); Yong (2011a).

its primary efforts (Elford, 1981; Leavey, 2008; Stone, 1983). Betcher argues that a spiritualised conception of pastoral care is a fundamental orientation of Christianity, calling this approach “conspicuous salvation” (2007:112). She argues that when salvation is prioritised over earthly justice, it can be a distraction from the examination of systemic ableism in churches and Christian discourses (see also Broesterhuizen, 2005; Lewis, 2007). Drawing on disability theorist Paul Longmore, Betcher argues that such Christian compassion and charity is colonialist; it is a performance that centres the giver, not the receiver (2007:112). Similarly, Lewis asserts that there has been a colonialist context of Deaf churches with their hearing-led cultural model and charitable pastoral care discourse, resulting in the Deaf community’s segregation, marginalisation, suppression of language, and loss of agency to challenge the dominant culture (Lewis, 2007; see also Carter, 2011). The effects of charitable models for disabled people are rarely benevolent, as disability studies has explored (Albrecht, 1992; Borsay, 2005; Fleischer and Zames, 2011; Longmore, 2015; Mitchell, 2015), but similar effects of the pastoral model for disabled Christians have not often been acknowledged within pastoral theology itself. Exceptions include Pattison (1988, 1994), who has critiqued pastoral theology’s individualist orientation and neglect of socio-political contexts of suffering. Other examination of the socio-political contexts of pastoral theology and pastoral care has come from Black and feminist perspectives (Bennett Moore, 2002; Harris, 1991; Henderson, 2003). However, the majority of critique of the pastoral model’s dominance in Christian disability work, specifically, comes from critical disability theologians.

Freeman argues that disabled people in churches need a more radical and inclusive approach than their current marginal position in pastoral theology allows:

> Holding together the tension between the pains and also the insights of the experience of the disabled body has demanded a radical eclectic approach, one not content with the issue of disability being treated as an adage on the margins of Christian pastoral theology but one which scouts wide in medical sociology, disability culture, Christian reformist and radical feminist theology and thealogy in the bid for nuanced perspectives to affirm people with disabilities as theological agents.
>
> (2002:72)

Currently, however, critical disability theologians suggest that mainstream theology and the churches are not drawing on such a radical approach in relation to disability. In fact, models from disability studies and critical disability theology are being explicitly rejected in pastoral theological contexts, as I will now discuss.

2.2.1 Pastoral rejection of disabled people's theological models

Pastoral theology's individual model perspective on disability often overlooks both the views of disabled people and models of disability from disability studies. As a result of its focus on church communities and pastoral care programmes, pastoral theology often shows a stronger interest in the experiences of carers and non-disabled associates of disabled people than in disabled people's own models and experiences (Lawson Jacobs, 2012; see, for example, Edmonds, 2011; Gillibrand, 2014; Reinders, 2008; Yong, 2007). Again, this may be the result of the ideological division between those who have traditionally offered care and ministry in the church, and those who have received it. This invisibility of disabled people is widespread across theologies and, of course, is common beyond Christian writing; for Michael Oliver, it often shows that even writers who examine social oppression fail to see disability (1996b:133). The echo of these broader social trends towards disability in theology shows the extent to which the churches have both contributed to and absorbed wider social, individualised approaches to disability.

Dismissal of the social model of disability is common in pastoral theologies of disability (Hutchinson, 2006; McCloughry and Morris, 2002; Reinders, 2008; Swinton, 2011), along with concern expressed about other socio-political and emancipatory frameworks for disability.[13] Swinton, for example, is a particularly forceful voice against the social model, and often refutes the theologies of critical disability theologians. Dismissing disability theory, and disabled people's own models and perspectives, as "current politics or political correctness," his conclusion is that "[d]isability rights are important, but only as they relate to the goals of the coming Kingdom" (2011:304). Working firmly within the pastoral model tradition, Swinton does not reject the concept of justice, but establishes eschatology and evangelism as Christian priorities. Similarly, Reinders advocates moving "beyond rights and justice" in favour of moral examination (2008:6). Other pastoral theologians of disability remain committed to the churches' pastoral focus on care, including Morris and McCloughry (2002), who also express suspicion of the social

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[13] Criticism of the social model can also be found among some critical disability theologians (e.g. Weiss Block, 2002), together with calls for a new Christian model. However, the rejection of the social model is more common among pastoral theologians of disability, while instead many critical disability theologians start from a social model perspective as a basis for liberatory approaches.

model, despite their call for a move from a deficit model to a diversity model of disability in the churches. Compare this approach with the call of liberatory theologies for justice now, as a sign of the Kingdom, rather than postponed for a potential afterlife (Betcher, 2007; Lewis, 2007). A few pastoral theologians of disability are more supportive of the social model, placing it in the broader context of social model debates within disability studies (Reynolds, 2012; Yong, 2007).

Relatedly, some theologians adamantly refute the claim, made by many critical disability theologians, that disabled people have faced oppression in churches. Nichola Hutchinson (2006) argues that there is no evidence that disabled people have ever been excluded from church. Instead, she asserts, the social model is ideologically driven, rather than historical—creating a dichotomy between these concepts—and not relevant to Christian contexts. Hutchinson's concern, about the potentially over-simplified approach to Christianity taken by scholars who are not primarily experts in Christianity, is shared by some disability biblical scholars (Moss and Schipper, 2011), as discussed in the Introduction to the thesis. However, Hutchinson fails to address the evidence for oppression of disabled people in Christian contexts, including evidence which disabled people and disability theologians themselves have presented (e.g. Black, 1996; Eiesland, 1994; Kelley, 2011; Lewis, 2007; Long, 2015; Webb-Mitchell, 1994). In Hutchinson's dismissal of disability theory as "atheoretical" (2006:2) without addressing these concerns, there is an implicit dismissal of the voices of disabled people in Christian contexts.

Furthermore, it is not only the social model of disability that is often rejected in mainstream theology. Disabled people's own *theological* models, too, are often ignored, or strongly countered by other theologians. Some pastoral theologians assert, in contrast with the perspectives of liberatory theology, that all theologies should relate to all people (McCloughry and Morris, 2002; Swinton, 2011); this is a universalist theological approach (Wells and Quash, 2010). Swinton characterises Eiesland's "disabled God" approach as "a theology that excludes people who do not have disabilities" (2011:285). He expresses additional concern about the theological accuracy of Eiesland's image of the Disabled God (2011; see also McCloughry & Morris, 2002). Yet, Eiesland's aim in *The Disabled God* (1994) is not to write systematic theology, but to create a socially located disability theology which she locates within the broader tradition of liberatory theology. Eiesland anticipated many of these objections to the content of her theology, arguing that the disability movement has been overlooked by churches and theology in favour of the pastoral model:

> [The disabled people's] movement has been largely ignored by the Christian church….Many religious bodies have continued to think of and act as if access for people with disabilities is a matter of benevolence and goodwill, rather than a prerequisite for equality and the foundation on which the church as model of justice must rest.
>
> (1994:67)

Critical disability theologies draw on different theological traditions from those often used in pastoral theology. As Chopp (1987) argues, liberatory theologies employ very different models from other theologies, which cannot be compared as like with like. This difference in models can be compared to Schüssler Fiorenza's feminist theological critique of an "'add women and stir' approach to liberal Christianity" (Chopp, 1987:122; Schüssler Fiorenza, 1983) as compared with an approach which "grapple[s] with historical particularity and differences" (Chopp, 1987:136), through theologies which truly address the social location of all Christians—in this case, including disabled Christians.

Such rejection of disabled people's models and theologies has practical impacts for the participation of disabled people in church contexts. Lewis (2007) writes of a significant drop in the participation of Deaf youth in churches, not primarily for reasons that they might share with their young hearing peers leaving churches, but because of a lack of British Sign Language in hearing-led church services which have low cultural relevance to the Deaf community. For young Deaf people, the general societal perception of irrelevance of churches (Kinnaman, 2011; Pollack, 2008; Roozen, 1980) is exacerbated by the cultural and practical inaccessibility of non-BSL church services. Further research is needed to establish whether there are similar trends of low participation of other disabled people as a result of theological and cultural irrelevance, but this thesis begins to confirm this irrelevance and its impacts for the church attendance of disabled people.

In contrast with these pastoral theological approaches, liberatory theologies have focused on those whose opinions are routinely ignored and invalidated, who have been denied access to education and deprived of a voice, particularly by giving them access to the Bible, the understanding of which is a key source of power in Christian community. Levine outlines Liberation Theology's critiques of theology's neglect of the opinions of the oppressed and colonised:

> In a society whose majority is often poor and illiterate, where most poor people have long been given to understand that their opinions are of no value (or more precisely, that they have no opinions).
>
> (1988:244)

Disabled people are similarly treated by some theologies of disability as though they—and their community and its theology—have no opinions, or few of any theological importance (see also Dyrness, 1992). Thus, liberatory approaches to disabled people remain liminal in theologies of disability. Metzger notes that such liberatory thought can be found only at the very "edge" of today's disability theology (2011:297), intersecting with anti-oppressive theologies, including postcolonial and feminist theology and biblical studies, which have already paved the way for "resistant readings" of biblical texts (Exum, 1993:41). Emerging critical disability theology, rooted in disability studies and the disability rights movement, is largely ignored by mainstream theologians, even those with an interest in disability and the churches (Eiesland, 1994; Moss and Schipper, 2011).

2.2.2 Theologies of friendship and welcome

Theologians who reject the models and frameworks of disability studies, and disabled people, often have no alternative but to rely on ideologies and frameworks that are critiqued by critical disability theologians. A popular structural trope in pastoral theology of disability is to begin with a second-hand personal narrative, often the tale of a disabled family member or friend.[14] These experiences are cited as though they give insight into disability as a complete issue, and they add a claim of legitimacy to those writing theologies of disability. However, from a disability studies standpoint, such individualised approaches are potentially just as oppressive as more traditionally paternalistic approaches. The choice and presentation of narratives of disability is, as Waltz notes, "not a neutral activity, but an integral part of constructing and perpetuating a medical model of disability" (2005:422); power is at work through the selection of narratives and the lens used to examine them:

> [R]epresentation frequently obscures these complexities [of disabled people's lives] in favor of the rhetorical or symbolic potential of the prototypical disabled figure, who often functions as a lightning rod for the pity, fear, discomfort, guilt, or sense of normalcy of the reader.
>
> (Garland-Thomson, 1997:15)

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[14] See, for example, Brock (2011); Edmonds (2011); Gillibrand (2014); Nouwen (2012); Reynolds (2008); Vanier (1999); Yong (2007).

For Garland-Thomson, who calls these constructions “enfreakments,” such narratives render the social meanings of bodies invisible while simultaneously conveying them, and can contribute to the social construction of those with bodies which diverge from norms. In theologians’ uses of disabled people’s narratives to legitimise their theologies, these “enfreakments” tend to position the disabled person as the Other who exists to impact the lives of non-disabled Christians, drawing on an inheritance of *graciosi* theology (Cusack, 1997), which I discuss further below. The implied reader is non-disabled; the object of the theology is the disabled Other.[15] These individualising narratives also lack the collective force of the disability community and the theoretical context of disability studies. As I suggested in my Introduction, the use of disability, and disabled people’s narratives, for legitimation of Christian perspectives has an ideological and social history that requires scrutiny. Rejection of disabled people’s models and approaches to disability leaves theologians dependent on repetition of past ideologies of disability, including those which have been critiqued by critical disability theologians and other disability scholars as perpetuating individual models of disability.

Individualistic approaches to disability inclusion in the churches are often embedded in the language of welcome and friendship. One of the most widely-used biblical passages in this context, interpreted as being about disability, is the parable of the banquet (Luke 14:15-24) which centres on a man whose guests reject his invitation to a banquet, and which finds the host seeking guests at any cost:

> Then the owner of the house became angry and ordered his servant, “Go out quickly into the streets and alleys of the town and bring in the poor, the crippled, the blind and the lame.”
>
> “Sir,” the servant said, “what you ordered has been done, but there is still room.”
>
> Then the master told his servant, “Go out to the roads and country lanes and make them come in, so that my house will be full. I tell you, not one of those men who were invited will get a taste of my banquet.”
>
> (Luke 14:22-24).

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[15] *Graciosi* models can be seen in much disability theology that advocates welcome, to varying degrees. MacKenney-Jeffs describes Brad Jersak’s experiences of healing through people with learning difficulties and autism, without critiquing his representation of people with intellectual impairments as having special gifts from God that they cannot understand (Jersak, 2006; MacKenney-Jeffs, 2013). Webb-Mitchell’s (1988) criticisms of L’Arche also highlight the *graciosi* theology sometimes at work in discussions of this movement (e.g. Reinders, 2010; Vanier, 1999).

This parable is widely cited by theologians of disability as evidence of a positive directive of disability inclusion from Jesus to the churches (Schurter, 1994; Webb-Mitchell, 1994; Yong, 2007). Webb-Mitchell claims that the outcasts who become guests “stall because they do not feel worthy and decline the invitation” and that, in response, “they are reassured and gently taken into the house” (1994:89). However, a minority of disability theologians have argued the parable does not read as representing an invitation of love, that the motivations of the host for including the “cripples” are dubious, and that the disabled people in the story are denied both agency and a voice. Metzger argues that this is a parable of compulsion, not love. What he calls the “authoritarian, paternalistic rhetoric” (2010:23.6) of this parable, and its denial of agency for disabled people, may present a problematic image of God that disabled people will find difficult to trust. Yet the parable continues to be widely used as a template for inclusion, by pastoral and critical disability theologians alike—a model of bringing the oppressed into the house of the powerful, rather than changing society to accommodate them. Citing examples of the rejection of “unsavory” portrayals of God among the parables (2009:51), Metzger argues that biblical commentators tend to bring their own redemptionist image of God to their reading of disability in ambiguous biblical texts. In this case, a church agenda of inclusion without transformation is overlaid onto a complex biblical text, a point to which I return in Chapter 5.

A number of theologians of disability have argued, to varying extents, that friendship—sometimes described in terms of welcome, hospitality or relationality—is an ideal and uniquely Christian tool of inclusion for disabled people.[16] Such theological models of friendship are inspired by Henri Nouwen’s theology of hospitality (1986, 2012) and Stanley Hauerwas’s theology that centres welcome (Hauerwas, 1982; Swinton, 2012a). Amos Yong considers friendship the proper solution for issues of inclusion of those with profound learning difficulties in churches (2011a:113-114), while Thomas Reynolds attributes spiritual healing power to hospitality and relationality (2008). The focus of such friendship theology tends to be people with profound intellectual impairments (Hauerwas, 1982), sometimes while overlooking other disabled people. Theologians have cited this group’s

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[16] See, for example, Angrosino (2003); Epperly (2003); Gourgey (1995); Hely (2002); Iozzio (2011); Morris (2010); Nouwen (2012); Reynolds (2012); Steele (1994); Swinton (2012b); Yong (2011b).

exclusion from the disability movement, together with arguments that the church needs to be protection from society's marginalisation of this group of disabled people (Swinton et al., 2011; Yong, 2011a:112-13). The lack of a voice for those with intellectual impairments—often literally—may make them an expedient group for theologians to claim solidarity with, with the potential for their exploitation for legitimation of theologies. However, the singling out a group within the disability movement could lead to their distancing from that movement; this approach also allows theologians to disavow the voices of other disabled people. A related assertion is that the social model and disability rights rhetoric are irrelevant to people with profound and intellectual impairments (Swinton, 2011).[17] This allows theologians to overlook the social model and disability politics entirely, and encourages an individual model approach which positions individual friendships as the sole solution to the problem of exclusion from churches.

There are a number of limitations to theologies that present welcome and friendship as solutions to exclusion of disabled people from churches. Firstly, their focus may appear to be disabled individuals, but behind this often lies a focus on their non-disabled allies, and an interest in what the church can gain from including disabled people, especially those with learning difficulties:

> The result is a renewed church, one that is inclusive of the lives and gifts of those who have previously been the most extremely marginalized members of the human community. But beyond this, when the church stands in solidarity with such people, it fundamentally alters its own self-understanding and identity.
>
> (Yong, 2011a:115)

Similarly, where such theologies are applied on the level of individualised reflection, Betcher's "performance of giving" is often evident; the primary focus is not on the disabled person as much as on those who are changed through interactions with them. Nouwen's reflections on his interactions with Adam, who had profound and intellectual impairments, is far more focused on Adam's effects on him than on Adam's own needs:

> A few times when I was so pushy he responded by having a grand mal seizure, and I realized that it was his way of saying, "Slow down, Henri!

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[17] In fact, in disability studies there has been significant work with and about people with intellectual impairments, with detailed reflection on the relevance of the social model to this group and their inclusion in the disability movement (Boxall et al., 2004; Campbell and Oliver, 1996; Chappell et al., 2001; Docherty et al., 2005; Goodley, 2001, 2011; Kiernan, 1999; Walmsley, 2004). This debate in disability studies has rarely been acknowledged by theologians of disability.

> Slow down.” Well, it certainly slowed me down! A seizure so completely exhausted him that I had to stop everything I was doing and let him rest….Adam was communicating with me, and he was consistent in reminding me that he wanted and needed me to be with him unhurriedly and gently. He was clearly asking me if I was willing to follow his rhythm and adapt my ways to his needs.
>
> (2012:46)

A disability studies approach might look instead at Adam’s environment, the barriers he faced, and the unmet medical needs that might have led to his seizure; this approach would be less likely to focus on what Adam was “saying” to Nouwen through his seizure. Nouwen’s theme, of what non-disabled Christians can learn and gain from disabled Christians, forms part of a long church tradition of where some disabled people have, since at least the Middle Ages, been considered *graciosi*, given special blessing by God or able to come closer to God, in ways from which non-disabled people can benefit (Cusack, 1997). This stereotypical dualism is still evident in recent pastoral theologies of disability. Such reworking of longstanding ideologies, many of which have been critiqued by disabled people, is neither rooted in the disabled people’s movement nor in critical disability theology.

Furthermore, friendship as a sole solution to issues of access to churches for disabled people is likely to be unfeasible, given the current reported state of disability accessibility and inclusion in Christian churches, as my findings in subsequent chapters confirm. An examination of the broader social structures that exclude disabled people from churches is also likely to be necessary to create the conditions for inclusion. Reported consequences of inaccessibility and poor inclusion in churches have included the departure of Deaf, disabled or chronically ill people from church (Eiesland, 1994; Lewis, 2007; Reynolds, 2012; Webb-Mitchell, 1994; Zuckerman, 2011), injuries and deaths during deliverance ministry and healing services (Black, 1996; Jafri, 2012; Kelley, 2011), and the refusal of communion to Deaf people and those with learning difficulties (Lewis, 2007; Teahan, 2012). Knight and Knight (2009) comment on the unpreparedness of church communities to assist those experiencing mental distress, with few resources available to help, and little training for church leaders and ministers. Some theologians have argued that full inclusion in churches also requires access to church leadership, suggesting that this rarely happens because disabled people are considered only to be objects of ministry, rather than as potential ministers (Stookey, 2003:96). There seems to be a mismatch between the rhetoric of hospitality and the experience of exclusion of disabled Christians. Indeed, as Kunz argues, the rhetoric of church welcome can be positive while practical, systemic exclusion from churches continues:

> Of course no church would condone a sign that advertises, “Demented persons not welcome.” It is entirely possible that inclusion will be preached from the pulpit and that the sick and the weak will be included in the prayers of petition. The actual exclusion just occurs all on its own.
> (2011:23)

When theologies of friendship and welcome do not also address the social contexts of exclusion experienced by disabled people, they, together with churches that draw on this theology, risk this simultaneous positive rhetoric and practical exclusion.

Furthermore, amongst all the references in Christian literature to welcome and relationality, there is little comment to be found on the challenge of doing friendship with disabled people well, and what level of commitment it might involve. Rarely, theology and Christian writing does comment on the social challenge of churches’ commitment to inclusion through friendship. For example, Rennebohm describes the life of his church, which has taken on the major commitment of practical welcome for those experiencing mental distress; he details the need for cultural change that his church has faced, as a result (Rennebohm and Paul, 2008). For the most part, however, the potential social and contextual difficulties with friendship-based inclusion and welcome for disabled people are rarely addressed. As discussed in Chapters 4 and 5, a number of participants in my research shared ideas about what is practically necessary for their inclusion in churches where wider social contexts affected their ability to make friendships there.

It may be this tradition of pastoral theology to which Reinders alludes when he argues that recent theological work on disability “does not seem to be anything like a *theology of disability*” (2012:439, emphasis in original). His objection here is that many recent scholars of theology and disability are focused on a theology of being human, and the light that disability sheds on this universal experience. It seems that Reinders does not consider this a theology of disability because it does not directly address the care and inclusion of disabled people in the churches, but instead focuses on the human experience. Yet, disability theologians argue that theology of disability cannot be limited to discussion of disabled people, but must examine the impact of disability for all of theology, particularly in its reflection on humanity (Betcher, 2007; Eiesland, 1994). As Hull argues, disability’s alternative epistemology of the body challenges the ideologies of normalcy and the “hegemony of the average” that pervades theology and church practice (Hull, 2003b:22). Without a more universal approach to embodiment and normalcy, he argues, there will be no challenge to this non-disabled hegemony in theology and church practice. Disability theology that goes beyond the pastoral care discourse is a strong challenge to normalcy in church practice, from the often-disablist lyrics of familiar hymns (Hull, 2002; Lewis, 2007) to exclusive interpretations of the Bible (Hull, 2013). These are all examples of Inbody’s concept of embedded theology, as discussed above. Rather than the dichotomy of theoretical and pastoral (or practical) theology, an embedded theology approach assumes that theology is at work in every area of church life, and challenges the non-disabled hegemony of theology in practice. As explored in later chapters, many of these practical concerns were reflected in my participants’ theologies.

In Part B, I discuss the ways in which the participants in my study encountered and responded to these Christian discourses of disability. I examine ways in which these discourses and theologies impacted their experiences of worship, social interaction, service and leadership in churches, and how they framed their own theologies in response to these discourses. The following chapter begins by investigating participants’ physical and practical access to church buildings and cultures.

Part B: Misfits in the Pews

Chapter 3. Misfitting: Experiences of Church Normalcy

In this chapter I argue that many of my study's participants were included in churches only to a limited, conditional extent. Using Garland-Thomson's theorisation, I argue that participants often remained *misfits*, unable to fit into church environments that were created for a normative range of bodies and minds. I theorise the church-located disciplining of participants' bodies and minds, by their churches' spiritual traditions and social norms, as *discipl(in)ing*. The surveillance and policing of bodily deviance, in order to limit the effects of deviant bodies and minds on normative society, has a particular impact on disabled people (Shildrick, 1997; 2009; see also Foucault, 1979). For many participants, as they were discipled in their churches, their bodies were disciplined. In this chapter and the two that follow, I explore the effects of this uniquely Christian and church-located form of bodily discipline on the study's participants. I contend that many of these disabled people were welcomed into churches under the condition that they performed an acceptable 'fit' with their spiritual traditions and social norms. However, some participants' more positive experiences offer examples of churches whose models of disability inclusion were more transformative. Drawing on these experiences, many participants discussed ways in which disabled people could be better accommodated by their churches. Participants' strategies of resistance to poor inclusion, too, suggested alternatives to the common models of inclusion used by their churches.

This chapter considers participants' experiences of three keys areas of church life, where disabled participants showed that they misfit. First, I examine disabled people's experiences of church buildings, the most easily-identified and literal examples of misfitting. I argue that, for many of the participants, church buildings were not created for their impaired bodies and failed to sustain them, which led to their exclusion. The response of churches was often either to segregate participants physically, or to expect participants to rely on informal support from fellow congregants to help them to overcome physical barriers. Second, I examine participants' experiences of worship and denominational cultures, arguing that cultural barriers marginalised disabled congregants, preventing them from participating fully in a religious habitus (Bourdieu, 1984).[1] Finally, I consider the intrinsically social cultures of churches, with which some participants struggled, suggesting that these tended to marginalise participants who could not share fully in church social life because of inherent disabling barriers. These areas of misfitting—uses of buildings, cultural and social norms—often overlapped or intersected, and were so deeply embedded in church cultures as to be invisible to non-disabled church leadership and other congregants. Normalcy dominated the church environments of many participants' churches, as seen in the both the social and cultural norms against which participants misfit.

3.1 Disabled Christians as "Misfits"

Garland-Thomson's concept of *misfits* is both a social and materialist theory of embodiment. It theorises the ways in which "the particularities of embodiment interact with the environment in its broadest sense" (2011:591). The built environment is not designed for disabled people's bodyminds;[2] it sustains embodiment that falls within normal parameters, but creates misfits of those with non-normative bodies. Garland-Thomson argues that misfitting is dynamic and performative, produced when a disabled person encounters the materiality of the environment, and shaped through the ways in which that environment is used by non-disabled people:

> The dynamism between body and world that produces fits or misfits comes at the spatial and temporal points of encounter between dynamic but relatively stable bodies and environments. The built and arranged space through which we navigate our lives tends to offer fits to majority bodies and functioning and create misfits with minority forms of embodiment, such as people with disabilities.
>
> (2011:594)

Thus, misfitting is not simply environmental, but also social, creating subject positions through interactions that express and embody power relations. For those who fall within the norm, the ways in which built and social environments sustain the bodymind are usually invisible. However, disabled people are made aware,

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[1] The *habitus* is an internalised mode of being and disposition towards the world; Bourdieu argues that it is impacted by capital. I further define habitus in Chapter 6, where I also explore ways in which capital, or the lack of it, is embodied through religious habitus.

[2] Price's term "bodyminds" is a social and material concept that builds on Garland-Thomson's concept of misfits, which considers how disabled people's bodies and minds together are oppressed by and excluded from built and social environments (2015).

through their misfitting embodiment, of the arbitrary social construction of normalcy and its expression in built environments.

Garland-Thomson describes two consequences of misfitting that are relevant to the participants in this study. The first of these is “exclusion from the public sphere—a literal casting out—and the resulting segregation into domestic spaces or sheltered institutions” (ibid.). Segregation can be used to accommodate people who misfit in normative environments, by creating separate but parallel spaces where they may fit to some degree. However, as my analysis will show, segregated provision may be experienced as an inferior form of inclusion (Barnes et al., 1999:107), a substitute for the transformation of a social or built environment towards a better fit for a more diverse range of bodyminds (Barnes et al., 1999; Erevelles, 2005; Price, 2017). The second consequence of misfitting is the creation and maintenance of vulnerability among disabled people. For Garland-Thomson, vulnerability is not inherent to individuals and their bodies, but is “a potentiality that is realized when bodies encounter a hostile environment and is latent in a sustaining environment” (2011:600). This might involve a reliance on non-disabled people for inclusion in an environment in which one would otherwise misfit. As I explore below, many of my participants encountered segregated provision in their churches and found that they were made vulnerable when church environments did not sustain them, forcing reliance on non-disabled congregants.

Carol Thomas’s theory of psycho-emotional disablism (2007), as developed by Donna Reeve (2012), also helps to clarify the experiences of participants who misfit and the consequences of misfitting. For Reeve, disablism has four dimensions: it can be direct or indirect, structural or psycho-emotional. Thomas argues that psycho-emotional disablism is not isolated from impairment; it is “fully embodied” (2007:152) in the social locations within which the body moves. While some disabling barriers are structural, others arise through power relations and are expressed in personal relationships. Psycho-emotional disablism was a recurrent feature of many participants’ experiences.

However, misfits are not simply passive victims of the normative environments which shape them. Garland-Thomson explores how, when confronted with environments that create a poor fit for their bodyminds, disabled people often exercise agency and press for change. Their strategies of resistance, in and through embodiment, reveal a “resourcefulness and adaptability that can emerge from the interactive dynamism between world and body" (2011:604). The skills that disabled people develop through misfitting, and their resulting subject perspectives, are valuable and can contribute to transformation of environments. Many participants described such resistant and compensatory strategies, together with the effects of these on their churches.

3.2 "Where can I put you?" Buildings and Spatial Segregation

Participants' narratives showed that physical church spaces, and the ways that these are used, can shape church practices and cultures which can exclude people from churches. A number of participants described situations in which church architecture took priority over disabled people's needs. It was often designed around the needs of the majority of the congregation, and consideration was rarely given to non-normative bodyminds in church design. Furthermore, institutional choices were often made about the uses of church architecture, in worship and other events, which marginalised non-normative bodyminds further. However, participants' experiences also suggested that some disabled people's experience of church can be transformed by changes in building use, as part of church cultural shifts that take account of disabled people's misfitting and attempt to reshape cultures for a broader range of bodyminds.

A number of participants spoke about being seated in places where they did not wish to sit. Focus group 1 discussed being unable to assimilate into church environments without difficulty, and their subsequent misfitting. Zoe described her experience of being "put" into places where she did not want to sit at the Anglican churches that she attended. She discussed how this affected her experience of worship, including her access to the Eucharist. She also suggested a number of ways in which church architecture could be made more accessible to disabled people, and other congregants who face access barriers, such as parents with children:

> "Where can I put you?" Don't put me anywhere because it won't go well. Hence the no handles [on wheelchair]. But taking out pews from the middle…There are a number of us now in church but it's also signposted. Priority seating, reserved seating for disabled worshippers and those with buggies and children. And it's just a big space and there is enough space underneath it. And the experience of just being a worshipper there is so profoundly different. Because I don't want to be at the back or the front, actually….And at the back you just see bottoms. Because that's the other thing. If you're in front of somebody who remains seated, just make sure you

> move over, because otherwise the Eucharist is invisible. So those—just making it all right to talk about those things makes such a difference.

Here, Zoe drew a contrast between churches where she had been seated at the back or the front, because of poor architecture, and those where more thought had been put into planning where wheelchair users and other disabled people could sit. Her positioning in the congregation, as a wheelchair user, affected her inclusion in various aspects of worship. Several other participants echoed Zoe's frustration at being sidelined into a position where "you only see bottoms," and how this affected their worship experience. Brianna, who attends an Anglican cathedral, also said she felt isolated when she was segregated at the back. For both Zoe and Brianna, this was a question both of their physical *and* spiritual access. Consequently, they were isolated from the body of the church; they could not form a religious habitus along with their fellow church members when they could not participate fully in ritual and worship.

In many cases, participants were segregated in churches because of the negative impact that their divergent embodiment might have on liturgical practice, ritual, and the order of worship. Wheelchair users, in particular, were often literally "in the way," and treated as such. However, removing and segregating disabled people from ordinary worship in favour of undisturbed ritual for the majority had a noticeable and profound impact on their experience. Brianna (individual interview), for example, described being excluded from a number of services because they were held at the cathedral's high altar where there was no access for wheelchair users. These tended to be the services that were particularly important to her, including Easter and Christmas. Brianna considered that, in choices made over uses of buildings, the liturgical ritual requirements of the service were prioritised over the needs of disabled congregants:

> If there's a service actually at the high altar, somebody in a wheelchair cannot sit as part of the congregation, because even the seats which are just outside the high altar are on the platform, which is inaccessible by a wheelchair….Lots [of services] these days would be held there….With things like that, it's very, very difficult then when you're in a wheelchair, because the people…are excluded, unless somebody thinks about how to include them, and they don't.

Brianna's exclusion was specifically from liturgically significant spaces in the cathedral. Yet she believed that ways could be found to use the buildings, including the high altar, that would be accessible to more people. Not considering disabled people’s existing uses of the cathedral building signalled their insignificance to cathedral life.

Exclusionary uses of buildings could lead to interpersonal conflict and psycho-emotional disablism for some participants. Brianna spoke of several occasions she had experienced, or had seen others experiencing such disablism, in situations where the uses of cathedral spaces communicated a low prioritisation of access to disabled worshippers. These included being forcibly moved in her wheelchair without being asked, and seeing wheelchairs being accidentally kicked because their users were not given enough space to sit in the sanctuary. She also observed that poor management of admission and spaces led to wheelchair users feeling they were responsible for disruption of liturgy and ritual:

> [A]t big services I’m constantly seeing people arriving with nowhere to go, and the seats already filled up. What the stewards then have to do is ask people to move, “Would you please go and sit elsewhere?” and seats are then taken up. This poor person in the wheelchair is going, “I’m so sorry, I’m so sorry to cause this fuss and I’m so sorry.”

Brianna was also concerned about the cathedral’s requirement for disabled congregants to contact the cathedral in advance if they wished to attend services. In her experience, psycho-emotional disablism and exclusion of disabled people from church life appeared to be institutionalised.

Although participants’ visions of the ideal church layout varied significantly, many wanted more agency and choice over their uses of the space. Brianna wanted to sit at the front, so that she could take part fully and go up for communion easily. However, she was only offered seating in an area of the cathedral where she was not comfortable and where she was separated from her family. Conversely, Shona (focus group 1) disliked being seated at the front. She explained some of the difficulties involved with requiring D/deaf people to sit at the front of church, discussing with Rhona how being seated in assigned spaces at church may prevent D/deaf people from being able to lip read. Speaking of a deaf member of her own church, Rhona said:

> If you’re deaf you sit near the front and make sure your hearing aid is switched to T. Well she lip reads. So she can’t go right up the front…because then…she’s too underneath the lips.

> Shona: …You don’t like to be right at the front. People seem to put you right at the front. [They] think: Oh you can see better to lip read.…Also if you’re right at the front you feel like a bit of a geek as well.

The group went on to describe the shame and frustration of being forced to sit in sanctioned or segregated areas in churches, without being asked for their input on how seating arrangements could affect their access needs. For Rhona, who experienced this as a blind person, this also involved limitations on her agency:

> You know when some people grabs you by the arm and says: Well you can’t see, sit here. I don’t know whether it’s about me and submission and rebellion…And that’s what must be, as disabled people should be comfortable to be where they want to be.

While many of the participants shared similar experiences of being seated in locations in church that were unsuitable for them, reactions to misfitting varied. Some wanted more alternatives to segregated seating provision; others were more willing to acquiesce with church policy on seating arrangements. However, participants generally found seating issues to be a marginalising experience.

The built environment also impacted choices around extra-church activities, for a number of participants, which isolated participants from their churches and other Christian groups. Isabelle (individual interview) had self-excluded from Spring Harvest, an extra-church Christian conference, where decisions were made around uses of buildings which excluded her:

> [Y]ou were treated as if you were a bit of a pain. And they had a separate little area at the side. Very near the front. Right in front of the speaker, which for me is a problem. And, you know, separated from everybody else. We went to a seminar once and there are two places where you can put a wheelchair on the end of a row in this place upstairs and there's a lift. And they said they couldn’t possibly let us in before the others…otherwise it would be discrimination.…So they let the other door open before they'd let us in the lift.…So what it meant was they then filled [the wheelchair space].…It was just difficult basically. And…it detracts from going along and enjoying it. And the being by yourself actually does matter when you go for a whole week somewhere and having to keep splitting off from the group you're in.

In Isabelle’s case, decisions around the uses of buildings were made based on the needs of the majority, and did not provide a good fit for her. The result of misfitting in these built environments was social exclusion from group Christian events, where events and churches prioritised bodyminds that fit the norm.

Negotiations over access to church built environments could be protracted and disempowering for participants, especially where independent access was limited. Brianna's situation (individual interview) was one of the starkest examples of difficult, ongoing negotiations over access, revealing institutional power at work in decisions over uses of church buildings. She described how her campaign for better access for all disabled worshippers at the cathedral was not well-received by staff and clergy. Speaking of her responses to seeing wheelchair-using visitors being confused by seating policies, she said:

> Now, since then, I have [witnessed] other people go through that same hideous ordeal.…[B]ut when I say "there should be spaces left for wheelchairs," they think that what I'm asking is…a seat reserved for me every service.…They can't look at the wider picture. They think that I'm being selfish and needy. You see, we do have an awful lot [laughs] of very selfish and needy people at the cathedral. You do…in churches, don't you? You get people who need to be cared for, and who like to complain and cause problems.…That, you know—the petty trivia of church on a bigger scale is the cathedral.

Brianna spoke about other ways in which disabled people experienced "ordeals" in their attempts to access cathedral worship and community life. For example, she related how disabled people were routinely prevented from accessing communion or key events in cathedral life, such as anointing with oil by the bishop at his visit to the cathedral, because of access policies and choices over building use. Brianna considered that the disabled people attending the cathedral were essentially unable to practice their Christian faith in the cathedral context. These experiences of exclusion were therefore not trivial to her or to the disabled Christians she observed at the cathedral. The ways in which their misfitting was managed by the cathedral institution was a source of disempowerment.

In contrast, when some participants experienced full physical inclusion in a church, as part of the body of congregants, this had a positive spiritual impact and enhanced their sense of welcome. In some cases, where churches made simple improvements in accessibility, such as removing pews, segregation was significantly lessened, and disabled worshippers felt more included. For Zoe (focus group 1), physical inclusion was so exciting and spiritually significant that she described it in evangelistic terms, as a message of how important this could be for some disabled people:

> But when it happens, when you can just join in like everyone else, when I can stay in my chair and be in the body, it's so powerful. And I just keep telling everybody: Go and look at that and you need to tell people that is there. Because it is the gospel.

Similarly, Brianna (individual interview) very positively contrasted a visit she made to another local church with her own cathedral church:

> So I decided I wouldn't go to Easter Sunday, which for me is a really sad thing. The community's together and…it's important. So we went to our local church. And, oh my word, the welcome! There were wheelchair spaces, and it's a hodgepodge building, but there were two other wheelchair users in a congregation of about 30....It made me think: Right, maybe I should just give up on the cathedral and go to the local church, because I…will feel part of the community. But I have this fight....I try very hard to do it through education, through talking, through…creating a cause….But…I have cried bucket loads over it, because I do feel completely invisible and violated by it.

The "welcome" that Brianna experienced at the other church was primarily due to a sense of hospitality that arose from her embodied encounter with a church environment in which she could more effectively fit.

Furthermore, while access to worship spaces was widely discussed, much more routine access features could also be central to participants' worship experience at a church. Toilet facilities were one example, emphasised by several participants as very important to their choices and experience of churches. Maria (post-interview email) gave detailed thought to the kind of toilet provision that would allow her to worship in a church unhindered:

> [A]nother thing I look for in a church—good toilet facilities! Not a building with just one toilet that opens out directly into the foyer where everyone else is stood around, but more than one toilet, with cubicles that open out into a self-contained room, so you can be as slow as you need to be, without feeling like you are being timed; and with a subtle exit from the main part of the church…so you don't have to create a scene if you go out part way through the service. Important stuff!

At the time of writing, Maria was looking for a new church, prioritising her accessibility needs over other reasons for choosing a church. Miranda, Isabelle, Brianna and Katie also mentioned access to toilets as an essential aspect of their experience at churches and church events. However, the importance of such ostensibly routine access was often overlooked by church authorities. The social location of participants, as disabled people, was key to a church's understanding of what they valued in church accessibility, but their input in access decisions was rarely sought. The related issue of disabled congregants' influence over accessibility decisions is discussed further below.

However, for a few participants, welcome and informal support in churches were more important than physical building accessibility. Stephen (pre-interview sampling form) had moved from a large church which had been undertaking disability accessibility work, to a small village church where there was no specific disability expertise:

> In my previous church, the original structure of the building was greatly altered, in part in the name of accessibility. However, this was done with no real understanding of what makes a place accessible. The acoustics were ruined and amplification systems installed which made the environment too harsh for me to easily [cope with]. Although seating was made up of individual, removable chairs, arriving with a scooter, for example, would send people into a state of shock and they would rush to remove chairs which they couldn't do easily. And whilst the church would consider itself more forward facing and family orientated than the church we now attend, they had very little understanding of social justice issues. Because of this, I don't trust their attitudes to me as a disabled person.

In contrast, Stephen described his new, smaller church as much more inclusive, despite poorer physical accessibility for his needs (pair interview 3). He and his wife, who is also disabled, preferred the familiarity of this small, welcoming community:

> They've been absolutely brilliant. The church that I used to go to was a very rich church, lots of people there, lots of money and they really struggled. Whereas the church here is full of locals, lovely people who don't care at all what state they're in. And who welcome you and who do their best to accommodate whatever you've got. And they're wonderful. And I don't imagine they've had special training. They're just sensible people.

Stephen here shared an experience in common with a few participants who found an ease of belonging in churches which were familiar with them as people. However, for many, inclusion was closely connected with building accessibility, which could itself communicate a sense of welcome or exclusion.

3.3 Worship Norms in Churches

While buildings were one significant feature of churches that led to fitting and misfitting, many participants were marginalised by conventions and practices in church services that bore little relation to the built environment. Churches made choices about how to "do church" which had negative impacts on participants' access. Victor (pair interview 2) called these accessibility choices “the other accesses,” spiritual conventions which related to churches’ customs, and formed part of their worship and liturgical cultures:

> I mean physical access into the building is alright. I’m talking about from the blind point of view. Wheelchairs, they can get in. There is some restrictions. They can’t get upstairs very easily…they have to go into like a lift—goods lift….So, building wise. But as far as what I call the other accesses, like the format that stuff is in and the thought that’s put into actual practicalities, not very good.

Interview discussions revealed that such accessibility choices were often based on normative practices where spiritual, liturgical or theological decisions took precedence over disability access needs, including access challenges around receiving communion, sitting and standing conventions, the audio and visual content and structure of services, and the size and style of churches. The spiritual norms inherent to these aspects of church were particularly challenging for participants to deviate from or oppose, because they often touched on religious or denominational values, including respect for God and ritual order.

3.3.1 Communion

One frequently-discussed context of worship norms was that of communion, where several participants faced routine exclusion, causing significant distress. This often, though not always, related to ritual order as constrained by the church built environment. It was, therefore, an access issue that related both to physical accessibility and cultural practices of churches.

For Brianna (individual interview), watching the experiences of other disabled cathedral-attenders alongside her own routinely poor access to communion was a painful experience of psycho-emotional disablism. She noticed that segregation and the resulting communion policy at her cathedral created significant confusion for some of her fellow wheelchair users. They could not see how they might access communion, and no advice was forthcoming from stewards and cathedral staff:

> [P]eople in wheelchairs, because the stewards don’t go and talk to them about the possibilities, they just don’t take communion because they don’t know how they can access it…[The] steward doesn’t communicate with a disabled person ever. They say, “Do you want to go for communion?” They don’t actually say, “Right, if you want to go for communion, you can either cut in,

> like—and I will cut in for you, or you can go right around and come around...” Because that conversation doesn’t take place, they don’t go for communion. And although I’m there and I go for communion it's often too late for them. By then, they’ve committed to saying, no, they’re not going. They’re not *invited* to have communion.

In the busy environment of a cathedral church, communion needed to be delivered in a way that was efficient for the majority, but Brianna experienced these practices as intimidating for wheelchair users. Cathedral leadership would likely interpret the stewards’ question to these disabled people, “Do you want to go for communion?” as sufficient invitation to participate. However, without going further to dismantle barriers around communion practices that were not designed for their bodyminds, disabled people were more likely to self-exclude. In this “high church” liturgical environment, where communion is the pinnacle of the church service, it was particularly egregious to Brianna that the exclusion of disabled people was not addressed by the cathedral hierarchy.

The response of the vergers and servers at Brianna’s church to the problem of exclusion from communion was to focus on Brianna as an individual rather than to address church policies and the inaccessibility of the building. They drew on a tragedy model of disability to reinforce their individualising response, as Brianna noted:

> For the Maundy Service…I want to take part in in it, so we go very early.…Michael pushes my wheelchair to the high altar, and I sit in a chair. At communion, although it’s very difficult, I walk to the high altar. I mean, they’re only steps, don’t get me wrong, and I kneel. The vergers always say to me, “Oh, you’re very brave.” I don’t know what to say to that because I’m not doing it because I’m brave. It’s about humility at that service, isn’t it?…Their comments are so inappropriate.

This institutional response allowed them to ignore Brianna’s exclusion as a social issue, or as a responsibility of the cathedral. Brianna’s reaction, in turn, was to reassert her theological view of communion, where she had the right to experience humility as part of her religious habitus, rather than being forced to focus on her impairment. However, in order to participate in the communion service as much as possible, Brianna had to use compensation strategies that negatively impacted her body; a discipl(in)ing of her body was the result. Although she minimised the difficulty of the steps, instead emphasising her ability and right to participate in the service, she also admitted that “it’s very difficult.”

Similarly, Miranda (individual interview) was frustrated by her experience of communion at her Anglican church, where she described being left at the mercy of church volunteers and their willingness to include her in communion. She suggested that some vergers actively chose not to prioritise her needs and decisions in communion, instead prioritising institutional choices to make communion an effective and simple experience for the majority. The church's leadership did not consider the negative impact on Miranda's inclusion in this central aspect of worship. Policies and practices that were embedded into church or denominational cultures also marginalised participants at communion. After a policy change regarding communion at her church, Miranda read in the church newsletter that intinction (dipping the bread or wafer into the wine rather than drinking from the cup) would no longer be an option an option available to her, even though this was the only accessible way for her to take communion. In an email following our interview, she explained that she did not find the response from her vicar reassuring:

> It upset me + scared me enough not to go to church the next day as I couldn't bear being refused to dip my wafer in the wine. I emailed the vicar that day + he replied…telling me "under my circumstances it would be acceptable to continue with Intinction" + that he was sorry I'd not felt able to go + he would meet me if his reply didn't answer all my concerns. I was hopping mad + asked to meet him. It took him 10 days to reply saying I'll see you tomorrow at the vicarage after the…service. He assumed I was going to the [service] + had time to meet him, so my reply was I'm happy to meet you but the vicarage isn't accessible!.…He wouldn't budge about it…Writing this, I'm wondering why I'm even going to [St B's]. There is a small church belonging to the next parish on the other side of…my road, only 5 mins away ([St B's] is 10) but I like [St B's]…I'm juggling Sunday services while I consider what to do long term but I'm a minority + who really cares[?]

As with many poor experiences of communion among participants, the exclusionary effect for Miranda stemmed primarily from a policy issue that was designed to suit servers and other congregants, but which took no account of her divergent bodymind. Miranda's language revealed the depth of hurt caused by this psycho-emotional disablism, exacerbated by what she considered an inadequate response from the vicar. His solution of a segregated practice for her singled her out, and she was not confident that all servers would follow instructions. Miranda's frustrations led her to petition the vicar for policy change for all disabled people, and to consider leaving her church of many years.

However, not all participants were unhappy about the ways in which they were included in communion. Some, like Jean (individual interview), were happy to have communion brought to them at their seats. In these cases, the participants' churches were able to adapt procedures around communion to ameliorate the misfit between disabled people and routine "ways of doing church." Several factors may have made this easier for some churches. It may have been helpful for her church that Jean was willing to participate in communion in ways which caused minimal disruption. For others, church willingness to accommodate difference from the norm was important. Clare (pair interview 1), who has mobility difficulties, described the importance of a church understanding and responding to different needs during communion, rather than prioritising the normative requirements of the majority:

> There are some steps up to the altar but you know, it wouldn't be a big thing if you asked somebody: Oh, can you come down for communion? Nobody would say anything—it would be perfectly normal and reasonable. So yeah…there's no expectation from you. It's more about what can we do for you rather than how can you fit in with us?

Clare considered communion access as part of her church's willingness to minimise misfitting for disabled congregants. However, she did not consider what might happen if a wheelchair user had needs or requests for very different ways of receiving communion that were not so easily responded to by churches, such as Miranda's.

3.3.2 Standing and sitting

Sitting and standing procedures in church were another example of spiritual norms in practice, and presented participants with access issues crossing denominational boundaries. Almost all participants' churches followed the procedure of encouraging the congregation to stand for singing and at other key liturgical or worship points in the service. Particularly for participants with invisible or less obvious conditions, this spiritual and liturgical norm was challenging. Many of these participants faced dilemmas about whether they should force themselves to stand during specific parts of the service, despite this being very difficult for them: the practices involved discipl(in)ing their bodies.

Clare (pair interview 1) felt that she was drawing attention to herself by sitting down throughout singing and prayer, and thereby visibly defying liturgical norms:

> [I]t’s the accepted form that unless you are a wheelchair user, you stand up at church—singing and for praying and all sorts of things…But everywhere but at the most recent church, the expectation has been you should stand. It’s not like you couldn’t sit, you just look a bit strange. Whereas the church I’m going to now, on the service sheet it says we will all stand for singing and for praying but if you want to stay sitting down, that’s absolutely fine.

For Clare, it made a difference when her church clearly signalled that sitting was acceptable. However, she had not experienced this concession at most of the churches she had attended. Faith (focus group 2) experienced a similar expectation for all to stand during worship, describing this as “pressure.” Where no statement was made about sitting or standing, Faith considered that she was not permitted to sit. For Susanna (individual interview), the presence of an institutional policy statement communicated a church’s attitudes towards disability access:

> [At] the church that I go to at the minute, the Methodist church, and the church I went to in London, the minister would generally say, “Stand if you’re able or sit if you prefer.” That just makes such a difference….I was going to a church in the city for the last few months, which I decided was not just the best fit, but one of the things was I never heard that said.

Susanna reached conclusions about churches’ inclusion in part based on the attitudes they communicated—or did not—about sitting and standing for disabled congregants. Such permission made her comfortable without the “barrier” of liturgical norms and expectations. When she did not have to discipl(in)e her body, she could be more focused on worship.

Participants also expressed concerns regarding the sociocultural attitudes to disability exemplified in spiritual norms of sitting and standing for worship. For Susanna (individual interview), the spiritual norm of standing for songs was about showing respect through her actions in the service:

> I’m thirty-three. These people who are eighty or ninety-odd, are standing up and able to do that without seemingly much of a problem. I feel a lot less able then just to sit down because I don’t know the people as much and I don’t want to come across as being disrespectful. You just feel a bit of shame, almost, because it’s like: Well, if the ninety-year-old can do it, I should be able to do it.

Susanna mentioned this issue of showing respect in worship several times, although she was ambiguous about whether this meant showing respect to God or to other congregants. Zoe (focus group 1) was clearer in her personal theology of why she found it difficult to sit through the service, understanding her reluctance as related to cultural attitudes towards disability, including what could be called her own internalised ableism:

> Actually I was led as much by other people in order to make changes to start using various mobility aids. And so a lot of those things were very positive and it was me that was prejudiced. And it was me that didn't want to do things differently. And it was me that resisted, you know. Well you can't possibly sit down during the Eucharistic Prayer. Because then people will think you don't love God.

Although her statement here was slightly ironic, it also communicated her real concerns. Zoe's own sociocultural attitudes towards disability, when she first acquired her impairment, were more significant than the prejudice she met from others. Standing and sitting were the first examples she gave of how these pre-existing attitudes had impacted her attitudes towards her body in her own Christian practices, resulting in her desire to discipl(in)e her body. The positive attitudes she received from other Christians helped her to transform this internalised ableism and her embodied responses to it.

Being unable to follow convention around sitting and standing in services often impacted disabled people's ability to pass as non-disabled in services. For Susanna (individual interview), not being able to achieve this norm was causing her "shame," while others were, to varying degrees, discipl(in)ing their misfitting bodies to conform better to norms of sitting and standing. On the whole, participants followed their own informal conventions, but few felt entirely positive about this. Emily (focus group 3) understood her concerns about standing and sitting as largely about her own reactions to sociocultural attitudes around disability, but she felt residual discomfort about prioritising the needs of her body over spiritual and liturgical norms. Similarly, Susanna (individual interview) was aware that worrying about others' attitudes to her when she stayed seated could be a distraction from her worship:

> To be honest, generally, I think if I need to sit, I'm going to sit, because I want to sing the song to God or I want to pray the prayer to God. I don't want to be appearing to do that because that's what everyone else is doing, but all my energy is going into what I'm appearing to do rather than what I'm actually doing in my head.

Susanna's persistent concerns about not wanting to put all her energy into passing, rather than into worshipping, showed the significance of her divergent body in this environment. A combination of church spiritual cultures and broader sociocultural attitudes gave rise to a misfit for bodies unable to follow the norm of liturgical practice. However, several participants' discomfort around misfitting in relation to the sitting/standing norm was at least partly resolved where churches gave permission for people to stay seated according to their needs.

3.3.3 Audiocentric and visiocentric church cultures

One common feature of participants' churches spiritual cultures, across denominational backgrounds and styles of church, was the audio- and visiocentricity of church worship styles and cultures. A number of participants' churches privileged seeing or hearing in worship, creating spiritual norms with which not all participants could align, and leaving them with a poorer worship experience. These audio- and visiocentric spiritual cultures had a particularly marginalising effect on blind or visually impaired and deaf participants, amongst others.

One significant audiocentric feature mentioned by a number of participants, the sermon as the focus for reflection and teaching on biblical texts, is central to many church services. Length of sermon was subjective—a "long" sermon could be measured differently for each participant—but many found sermons difficult to access. Underlying this exclusion is the hierarchical spiritual norm of a specifically *verbal* sermon, delivered by a usually-ordained speaker addressing a listening lay audience. Such sermons often call for a level of educational and cultural capital among congregants, which not all disabled people will have. For Andrew (focus group 2), as a deaf person, the audiocentric structure of the sermon excluded him to the point where he could no longer attend church, because sermons were not subtitled. In response to a question about whether the speakers at his church could give him a copy of their notes, Andrew said that this did not suit their preferred, informal ways of preaching:

> Well I did ask about copy [of the notes], but a lot of the preachers at my church…they often just have bullet points. They like to preach more informal, making it up as they go along. So they might know that—you might have the OHP having three points….So I know what the three points are but I wouldn't know what the actual detail was of that.

The speakers at Andrew's church prioritised their spiritual culture of improvised sermon performance over his access to the sermon. Other participants were given similar justifications of audio- and visiocentric worship and teaching cultures, rather than changing church practice and culture to better include disabled participants.

Andrew also spoke of how audiocentricity filtered from the sermon into social interactions after the service, where, for example, a joke made in a sermon was the focus of ongoing discussion, strengthening social bonds between church members. Andrew could not easily fit into this audiocentric culture of the churches; his misfitting was cultural, as he diverged from the norms expected of church attenders.

Other participants were excluded through the structuring of church services around audiocentric elements. For Lucy (individual interview), who had learning difficulties related to Asperger Syndrome, sermons could be difficult to follow and understand, and it was difficult for her to retain information delivered in this way:

> I often haven't got a clue what they talked about in the sermon because I just can't keep track. And…some people will do, you know, the summary on the slides and they have—through bullet points. But ten minutes later I've probably forgotten them anyway.

At churches Lucy had attended, presentation slides and bullet points were sometimes used to make information more accessible to a listener who might find it difficult to follow a sermon, but who nonetheless still fell within the range of norms of an ideal worshipper. However, there were no accommodations made for Lucy's poorer memory in comparison with this "ideal" worshipper. Lucy had been to some services in which the sermon had been delivered more interactively:

> I guess one thing we had recently was we changed the evening service. We stopped having one sermon and we started having two five to ten-minute talks and one ten-minute discussion. And I think I found that much better. So there'd be like a theme. You'd have a couple of different speakers and then there'd be a…"Turn around and discuss these three questions with the people nearby…". And that…broken up with a summary after each bit was…helpful, because I had a chance of understanding what was going on when there's only five minutes to remember.

However, this alternative sermon structure was rare at her church. Most services at Lucy's church used the longer, traditional sermon format. Lucy's church had a Baptist heritage, with a strong emphasis on preaching in services (see Dare and Woodman, 2011), which likely impacted sermon length. However, even some participants who attended churches with shorter sermons found these difficult to process and sit through.

As with conventions around sitting and standing, some participants were affected by norms of appearance in relation to sermons. Some were concerned about appearing to be listening carefully to the sermon, despite difficulties concentrating or following the sermon. Susanna (individual interview) had difficulties sitting still for extended periods of time, as a result of impairment effects:

> In a church service, it's probably one of the few contexts where I'm having to sit and listen for half an hour, forty minutes or whatever to the sermon, and it's hard….I can't take in someone talking for two minutes. I can't make notes and listen to someone talking, so everyone else might be making notes....I'm putting all my energy into keeping my head upright and not closing my eyes because I don't want the person speaking to think that I think they're boring or something.

Susanna's concerns about how she was seen by others during sermons led her to discipl(in)e her body in order to pass as less disabled, and to appear to be listening, according to expected church norms. This sense of an appropriate self-control of bodyminds was mentioned by several other participants in relation to sermons, including Lucy and Andrew. As with sitting and standing, maintaining appearances during sermons often related to participants' aim to pass as less impaired than they were, and therefore to be seen as less of a misfit or cause of disruption.

Although audiocentricity in church cultures affected people with a variety of impairments, church visiocentricity particularly affected those with visual impairments. Hazel and Victor (pair interview 2), who are blind, attend a Baptist church whose charismatic worship culture is spontaneous and informal. Victor said that accessibility for their needs as blind people was "not very good." The visiocentricity of a number of church practices and policies excluded them. For example, Hazel was frustrated that songs were not taught to the church anymore, but were just shown on an overhead projection screen. She and Victor were not informed in advance about what the songs would be, so that they could learn them on their own. At some times, the church made some effort to adapt or describe their visual materials, but Hazel considered these efforts insufficient:

> Hazel: They read the overhead projector. They always read the scriptures. However, if they show a video they say, "We're just going to show you a video." And it might have some speech on it and it might not but they don't tell you what it's about…
>
> Victor: I just don't think they think enough about when they do something visual. They're going to show something visual—then you've got the website that's sort of accessible but not [entirely].

To some extent, they disagreed over how—and indeed whether—they could be accommodated in this visiocentric context. Victor wanted better communication and support from the church leadership. However, Hazel considered that, given the spontaneity and informality of their charismatic church's worship culture, there was little that could be done to include them. She did not expect them to be prioritised, although she was frustrated with their lack of inclusion in the church's worship culture. Conversely, Victor believed that, with forethought, some effort could be made to meet their needs. However, this would have required a reconfiguration of the visiocentric elements of church culture that Hazel and Victor identified.

A few participants spoke about assistive technology in churches, particularly in relation to visiocentric cultures in churches. Assistive technology has significant potential for disabled people's inclusion in society, but it is not always considered socially acceptable among non-disabled people (Finkelstein, 1980; Söderström and Ytterhus, 2010). Many churches use technology in services. However, disabled people increasingly use assistive technology themselves, informally, to aid their own access and overcome barriers (Lancioni, 2014). Participants' personal uses of technology revealed church norms about what devices are, and are not, accepted in services. Rhona (focus group 1) spoke about fellow churchgoers' reaction to her smartphone use for hymn words in large print:

> And that for me is one of the most blessings…because I can do it in large font and I can see. And again it's "the prophet is not welcome in his own home." It's getting more used to now, but when I first had my iPhone 6 years ago, because you could make it large font…the tisking and the tutting that went on. What are you doing with mobiles?

Rhona's use of her mobile phone was a visible signal of her poor fit in church culture, where there using phones was viewed as disrespectful. Her encounter suggests ignorance about the ways in which visually impaired people use technology to access printed and textual materials. This psycho-emotional disablist response to Rhona's use of technology impacted her future use of it in church settings. She went on to talk about churches she had visited where disabled people's use of accessible technology was better supported by institutional policy:

> I get—you know, the Minister says hymn number whatever. So I'm getting the thing on the internet, getting the hymn up. And this guy taps me on the shoulder. I thought: Oh no, for goodness sake, here we go again. He said, "Are you using your mobile phone to find the hymns?" And I went "Yes"

> and I thought: Don't start, just don't start….Anyway, he comes back 2 minutes later with a huge iPad saying, "Oh we're collecting iPads year after year, adding them. So what we do on a Sunday morning is we download onto the iPad all the hymns. And all you have to do is scroll." And I thought: Can I invite you to my church? …It was fantastic…just the being accepted, you know.

Rhona's comment about the ways in which "a prophet is not welcome in his own home," a biblical reference (Luke 4:24), repeated a similar comment she made earlier in the interview where she said she felt that her efforts to create better disability access in churches were more accepted in churches other than her own. This she interpreted as a negative effect of churches' over-familiarity with individual disabled people, echoing Brianna's experience. However, she also remembered and appreciated the more positive experience elsewhere, where her needs as a visually impaired person were given forethought.

In Rhona's and other participants' experiences, there was a difference between use of technology sanctioned by churches, and "informal" personal technology, which was often discouraged. The use of assistive technology signalled deviations from a norm that encompasses the bodymind of an ideal worshipper, who is expected to find videos helpful but also to be able to read the small print in hymnbooks. Given Rhona's acknowledgement that fellow congregants were becoming more accustomed to her use of personal technology, this attitude may progress as technology becomes more acceptable in churches in general—for example, as more people take sermon notes on smartphones.

3.3.4 Size and style of churches

For a few participants, the spiritual cultures or styles of worship of particular denominations of churches had a negative impact on their impairment-related needs. Churches vary in their standardisation of expression, which ranges from formal liturgy to informal worship. Charismatic churches, for example, are characterised by expressive and spontaneous worship cultures. However, McGuire argues that, even in denominations where spontaneity is emphasised, institutions often encourage regularised forms of spontaneity in worship and discourage those that depart from these parameters (1997:97). Churches with charismatic and informal worship often created particular access implications for participants.

For Lucy (individual interview), expressive charismatic worship practices were challenging because of social difficulties and anxiety related to Asperger Syndrome:

> I went to a few [churches] that scared me. They kept standing up and dancing and things….We were stood there singing a song, and at one point I found that all my row had gone and they'd gone to the back where they just all started dancing together. So I didn't go [there] again.

Lucy deliberately avoided those churches which worshipped in spontaneous and informal ways in which she could not easily participate. Andrew (focus group 2) also misfit in charismatic churches' spiritual structures, where they encouraged informal, unstructured spoken prayer:

> Well my church, charismatic church, they quite like it when people—anyone in the congregation just stands up and prays. And it seems very positive—you know, that's what the New Testament Church did. Anyone could get up and pray. It wasn't just done from the front. So, it seemed very positive in my church I suppose. But as a deaf person…it wasn't accessible to me at all.

Although audiocentric and thus exclusionary, there were specific theological reasons for this spiritual norm of spontaneity in worship. Andrew contextualised his church's spiritual culture as New Testament church-inspired, locating it in the milieu of the charismatic and Restorationist churches with which he was familiar. However, despite this theological rationale, the informality of congregational prayer, rather than prayer led from the front with a microphone, was inaccessible to Andrew. He found it difficult to see what could be done to assist with this, as the practice was so central to the cultures of the charismatic churches that he had attended.

In contrast, some participants found particular church styles and traditions more supportive of their access needs and impairment effects. For many, liturgical churches were a better fit for their needs, particularly those with high ritual content, such as Anglo-Catholic churches. For some, familiarity with liturgical order gave them a framework within which they felt safe. George (individual Skype text-based interview) was drawn to "high" Anglican liturgical church ritual specifically because its predictable familiarity was more accessible for her as a person with an autistic spectrum condition:

> [G]enerally I like the services, we have our own musical settings and once I learned those…I could say the whole service from memory really…so it's very comfortable and comforting for me to have that routine and familiarity.

Mims (individual interview) found the familiarity of liturgy similarly comforting and reassuring, in the context of her mental health impairments. A church that she occasionally attends instead of her home church had a non-liturgical structure, which could lead to access problems:

> They often don't follow a liturgy. I find a liturgy really helpful. Even if I am not going to church, I quite often read the services of the day. I often find it quite hard to pray on my own so following a formal service and also knowing many people around the world are saying similar things at the same time is really powerful to me.

Andrew, too, was more comfortable in liturgical churches where there was a clear structure or a service book which he could follow even when he could not hear the words. However, many of the churches he had attended were moving away from such structure. For Charlotte (focus group 2), too, churches' shift from liturgical to informal styles of worship was concerning in terms of its potential impact on some disabled people, since she had known many who found liturgy helpful. Liturgical and sacramental church environments could be beneficial for those whose impairments meant they preferred structure, predictability, and lower sensory input in church, which included all of the participants diagnosed with autistic spectrum conditions. However, the move of many churches towards more unstructured informality in their worship cultures, as part of church modernisation, negatively impacted a number of participants, while others were concerned about the potential effects on some disabled people.

However, it was not simply the case that liturgical churches were positive for disabled people's inclusion and charismatic churches were negative. Many of the stories discussed above, including Brianna's story of exclusion from her cathedral's high altar, show how the inflexibility of "high" liturgical church cultures can also marginalise disabled people. Participants had a range of differing stories of marginalisation through worship style and institutional culture, in both charismatic and liturgical churches, but many had in common experiences where the rigid spiritual structures and cultures of those churches were given priority over the access needs of disabled congregants.

3.4 Friendship and the Normative Social Church

In parallel to the institutional and spiritual norms described in previous sections, *social norms* were discussed by many participants. Churches are social institutions:

community and social cohesion is a central part of Christian life in many churches. Thus, informal social encounters shaped participants' experiences of churches, often based around social norms central to the working lives of churches, which not all participants could achieve. Furthermore, spiritual and social contexts often overlapped in churches: for example, participants' church home groups were social, but had spiritual values underpinning them. I discuss five contexts—small fellowship groups, the post-service tea and coffee hour, attendance requirements, church norms of friendship, and social encounters with institutional structures—to illustrate participants' experiences of church social activities and their associated social norms and expectations.

3.4.1 Home groups

A majority of participants commented on the barriers they faced participating in small groups or home groups in churches. Small fellowship groups are a central feature of many churches in the UK, and are structured around bible study, prayer, social fellowship and hospitality, or a combination of these (Harvey, 2003). They mix spiritual growth and social cohesion aims, and in some church movements have been linked with church growth efforts (Aune, 2016; Wuthnow, 1998). Larger churches often consider small group activities to aid a sense of belonging through closer connections with other church members.[3] It was the experience of a majority of the participants in this study that attendance at small groups was strongly encouraged, particularly, though not solely, in evangelical churches. Participants commonly experienced these small groups as physically or culturally inaccessible. Access issues included the groups' timings, their physical location, their informality, and their focus on social relationships. However, given their intended aims of group cohesion and spiritual growth, access to home groups was often important for participants seeking full inclusion in church communities.

Several participants highlighted the physical barriers associated with home groups. Sheila (pair interview 1), who uses a powered wheelchair, faced physical barriers because many of the homes where the groups were held were not accessible

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[3] Aune refers to this as "'cell church' ideology" (2016:65), in which groups are created by splitting larger groups when they reach 14-16 members (see also Harvey, 2003; Wuthnow, 1994).

for wheelchairs. While there were some alternative groups, she was separated from her husband when she attended these:

> We don’t find that we can go to a home group now either because getting into people’s houses with a wheelchair…[isn’t] necessarily very easy. So I tend to go to group during the day to make it easier….I go to a group that meets in the church and call that my home group. But my husband and I can’t go together because that’s a ladies’ group. So we just can’t go out to the evening groups so easily together.

Sheila’s language here suggests that she did not consider the ladies’ group an authentic home group: “I…call that my home group.” It was important to Sheila to stay connected with a more traditional home group, but making her own access arrangements was challenging: she later said that “We have the home group here [in my house] all the time, which might be more than we can cope with.”

Other participants faced barriers related to the cultures and structures of home groups. Clare (pair interview 1) and other participants mentioned that most home groups at their churches were held in the evenings. Clare’s chronic condition, with impairment effects including fatigue, meant it was difficult for her to attend a home group late in the evening after work:

> For me the challenge is that home groups are always really late….Home groups can be quite hard because they’re often about eight o’clock at night so they finish at about ten o’clock.

The scheduling of small groups was a significant barrier that impacted Clare’s health, yet she valued home group so much that—like Sheila—she continued to try to attend. In the past, she had had positive experiences when other church members had offered to help with the barrier of the lateness of home groups, by giving her a meal between work and home group. However, while this helped, it did not solve the timing access problems and made her reliant on informal support which was not always forthcoming. Timing of church activities, including small groups, was similarly an issue for Maria, Charlotte, Faith, Susanna and Mary. All of these participants had health conditions of various kinds that impacted their ability to attend church events at particular times of day. There was a parallel here with those who had difficulties with the timing of Sunday services on church attendance, discussed below. In many cases the same people faced both issues, and were thus excluded from both small groups and Sunday services.

A number of other participants expressed difficulties with small fellowship groups' informal cultures, which could lead to disabling and excluding practices within the groups. Andrew (focus group 2) found that he could no longer attend home groups because informal small group conversation was not possible for him as a result of his deafness. Speaking of an experience, four years prior, of feeling excluded from a home group when he could not follow informal conversations there, he said "I have not been to a home group since." The practice of praying with closed eyes was one of several norms of small groups that excluded Andrew from the social belonging that other members of his church could experience through small groups:

> What I say to people now is I hear with my eyes….I can only look at one person at a time….When I wasn't so deaf, I could just about follow. But when [hearing] got bad, I can't follow form of informal groups, and that's after church and, you know, the coffee.

Similarly, conforming to the social norms of home group was difficult for Lucy, although attendance was strongly encouraged by her church. In her group, everyone contributed to group discussion about the week's bible passage, and she found this anxiety-inducing. To compensate, she volunteered to read, so that her voice was heard and she was under less pressure to speak more informally later on. For similar reasons, Mary (individual interview) struggled with anxiety provoked by the social culture of home groups; the large size of the home groups at her church impacted her ability to cope with their informal social norms.

Furthermore, there was a significant social and spiritual impact when participants were not able to attend small-group fellowship, which could isolate people within their churches. Andrew (focus group 2) highlighted the significance of home groups to him, even though he could no longer attend:

> [S]mall groups or home groups or cell groups or whatever they call them, I've always…loved them, I've always been involved….I tend to look for people to meet one-to-one and have a one-to-one chat. But groups, can't do.

Andrew noted that his sense of loss around home groups was related to his isolation from groups in society in general. However, this had implications for his isolation in his evangelical church, which was organised around small-group fellowship. For Maria (pair interview 3), too, not being able to attend groups and activities for reasons of impairment, impacted her experience of church where she was left out of important church networking and community building:

> I do notice that I don't know what's going on in church. We'll be praying about something and I'll be going: That happened to so-and-so? I had no idea. I'm not just part of the gossipy network and the grapevine. I miss out on that kind of thing.

Many participants who had to use the compensatory strategy of self-exclusion from groups experienced isolation in their church communities, because groups were integral to membership and belonging in their churches.

Given their various difficulties accessing home groups, some participants sought out alternative groups, held at different times or meeting in different places, in order to overcome some of these barriers. Many, however, found that these alternative groups were unsuitable for them because they were aimed at demographics that did not include them. Clare (pair interview 1) had attended alternative groups in the daytime, so that she would not be affected by late timings, but was frustrated that there were no daytime groups that were not aimed at mothers. Similarly, Mary (individual interview), who was twenty-four and did not work for disability reasons, found that there were few groups aimed at her age group during the day:

> So if I want to do something during the day with someone from church it's got to be someone who's old, you know, who's middle aged or retired. And…I'd rather spend some time with people my own age, but they have other lives as well.

Mary conceded that her experience reflected a wider social problem potentially faced by any younger people who did not work and were lonely during the day, rather than solely a church issue. However, as shown by her experiences and Clare's, there is a need for alternatively-timed groups for some disabled people. In contrast, a few participants were happier to adapt to the groups that were offered to them. However, for the most part, demographic and culturally specific issues around small groups seemed to cause frustration to disabled participants whose lives were not structured according to predictable social norms of working in the day and socialising in the evenings.

There were a few examples of participants who had more positive experiences of small group fellowship, often as a result of their own compensation strategies, or informal support from other church members. Susanna (individual interview), who becomes fatigued very easily, substituted her small group for church services as the centre of her worship life:

> There's the house group during the week, which I think because I find most helpful, I really count as my church. I think God is fine with that, and God is the one that I'm worried about.

Susanna prioritised her relationship with God over social norms and expectations. She was aware that attendance at both small group and church services is the norm in the churches she had attended and had some discomfort at doing things differently, but she was able to justify this with her own understanding of God's acceptance of her different needs. She was very positive about the social support she found in the small group, where members were familiar with her needs as a disabled person. Similarly, Mary (individual interview) attended her church's young adults' Bible study, which had a supportive culture, particularly when she communicated a need related to her mental health problems:

> Last week I sent a message to…the young adults' thing, just before it [saying] "If you get this before [the group] finishes, could you ask people to pray for me? I'm not doing good at all. Might end up in hospital tonight…" And [the group leader] said, "Just seen this, we're praying for you now…" And it's not like, you know, he didn't say, "Oh, come along next week and ask everyone to pray for you," because he knows I wouldn't want that.

Here Mary contrasted an experience in a previous church of feeling under normative pressure to be prayed for, with this alternative approach where group members understood her needs and preferences. The group's willingness to adapt its social norms in ways that allowed Mary a better fit helped her to manage her discomfort with groups' social culture.

A few participants created their own, more radical alternatives to church groups, rather than trying to force themselves into structures that did not suit their needs. Maria (pair interview 3) had created a very informal, ad-hoc Bible study with a friend as an alternative to the groups at her church that she could not attend:

> A couple of my best friends go to the same church as me and we do see each other because we want to, outside of church. And we also include prayer time as part of that. And some Bible study and that kind of thing as well.

Some months after her interview, Maria contacted me to say that she had stopped attending Sunday services, for accessibility-related reasons. Her key sources of spiritual input at this point were evangelical Christian television channels and Premier Christian Radio. She found in these her own informal alternatives to church groups, despite the shrinking of her Christian social and spiritual world. Likewise, Faith was involved in an informal social-spiritual group of other disabled Christians: hers was mainly conducted on the Internet. I raise the question of why such alternative informal groups might be necessary, below.

3.4.2 Post-church coffee

Another social ritual at church that many participants mentioned was post-church tea and coffee. This activity was significant to many participants who often wanted to attend for social fellowship and support, but found there were a number of marginalising social norms involved. As with home groups, some participants with atypical bodyminds and divergent social behaviour needed to access the coffee hour differently from the majority.

A number of participants were critical of the coffee hour's typically crowded, noisy environment. It required managing sustained social interaction, including chatting informally while circulating, or "mingling," which many found difficult. Susanna (individual interview) found the social obligation of coffee very difficult, as it took place immediately after a service that she had already found physically and socially challenging:

> I also think by the time we've got through the service, which…is an hour to an hour and a half, then everyone at the church in town will go out to the back for tea, coffee and things, and I never do. I might quickly nip out and get a cup of tea, but then I'll bring it back into the church….I just find I get drained so quickly because I'm overhearing everyone else, I'm having to struggle to listen to someone, I've got to stand, and then I've got to think of what to say.

Susanna was not alone in this. A number of participants felt marginalised by both the social aspects and physical environments of the coffee session, while also feeling under pressure to participate in post-church socialising:

> So we also go through to teas and coffees at the back and you're just crammed in there….I'm still not very good with like post service chatting and mingling but I do it anyway.
>
> Emily (focus group 3)

> I don't do tea and coffee. Well, I do tea and coffee. I drink them…just not at church….I try and escape, which is usually difficult in itself, to try and work out a path to get out. I did an anxiety course for a while and, you know, you had to set goals each week. One of my goals was to have a coffee, and I did it one week. But then you've got the coffee and you've got to stand…awkwardly. You can't leave until you've finished the coffee.

Lucy (individual interview)

Lucy, whose Asperger Syndrome affected her social skills, found the coffee hour particularly disabling. Her compensatory strategies for these disabling structures involved strategic avoidance, ensuring that her formal role in the music group meant she would always be busy tidying up during this time. She rarely took part in post-church coffee.

However, it was not just the social culture of post-church coffee that excluded participants. Coffee culture could also be physically inaccessible to some people with sensory impairments and physical impairments. Rhona (focus group 1) misfit in her church's busy coffee culture, because its informal, arbitrary norms were visiocentric:

> One of my biggest problems is tea and coffee afterwards….I have to rely on somebody asking me if they would like to go for a coffee for me. And most days I can't bring myself to ask them….So I sit there and if nobody asks then the exclusion woodpecker comes on….And if I go out and try and do [coffee] I either have to be first so that there's no queue so I get there and then I just have to stand absolutely still. Or, I have to be last. And then no doubt the nice tea and coffee lady will say, "We did finish ten minutes ago. You're a bit late."

Rhona found herself either having to rely on unpredictable informal support to access church coffee, or having to compensate for inaccessible arrangements. As she noted, this sometimes caused further social problems, including frustration from volunteers. Hazel and Victor similarly described how they relied on the precarious informal support of fellow congregants during coffee time because of accessibility issues they faced as blind people in their church.

Beyond the level of avoidance of coffee itself, a few participants found that post-church coffee discouraged them from attending church altogether, impacting their inclusion in church community. Mims (individual interview) said that coffee hour was one reason she often no longer attended church services:

> When I am depressed I can't do it. When I am manic I can't do it….[I]t is one of the main reasons I very rarely go to the Sunday morning service now. It has got too big, too. Even just the noise level in the coffee room—you can hardly hear yourself think. You have to shout to have a proper conversation.

Mims employed active compensation strategies to cope with this barrier, inviting church friends out to coffee at venues external to the church instead, but this was dependent on fellow congregants' willingness. Likewise, one of the reasons Andrew (focus group 2) stopped attending church was that informal social engagement after church became such a significant barrier to his participation, because he could not hear small talk. For him, this was partly related to the link between post-church coffee and the content of the service:

> [Y]ou end up being quite excluded because people might talk, after, about a great preach….Or if they make a joke, the preacher makes a joke, you miss that. So yeah, you end up feeling…very excluded. Before, I just managed to cope, but when it got worse I couldn't get the gist anymore. I stopped going.

To Andrew and Mims, informal post-service coffee was an inherent part of spiritual-social community engagement that extended beyond the service, but from which they were excluded. This contributed significantly to their exclusion from wider church life.

A number of participants were concerned about a lack of adapted facilities in the church built environment to allow disabled people to join in more fully with informal socialising. They suggested that the creation of a more accessible church environment can make a difference to social inclusion for disabled people. Clare (pair interview 1) was concerned about how physical facilities for disabled people conveyed normative assumptions:

> One thing I did notice is that they have chairs in their coffee area. So it's quite usual for people to sit down and chat, which means that if you're a wheelchair user, people are at your level….So…the expectation [is] that it's normal to want to sit down, so you don't have to ask for a chair, like a friend I know had to do at her church. They said "Oh, you don't need chairs because no one sits down."

The positioning—physical and social—of disabled people at church coffee was a factor in the ways that social norms of standing and "mingling" marginalised them. Sheila (pair interview 1) also found that physical positioning and physical access impacted her as a wheelchair user during informal socialising: "I find that you're lower than everybody else so it's more difficult to be social." She was dependent on the efforts of others to include her, as a result. Similarly, Miranda (individual interview) was frustrated by her church's refusal to alter the height of a counter where coffee was served, when a refurbishment was already taking place. Clare (pair interview 1) also noted that it could be difficult for disabled people to request facilities for better access in informal church settings:

> The experience of people who are limited in some way—we always have to ask for what we need….You shouldn't wait until disabled people or people with chronic health conditions join to find out the solution. You should be looking for it, so that people feel able to come….Especially if you're talking about a small thing like having chairs around—something that could benefit so many people.

Full participation in churches, Clare's reflections suggested, is about access to all church environments—not just to worship spaces, but also those where informal social contact and belonging takes place. However, in the coffee hour, many participants had to struggle for the access that they needed, rather than being able to depend on an anticipation of their needs within church cultures.

Nonetheless, a few participants found that members of their congregation responded positively and proactively to the barriers they faced during post-church coffee. Susanna (individual interview) often found that fellow church members offered informal support. When she brought her tea or coffee into the main church, so that she could sit in a quiet environment, other people would join her. Similarly, although Sheila's inclusion by fellow congregants was dependent on their willingness to provide informal support, when they were willing, this helped her to achieve a better fit in informal socialising.

3.4.3 Attendance

The requirement for consistent church attendance caused problems for a number of participants who could not maintain participation at the same level of intensity as non-disabled people, for reasons of access or impairment effects. Sometimes the requirement for consistent attendance was institutionally mandated and codified. At other times, church social and cultural norms created the expectation that participants would attend regularly and frequently, but without clarity over how often. This section will look at some ways in which expectations of consistent involvement at church, and church activities, caused difficulties for participants, and how they negotiated these social expectations.

Some participants' churches effectively made membership contingent on involvement in groups, and this could cause difficulties for participants who struggled with attendance. Maria (pair interview 3), who attended an independent evangelical church, was summoned for what she called a "telling off" because she was not attending additional meetings and groups:

> I got called in for a work meeting for a big telling off without being warned what it was about. My lack of attendance at church meetings because I'd stopped attending so many things….It was kind of harsh from my point of view because it was just [because of] my deteriorating health that I'd stopped attending a lot of the things I used to go to. So I did explain that, but they weren't sympathetic because they were annoyed with me.

Although compulsory group attendance was perhaps being enforced more strictly for Maria than for other members, because she also worked as a part-time administrator at the church, this attitude seemed to reflect her church's general policies on small group and activity involvement. Maria said that church members were expected to provide a "legitimate reason" for not being present at church activities and services, and were regularly reminded to attend. She felt that this put her under pressure. When I asked Maria if she could imagine any alternative structure where she could be included, she said she thought it would be difficult at her small church; she was "sympathetic" to the problems that church leadership faced with encouraging belonging through activity at the church. However, as with many of the unintentional disabling effects of participants' church structures, the indirect disablism remained nonetheless. Maria was also suffering through being required to attend over-stimulating Sunday services every week, leading her to spend many Sunday mornings in the quieter church kitchen. The culture of Maria's church was based on an assumption that people should, and *could*, attend groups and activities. Likewise, Lucy's experience was of being placed into a home group and very strongly encouraged to attend it, which she did despite her discomfort around the social structures of the group. Normative assumptions that people could, and wished to, attend groups were difficult for a number of participants, including some who would have preferred to find alternative, more accessible ways of participating in churches.

For some participants, there was a loss of social support—and, by extension, spiritual support—when they could not be deeply involved in church communities. Regular attendance was expected, and some felt forgotten when they could not attend and then had no contact with their churches. Stephen experienced social neglect from his church when both he and his wife could not attend for some time, due to illness, when no one from the church contacted them. He thought that this was specifically a problem that disabled people could face, of "fall[ing] through cracks" (follow-up email after interview). Faith (focus group 2) had a similar experience. She was often housebound, with long periods when she could not get to a church.

She had not settled into what she called a "home church," as a result. The resulting absence of church community had both a social and spiritual impact of isolation for her. She particularly missed communion:

> I think one of the things I find with a fluctuating condition is that because I'm young and I don't look disabled, when I have too much fatigue and pain to get to church, nobody thinks: Oh, we could ask somebody to come and bring you communion. Because I'm not elderly and it's not all the time. But communion is really important to me….I'm not on the radar when I'm too ill to be in church.

Charlotte (focus group 2) had a less frequent but equally significant experience of going unnoticed when she could not attend, in part because of the invisibility of her impairment:

> I suppose the thing is, because I go every week most of the time, they think: Oh, she's just gone away for the weekend.

Participants in this situation were often frustrated that social support from church was contingent on a level of frequent and regular attendance that they could not meet. For many participants, in terms of the reasons why people might be missing church, their churches could not think beyond norms and disability stereotypes.

However, a few participants' churches seemed more able to accommodate those who could not attend regularly. As described above, Susanna and Mary were being accommodated in groups which informally made space for their access needs. Nonetheless, it could be a challenge, even for churches which actively wished to include disabled people, to find imaginative ways to involve those who could not attend church. Deirdre (individual Skype text-based interview) was restricted to her home because of her condition. Her church made efforts to continue to include her, despite her inability to attend physically, for which Deirdre was grateful. However, she perceived a need for emotional labour on her part to remind the church that she was there. To some extent, her inclusion was dependent on potentially unreliable informal support, including a friend who recorded sermons for her:

> The sermons aren't on the Church website yet (sore point)….[T]hey have been promising them on the website for at least 6 years….I have a private arrangement with a friend. If she stopped [sending them] I think I would stop receiving sermons again.

While the church was making efforts to compensate for the misfit that its structures created for Deirdre, they were only able to go so far to accommodate someone whose attendance patterns were so different from the church's normative attendance model.

3.4.4 Church norms of friendship and belonging

Groups and other church social activities were difficult for some participants where a social norm of friendship was prioritised. One of the functions of small church groups is to normalise and encourage friendship within churches (Harvey, 2003). As we have seen, friendship is a recurrent theme in much theology of disability, where it is presented as a possible solution to exclusion of disabled people from churches. My research found many examples of churches for whom friendship and social relationships between members was a strong priority; this was a positive experience for some participants, but exclusionary for others who found it more difficult to achieve this social norm.

Anthony (individual interview), a participant with Asperger Syndrome who had attended Anglican churches, encountered the normative cultural priority placed on *being social* in churches. He himself placed a low priority on social aspects of churches; he found that the requirement to "join in" was the most excluding feature of his experience. He spoke of a socially-focused contingent in churches, which he called the "'everyone must have fun' brigade." He felt that many churchgoers, not just neurodivergent people, took part in church activities because they felt they should:

> [Y]ou come across people with Asperger's, who often don't particularly enjoy joining in, sometimes putting pressure…on them to join in, which in fairness not all of them do, but some do, thinking they're doing the right thing. It's actually completely counter-productive, because it seems like they're…refusing to take no for an answer.

Anthony also suggested that churches expected social involvement according to their own norms, through established groups and activities, rejecting other forms of being social. Instead of (mis)fitting into church norms of friendship, he recommended an alternative approach, in which non-disabled people in churches learn about disabled people's own, potentially different norms of friendship:

> [F]riendship in the church is absolutely a good thing, but ultimately if someone was a true friend, they wouldn't try and force you to do something you didn't want to do….I think like anything else, when people think of friendship, they think perhaps of what *their* idea of friendship is. And if they are…a non-disabled person, who is active in the church and has a lot of

> friends who are likewise, as far as they're concerned that's what friendship is….But it's sort of a question again of them having to learn about us, and us having to learn about them.

This solution moves the responsibility for change away from neurodivergent and disabled people, asking churches to change their normative social structures instead; it is a social model solution to the difficulty of normative social structures in churches. From Anthony's perspective, churches' focus on group activity are not necessarily central to spiritual growth. Instead, churches are shaped by models of group membership and "joining in" that involve normative social standards, which not everyone can achieve.

However, for some participants, the central Christian cultural emphasis on friendship was more positive. James (focus group 3), who also has Asperger Syndrome, identified the value of friendship in the Bible, and was motivated to compensate for his social difficulties because he believed that God valued social ability:

> For autism/Asperger-specific stuff…[w]hat's interesting is that in the Bible the very first thing we're told, the very first reason we are given for Eve's creation is that it's not good for man to be alone....And then that also brings into question—well hang on, if we're made for that social interaction why do we have people who struggle with social interaction?

It was important for James to aspire to fit into the social norms of church culture, despite his difficulties. His theological understanding of social relationships as important to God framed these efforts. In common with many other participants, he did not reject church social culture.

Where participants who valued and wished to pursue friendship in their churches, there were often barriers to involvement in church community. The normative structures of church groups and organised social activities excluded Mims (individual interview), who found that her mental distress clashed with the ways that groups were structured, meaning she was unable to take part in the very groups designed to allow her to feel more included in her large church:

> [I]f you don't actually join one of the groups it can be quite…it's kind of like, at what point do you actually feel a part of the community?

There were few alternatives to groups that allowed for social involvement and community belonging in church. For Mims, as for Anthony, there was no access to alternative ways of being part of church community, and church social culture remained untransformed. Mims' only available compensatory strategy was self-exclusion from social activities, and this meant a reduced sense of belonging. Other participants, including Mary and Lucy, shared similar experiences of exclusion from the wider church community when they could not engage with social groups.

Other participants were prevented from engaging in social aspects of church as a result of institutional policies and practices which did not take account of disabled members' access needs. Hazel (pair interview 2) offered an example of this institutional exclusion from the social life of churches:

> [I]n a couple of weeks' time they're going to have what they call a big lunch. Now, there are a hundred and twenty places, so obviously first of all you have to get through Eventbrite. Secondly, what we were informed lovingly on Sunday was that for the first course…we were going to sit with people that we knew. For the second and third courses we were going to be mixed amongst everybody….They might have come and said: Look, how best could we help you? If you'd like to come, you sit where you think you can for the first time, then we'll come and help you....I don't want somebody to say: Oh, please come, please come….But they could give you a little bit of encouragement and say: Well, we'll help you. Don't worry about it.

The church had a normative approach to helping people to make friends at this social event. The meal was structured around the abilities and needs of the majority: being able to move around during the meal is something that sighted people can do unassisted, but which presents barriers to people with visual impairments. Hazel's ironic choice of the word "lovingly" is central to the issue here: she specifically did not feel loved or included in the context of this event. Here she also referenced the recurring problem of inaccessible booking systems for the church's events through the website "Eventbrite," a problem which the church had not solved despite Hazel's offer of technical help. Church institutional policies and practices routinely prevented Hazel and Victor from engaging in the social and community side of church.

A number of participants faced external barriers which limited their participation in church social community. External barriers to church participation are not widely discussed in theology that reflects on friendship as a way to include disabled people in churches, yet these can be significant reasons why disabled people are prevented from involvement in churches. Jean (individual interview) had limited time for social contact after church because she had only been allocated a few hours for her son's carer to support them both at church. Faith (focus group 2) and Deirdre (individual Skype text-based interview) could not attend church activities at all, in Faith's case because she often could not leave her home, for disability reasons, and in Deirdre's case because she was unable to leave her home at all. Yet both had suggestions and ideas for ways in which they could be better included in church socially despite external social barriers, such as Deirdre's attempts to be included as a pray-er for church prayer lists. As with worship and ritual structures, participants sometimes experienced a lack of will to do church differently from church hierarchies. The needs of the majority were often prioritised over the disability access needs of the few.

However, for a few participants, their churches' efforts to accommodate their social needs were examples of alternative structures for more inclusive community. Clare (pair interview 1) highly valued friendship and social contact at church. Her experience of church was improving, thanks to small institutional measures her new church took to dismantle cultural barriers. She found that her new church was proactive around her needs, without overwhelming her, which helped her to be better integrated into community:

> The new church I've started to go to…they've been really good at getting to know me and talking to me whilst I'm there rather than assuming they'll get to know me at some other time.

The proactive steps taken by her church to include her and other disabled people took place on an institutional level, but they appeared to filter down into congregational attitudes towards disability. Clare did not perceive any expectations that she had to fit herself into the church culture of home groups and activities. Susanna, who attended a home group instead of church services, also found that congregational informal support was positive when supported by institutional measures to include her. In both cases, their different methods of accessing church community were informally and institutionally supported by their churches.

3.4.5 Social encounters with institutional power

Informal socialising in church contexts could result in negative social encounters with representatives of church institutions, especially where access or impairment needs were the cause of conflict. This included situations where participants' misfitting resulted in psycho-emotional disablism, for example where church leadership inappropriately emphasised some participants' impairment or disability needs in social encounters. For Clare (pair interview 1), such an encounter was brief, but memorably negative. At the non-denominational evangelical church she attended for many years, a pastor questioned the veracity of her impairment, resulting in an experience of epistemic invalidation:[4]

> At the church, I'd been there for a long time, we had a new pastor and he asked me if—his wife is a GP and some GPs don't think it has any biological basis…he said, "Are you sure it's real? Are you not depressed?" I was mortified. It was so embarrassing. Is it not enough that my GP thinks it's real? I'm so sorry. I don't really trust you anymore if you don't trust my judgement.

The psycho-emotional disablism Clare faced here had an ongoing negative impact on her responses towards churches. She generalised the pastor's attitudes to the congregation, worrying that she was being judged by her behaviour and access needs in church. It was particularly relevant that this encounter was with the pastor, who represented the church institution.

However, for other participants, negotiations with power in social settings were not singular events, but ongoing. Some faced long-term conflicts with church institutions and hierarchies over their access needs, via social encounters with institutional representatives. Brianna (individual interview) related several incidents when she had to self-police her responses to hierarchical power at the cathedral, and the institutionalised disablism that often came with it. On one occasion, her husband was asked about her toileting needs on her behalf, although she had told staff that she preferred to be asked directly about such matters:

> You have to keep [the vergers] on your side because sometimes I need support in order to get to the high altar or whatever. What I did, I did a very deliberate: "[Verger], thank you so much for telling [my husband] about the toilets. I think I said in some sort of convoluted way, "You've asked my husband instead of me."…It's so, so frustrating.

The particular focus on toileting needs, in a public and informal social context, illustrated the level of psycho-emotional disablism and humiliation—to use Brianna's own words—that she sometimes experienced in this context. Furthermore, her intimate bodily needs were not only a focus of cathedral hierarchical power, but were also discussed with her husband rather than directly with her, despite her

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[4] Susan Wendell's theory of epistemic invalidation (1996), further developed by Deborah Marks (1999), recognises the common invalidation of disabled people's experiences of embodiment, especially but not solely by medical professionals.

requests that this should not happen. Her negotiations with power were also impacted by her ongoing difficulties in securing the support she needed to access the cathedral: she felt that she could not antagonise the verger because she might require his help accessing the building when it was being used in inaccessible ways. Negotiations with power permeated the whole of Brianna's experience with her church. A number of participants had similarly disempowering and disempowered experiences in negotiation with church hierarchies, when attempting to make vital access requests.

Social power was often informally expressed in informal church settings, and this led some participants to reflect on attitudes to disability in churches. A number of participants felt that social attitudes to disability communicated by church leadership and fellow congregants were just as bad, though no worse, than in wider society. Deirdre (individual interview) felt that difficult attitudes towards disability at her church were "a society problem rather than a church one," an opinion which Miranda shared. Conversely, Susanna and Clare reported finding more positive attitudes in church than in wider society. Maria (pair interview 3) highlighted one possible reason for some participants' particular frustration with negative attitudes towards disability:

> I don't think they're any worse than the rest of the world. I think the problem is, I have a higher expectation of Christians. I hope that they'll get the empathy of how to understand. And they're just as—as anybody else really, is the problem.

In common with Maria, a number of participants had higher expectations of churches and fellow Christians than they did towards society outside the churches. As a result, they felt particularly let down by disablism and barriers in churches.

3.5 Power and Access

Access, and the decisions made around it, is "not value neutral" but rather involves "political and power-laden choices" (Price, 2017:66). The subjugated perspectives explored in this chapter have highlighted the precariousness of fitting in churches. Church institutional and normative structures are invisible to those who fit easily in buildings that are designed for their physical range of ability, who fit worship norms designed around their sensory and neurological functioning, and who fit social norms. However, such structures were all too apparent for those participants who could not make their bodyminds fit into often-arbitrary norms and ways of doing things. Participants' experiences show how normalcy in churches sustains some bodyminds significantly better than others, leading to misfitting for disabled Christians attending churches and their exclusion from church communities.

Furthermore, disability studies is increasingly discussing the issue that "there can be no 'one-size-fits-all' approach to creating accessible infrastructures" (Price, 2017:66). Many of the stories discussed in this chapter show that, where non-disabled church leadership makes assumptions about the conditions that will create better access for disabled churchgoers without asking, this does not always lead to an improved fit for all; listening to disabled people in churches is central to ensuring good access for all. This issue will be explored in more detail in Chapter 6, where participants voice their own theologies and concepts of disability in churches. In the next chapter I will examine the sometimes-paternalistic approaches of the pastoral model in churches, where participants were often not enabled to express their expertise about their own needs.

Chapter 4. Serving and Being Served: Disabled People as Objects and Agents of Ministry

This chapter argues that the pastoral model in churches may create environments in which disabled people are more likely to be objects of care and ministry, rather than agents. To frame this contention, I examine how disabled people's inclusion in churches is shaped by a pastoral care model, and I trace the effects of this for the participants in this study. In Chapter 2 I argued that much current theology of disability is rooted in a pastoral care model that constructs disabled people as objects of care and support, via an established history of churches as providers of care to vulnerable people. I argued that this model has the effect of silencing disabled people, limiting their inclusion and engagement in churches, and leading to their segregation in churches. Further, I argued that this pastoral model conflicts with activist disability social models, which emphasise the liberation of disabled people rather than simply their care, and which are socially-focused in contrast to the individually-focused church pastoral model. The previous chapter's emphasis on misfitting in physical and cultural church environments also crossed into issues of pastoral care, especially where misfitting led to a need for support. In this chapter I ask whether, in the experiences of my participants, a pastoral care model enables full and meaningful inclusion of disabled people in churches.

To open the chapter, I briefly recap the concept of pastoral power, together with the Christian concept of service, as the theories which frame my analysis of participants' experiences of serving and being served in their churches. Next, in order to examine participants' level of engagement in churches, I examine three categories of ministry and service that participants commented on during interviews. First, I examine their responses to segregated ministries for disabled people, controlled by non-disabled church representatives. Second, I assess participants' lay ministry and unique service potential in churches, especially from their subject positions as disabled people, and how far they were encouraged and enabled in this service. Third, I consider the experiences of participants who pursued ordained and professional ministries, and how far they were supported or encountered barriers. To conclude, I draw on Pattison's analysis of pastoral care as an individualised framework, asking whether the pastoral model enables disabled people to *serve others* in churches, or if they must be satisfied with *being served*.

4.1. The Pastoral Model and Care in Churches

This chapter is framed by reflections on the pastoral model, and pastoral power, as participants encountered it in their churches. The issue of ministry *to* disabled people, that precludes the ministry *of* disabled people, was first discussed in the Introduction and Chapter 2. In reference to Foucault's theories, I suggested that churches are not exempt from the secularisation of the pastoral model, and that the spiritual capital[1] of non-disabled clergy often operates to exclude disabled congregants from participating in ministry and other forms of service. As such, disabled Christians are often targets of care in churches, and this tends to render them as docile bodies. Segregation—meeting disabled people's needs apart from society, through professionally-controlled service provision—is one way in which misfitting bodyminds are made docile, so that society need not transform to accommodate a more diverse range.[2] In the previous chapter we saw how spatial segregation within churches allowed for the control or exclusion of participants' bodyminds in church services and activities, encouraging them not to impact non-disabled participants or challenge cultural and environmental norms. However, there are other forms of segregation which develop in a society that cannot meet the needs of disabled people in mainstream activities. In the context of churches whose relations with disabled people are shaped by the pastoral model, segregation of disabled congregants can emerge through systems which represent them primarily as people with *needs*, and these needs are expected to be met by those with pastoral power. While several participants encountered explicitly segregated provision for and attitudes towards disabled people in churches and Christian contexts, many more encountered more subtle segregationist attitudes, framed by the pastoral model, which positioned them as objects of ministry and care in churches, rather than encouraging them to offer their own ministry and service to others.

The term "service" will recur in this chapter. Nesbitt outlines three aspects of Christian ministry: that of the *Word* (preaching and teaching); the *Sacrament* (liturgy

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[1] The concept of spiritual capital (Verter, 2003) refers to the skills, experiences and resources needed for an active engagement in church and spirituality, including religious knowledge and theological thought. This concept is explored further in Chapter 6.

[2] Morris (1991) argues that segregation arises from the routine devaluation of disabled people's lives which allows their needs to be left unmet in mainstream society.

and ritual leadership); and *Service.*[3] "Service" is defined as "assisting those in need either by helping individuals or by seeking social change in sources of oppression" (Nesbitt, 1998:301). In this chapter I relate the pastoral model to participants' experiences of *serving and being served* in churches, asking how far these participants are able to be actively involved in churches, offering their own ministry. I consider how far the pastoral model shaped their experiences in churches, what forms the model took in practice, and how far this was an empowering or disempowering structure for their inclusion. I argue that a pastoral care approach was common among participants' experiences. While this had positive and inclusive effects for some participants, it failed many participants by positioning them primarily as receivers of care and objects of others' service, when they wished to be more active agents with their own service and ministry to offer in churches.

4.1.1 Care and dependency: Disabled people being served by others

In addition to the theme of physical segregation for disabled people in churches, a few participants spoke about segregated, pastoral church programmes run by non-disabled people for disabled congregants. Participants had mixed reactions to segregated ministries for disabled people in church contexts. Of those who spoke about these groups, some disliked their segregated nature, preferring to participate in non-segregated church contexts with non-disabled people. Liz (individual interview), who is blind, had been involved in the Torch Trust ministry for blind people for some years, as a leader in outreach to other blind people, not simply as a member of the group. She had helped to establish a local group and had reached out to other Anglican churches, seeking blind people to join the group. She was somewhat frustrated that there seemed to be few blind parishioners in the congregations she had contacted, and we discussed some reasons why this might be the case. When she commented that she did not like segregated groups for blind people, I asked her why she chose to be involved in the Torch Trust group:

> Liz: I do have a problem inasmuch as…I don't regard myself as disabled, and also I live in a sighted world. I tend not to go [to segregated services for blind people]. There's a big service for blind people. I don't go to that, because as far as I'm concerned I live in a sighted world. It's not that I don't want to

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[3] This schema is broadly based on the structure of liturgical churches, though it can also be related to other church contexts.

> associate because I very much associate with people who have been through, or are going through, the torn curtain and they're finding it very difficult…
>
> NJ: ….What's the difference to you in the difference between a fellowship organisation like Torch Trust and a service for blind people?
>
> Liz: …Maybe because I was asked to help. Yes, I happen to be blind but I'm being asked to help so it's a different role, isn't it? I'm not just being a member of the group, which I am, but I'm being asked to help so it's a different role from being somebody who's been asked to come because they are unsighted.
>
> NJ: So for you it's helping other people with sight loss?
>
> Liz: Yes, I think that's the difference.

Liz had lost her sight in mid-life. Her comment on supporting people through the "torn curtain" draws on a theological metaphor of transformation that resonates with the sociological concept of biographical disruption (Bury, 1982). This pointed to Liz's commitment to supporting others through her own experience of sight loss, and, within the church context, her own ministry with blind people. She did not want to be a passive receiver of pastoral care, but to share her own ministry, gifts and expertise, preferring not to define as disabled, but just as an "ordinary person" with service to offer to disabled people as a result of her experiences. She emphasised this distinction between herself and other disabled people:

> We have decided to morph the group into an existing coffee morning for people, I think they have, what do you officially call it nowadays? They have psychological difficulties, and I think we're going to add to that in the community because there are more people we know that have onset dementia or are elderly, so we're aware of that down there particularly. I think we're going to invite those people to come because I think they won't find it quite so threatening as a whole afternoon. It'll just be a cup of coffee, a cup of tea and a chat, maybe a piece of poetry, a cup of tea and a bit of cake.

Through her language, Liz positioned herself in the "us" group, of those who lead, while she distanced herself from "them," the disabled clients of the group that she helped to lead. Instead of receiving ministry with the disabled members of the group, she wished to offer it to them. The representation of disabled people in churches as those who are ministered *to*, and others as those who offer ministry, may have had an impact on Liz's self-conception in this context.

However, reasons for disliking segregation varied. Helen (individual interview), who had been a minister in the Church of England for many years, felt that segregated groups were not reflective of wider society:

> Well, a huge, huge driving force in my life is to be as normal as I can be…which is why I don't like groups for the blind, partly [laughs], because the world is not blind. The world is…visual, and the world is sighted. And that's why, I think, I don't like complaining overmuch in church…because…there are times when…I do feel cross, and…when I feel sorry for myself. But on the whole, I think you have to understand the world as it is, and, you know, just as deaf people could get very upset if they can't go to concerts, I can't go to art galleries. It's just a part of life. But I think…the name of the game, really, is to get as close to normal life as you can, and not to—again, it's not letting the disability define you.

For Helen, in common with Liz, fitting into a sighted world was important. Her focus on being "as normal as I can be" was a minority view in this study, but an important one nonetheless. People who experience impairments or chronic illnesses may choose not to identify as disabled, or not to focus on disability. Helen was aware that others often defined her as a blind person before they saw other aspects of her life and personality, but wished to challenge this. Her achievement in becoming one of the first disabled female ministers in the Church of England was, for her, part of demonstrating that she could be "normal." She wished to be able to offer her gifts to the church in service and ministry, rather than simply to receive. For her, segregated groups did not offer her this opportunity, focused entirely on disability as they were.

However, a small number of participants found segregated pastoral support groups to be supportive, as a form of additional pastoral provision to that offered by their churches. In particular, Pauline and Talitha (pair interview 4) spoke positively about interactions they had in a Disabled Christian Fellowship group. They particularly enjoyed the opportunity to speak about topics relevant to them as disabled Christians, and to meet others in their situation.

4.1.2 Pastoral care, created dependency and informal support

A number of participants reflected on disabled people's reliance on informal support in churches, within a pastoral model framework. Among participants there was a range of views on the efficacy of informal community support in churches. For some, this support allowed them to be involved in church in ways that worked for them. Susanna (individual interview) related a very positive experience of her home group, which she treated as her church. She considered that this was unusual:

> I've not been managing so well recently, but that is because I've had other stuff going on, emotionally, and I had some surgery recently and stuff, so

> I've not been able to drive and that kind of thing. Again, people from the house group are the ones that have been there for me. They're the ones who have been calling and checking, took me to hospital and picked me up…brought me shopping and done things. The fact that I haven't physically been there—they're not calling me and harassing me to come, and they're not ignoring me until such time as I reappear, which I think is very special. I don't think that that's something that enough Christians have experienced from church.

Susanna's experience here was of support that was available when she needed it, but not imposed on her. We discussed a number of reasons why this might be an uncommon experience, including the small size of the group and the disability-positive and community-focused culture of the church. Similarly, Deirdre (text-based Skype interview) has ME and had been unable to attend church for many years, except at a distance, through online contact and recorded sermons. She nonetheless felt that was she not forgotten, and remained a part of the church, receiving regular visits from members of the community:

> They have been very good in seeking to support me (so glad I moved churches before all this happened). They visited, did shopping and at 1 point cooked for me as well. Nowadays I need less practical help but I still get visitors. It was the 'spiritual' side of things that has been harder to be involved with, though that has improved recently with monthly communion brought to me.

Deirdre felt less involved in her church in a spiritual sense, as I discuss below, but her experiences of pastoral support were positive.

However, there were a number of situations where participants were failed by their churches' pastoral support. For many, an expectation of reliance on informal support, often built into church cultures, resulted in social isolation in their church and exclusion from church services and activities. A culture of forced dependency was sometimes created as a result of church built environments in which participants misfit. This connects to Garland-Thomson's (2011) argument regarding the second impact of misfitting: the creation of vulnerability. Building inaccessibility forced a number of participants to rely on informal support in their churches in ways that they also found disempowering. Both Isabelle and Miranda encountered situations where they could no longer access church buildings independently. For Isabelle (individual interview), the issue was a door that was inaccessible to wheelchair users, which was eventually replaced with a different but still unsuitable door. This was in addition to doors to toilet facilities which could not be accessed by wheelchair users without the support of others:

> I kept saying, “Can I be involved with the access?” etc. “No. We’re involving someone. It will be fine. You know, we’ve brought in a company who knows what they're doing,” all of that advice or whatever. And then they make things that are really impractical….Instead of a single door on the church, we ended up with double ones which weren’t wide enough either side for a wheelchair by about an inch….And like changing the lock on the door so you can’t get to the toilet. I know it’s—you know, I know it’s fine. Someone should go and do it for you. But there's something about having to ask. You shouldn’t have to ask.

Isabelle here reveals a fundamental incompatibility between the pastoral model and an independent living model of disability access. The accessibility compromise that her church made, on which she was not consulted, ensured her continued reliance on others. This may be seen as an acceptable arrangement within a church pastoral model framework, which assumes that informal, community support will always be available. However, this model does not take into account power differentials between disabled and non-disabled congregants. For Isabelle, the dependency that resulted was not comfortable. Similarly, Miranda (individual interview) spoke about the poor accessibility of her church’s entrance, where disabled people were reliant on a portable wheelchair ramp that could only be used with the help of church staff, which they could not access or use independently. This concerned her so much that she was considering leaving the church.

The effect of forced reliance on other members of churches was often an overtly disempowering experience for participants. In focus group 1, participants discussed frustration with constantly having to ask for help in church because it meant they were constantly reminded that they were disabled and misfitting:

> Zoe: But I just never forget. I mean I still feel uncomfortable asking. And you [to Rhona] obviously also feel uncomfortable asking.
>
> Rhona: Because it’s all the time. It’s all the time you’re having to ask, aren’t you, ask for help. And therefore you just sometimes get fed up of it.
>
> Katie: There should be a good model of interdependency….The word “normal” is tricky isn’t it? The mainstream people who make all the decisions and build all the buildings are more than capable of functioning in that society without thinking about it, whereas those of us who are not mainstream are always having to process ahead of ourselves. And that question of: Could you give me a hand with this? We shouldn’t need to ask if mainstream people were more aware beyond their own ability. And it should

> model: Isn't it great we can help each other? But actually, it ends up being: And I'm going to have to ask for help again.

As Katie suggested, disabled people can never "forget" their impairments and needs in churches, because of the pastoral model's insistence on their reliance on others. They must compensate for a poor fit that means their bodies can never recede from their awareness, and this impedes their ability to sustain a religious habitus and participate fully in worship and church community.

4.1.3 Inappropriate and damaging pastoral support

Beyond cultures of forced reliance on informal support, institutional structures around pastoral support also sometimes had negative effects for participants. This was the case for a number of the participants who experienced mental distress, and who related experiences of pastoral support that were unhelpful, obstructive or damaging for them. Mary (individual interview) presented a stark contrast between a church where she had experienced exclusion, and her current church where she felt more included. She had worked for 11 months at a Church of England where, initially, she had disclosed a significant mental health impairment and they had been positive about their ability to include her. However, Mary experienced epistemological invalidation and psycho-emotional disablism. She also found that information about her impairment, which she had disclosed in confidence, had been shared within the church. Mary was concerned that the church's internal pastoral structures was expected to be sufficient to meet her complex mental health needs:

> I think people in churches are well-meaning but they don't really know what they're talking about. And it's really not the best thing to recommend that someone who has a mental illness talks to someone else who's not professional….It's fine…if you're just feeling a bit down. But once you started taking it out on yourself and you dropped out of uni and you're failing everything, then it's not really the best thing for them to have done.

It is possible that the church could not distinguish between more common mental health variations experienced by many people, and the severe, long-term mental distress that Mary was experiencing. Mary considered that the church's unconstructive pastoral approaches exacerbated her mental health impairment. However, in the church she was attending at the time of interview, Mary felt much more included as a result of their willingness to be flexible around her needs. They were understanding when she was unable to attend, and respected her wishes in relation to being prayed for and other church cultural practices. She appreciated the pastoral support of her church, but its success was contingent on Mary remaining the arbiter of her own access and other needs.

There were other participants with mental health problems who did not find church pastoral model approaches helpful. Maria (pair interview 3) also had experiences of churches' poor handling of mental distress:

> Talking about mental illness. Back in the 1990s that used to be more my problem than physical illness....I remember a negative [experience] at the church I was going to at the time of being told that Christians don't take anti-depressants because we're above that type of thing. Just stop being so anxious because I believe in God and I should just get over it all, and that was that church's answer to my mental health issues at that time.

Stephen recognised this experience, responding to this and Maria's other stories of psycho-emotional disablism she had encountered in church:

> Stephen: Do you feel like that damages your ability to be a Christian? Does it interfere with that part of your life?
>
> Maria: …Well, I feel like a rubbish Christian—or at least a rubbish church member. I'm all right between me and God…because I know he understands. I don't have to justify and explain.

Maria's implication here was that, while God understands mental distress, other Christians often do not. Inadequate and even damaging pastoral support appeared to be negatively impacting Maria's self-esteem in relation to her Christian faith, particularly where other Christians were concerned. Mims (individual interview) had comparably mixed experiences of pastoral care; she considered that some pastoral practices towards those with mental distress in churches could be dangerous. She believed that an inadequate theology of mental health was one reason for this, as I explore further in Chapter 6. Inappropriate pastoral support was harmful or stressful for a number of other participants, particularly for those experiencing mental distress, where the pastoral model was often proving both inadequate and damaging to their complex needs.

4.2 The Volunteer Service of Disabled People in Churches

Many of the participants in this study had gifts that they wished to share with their churches in the form of service to the church. Some participants were ordained, or interested in pursuing ordination. Some were lay ministers or involved in other volunteer leadership and ministry. Others were interested in offering informal service of various kinds in their churches, from serving on church welcome teams to helping to run Sunday schools. Often, their service was a unique ministry that arose from their subject positions as disabled people, and the expertise or skills that they had developed as a consequence. However, participants were often not enabled to pursue these ministries and service, as a result of pastoral model expectations that positioned them as objects rather than agents of pastoral care.

In the remainder of this chapter, I consider both participants' lay and volunteer leadership and ordained leadership. However, many of the issues affecting disabled people's leadership in churches crossed the barrier of ordained ministry and lay service, affecting disabled people's involvement in both. In the following section, I examine some of the examples of participants who had lay and volunteer service to offer their churches, often not just in spite of their impairments but *because* of them, and I consider how far they were enabled to offer such service. I also consider what some participants felt could be gained, for churches and disabled people, by empowering disabled members of churches to serve in churches, moving away from a pastoral model in which they simply are there to be served.

4.2.1 Disabled people's unique service and expertise

A number of participants had specific expertise in disability accessibility and inclusion, either relating to their own impairment groups or more broadly. Many were keen to offer their disability-related expertise in service to their churches, so that accessibility could be improved. Some had offered this expertise beyond their churches, in denominational and other broader religious contexts. As a Third Order Tertiary, Miranda (individual interview) arranged Braille services for her lay order, which involved consulting with blind people. As a sighted person, her expertise was not in the physical creation of Braille resources, but in her understanding of the need for this through other experience of disability and her professional work. She encountered some resistance and barriers to this service, but persisted:

> I organised anybody that wanted it, to have a larger print version of all the publications. Audio versions. Braille versions! Anything and everything. I think I did it about seven years after we got going. And they'd never done it before, and I got it all put in place, and then when it was all put in place, and it was up and running well, then I just left it for somebody else to take over….You have a handbook as a Tertiary, a bit like a manual. It's got your prayers for the day and things….I had three Braille copies done. And

> somebody said to me, “Ooh, well it’s going to cost too much money”….Then they said, “We’ll get somebody from the university to do it,” and they did it, and it was wrong….And then I had to get a person who’s fairly local to here, luckily, had to get him to tell me….and then an older lady…explained on the phone, how she needed it doing in Braille. And then I got that all set up….I persuaded them then, at that point, to start to send out to everybody in the Order things as PDFs—attachments. Because….you can save on printing.

As a disabled person with experience as the expert in her own needs, Miranda’s model was one of disabled people as providers of service and ministry, with expertise to offer.

Similar activism by other participants emerged from their own experiences of accessibility in churches, whether those experiences had been positive or difficult. James (focus group 3), who was generally very positive about accessibility at his church, created leaflets for the church about “the basics of Asperger Syndrome” aimed at better inclusion of autistic people in church. For other participants, a ministry of expertise in disability accessibility arose from experiences of exclusion or discrimination, which allowed them to see where their churches needed to improve. Mims was aware of how churches could exclude those experiencing mental distress, and she persuaded her church to think about better inclusion for church members in this situation. Liz advised her church on building improvements for blind congregants after experiencing difficulties with access.

Some participants offered more informal support to their fellow disabled Christians, often in ways that provided alternatives to pastoral models. These participants often aimed to work together in service *with*, rather than *for*, imagined or informal communities of disabled Christians. Faith, for example, was involved with an online group with other disabled Christians offering mutual support. Mary (individual interview) drew on her experiences to support other young people with mental health problems, including people in her church:

> I’ll do everything I can to help other people….So when I’m talking to young people…teenagers, I quite often tell them that what they’re going through now is gonna help someone else because…they’ll overcome it and then they’ll be able to help someone else.

Although Mary found it easier to help others than to accept support herself, she had a model of peer support for others which contrasted with the professional-led pastoral model approaches employed in the churches she attended.

In contrast, Susanna's interest lay in helping to transform attitudes of non-disabled people in churches, which would enable them to better understand and support other disabled people, seeing this as service she could offer. Susanna (individual interview) also felt that sharing her experience of disability would encourage non-disabled church members to have more compassion for disabled people because of their prior encounters with her:

> I think it's important, as a Christian, to have that humility as well to say, "This is what I'm struggling with. This is what I find hard. This is who I am, and my impairment is part of who I am." It's important that I'm open about that, so I'm not proud or deceitful, but I think, as well, it's important because you have almost a responsibility that people understand that this is what it's like…it helps people when they've not been through that experience. It helps them to be able to understand it a bit better…to be able to offer more compassion and…to meet you where you're at.

Susanna went on to say that she felt a responsibility to share her experience in this way, to benefit other disabled people in the future, knowing that others might find it difficult to be so open about the barriers they faced.

However, many of the participants encountered church reluctance to accept their offers to share experience and expertise. The resistance they experienced demonstrates the clash between the pastoral model's construction of disabled people as passive receivers, and participants' resistance, instead positioning themselves as activists or experts. As discussed in Chapter 3, both Miranda and Isabelle asked to be involved with accessibility improvements to their churches, but found their churches unwilling to listen to them. The result was poorer access facilities for wheelchair users in these churches. Likewise, Hazel and Victor drew on their experience of website design for visually impaired computer users to tell their church about accessibility problems with its online booking system for social events. However, their input was ignored. The resistance from the church to their expertise not only had an ongoing negative impact on their own social inclusion in their church, but also potentially on the wider disabled community, leaving the church using online systems that were exclusionary. Victor described their resulting reliance on precarious informal support from their church, having to ask church leaders to use the website on their behalf. For both participants, the rejection of their expertise in disability accessibility and support was frustrating, in part, because they were professionals whose expertise was respected in the secular world, sharpening the contrast with the way they were treated at church.

Other participants perceived the rejection of their expertise by churches as part a lack of interest in disability itself, as a broader issue or theological topic. Talitha (pair interview 4) was discouraged when she was criticised after leading a home group Bible study on an aspect of disability theology:

> Talitha: In my home group…I was encouraged to lead a study…based on the paralysed man, through the roof. It may have not been the topic, it may have been the way I handled it, but…I just felt very disappointed by the reaction. It was a long study, so I was having to make a decision about how much to cover….I was reminded that this group is partly for fellowship, and your study was too long….I guess I was a bit hurt by that [laughs].
>
> N: …because you were hoping for more in-depth discussion?
>
> Talitha: Yeah, and I never lead and maybe that was the complaint…But that did hurt a bit.
>
> N: …What was it about their reactions that was painful for you specifically?
>
> Talitha: I guess no encouragement…in the topic…And the reminder about how I shouldn't plan too much…how the group can't take in too much.

She brought up this topic after suggesting that there was little discussion of disability in her church, saying that she would have liked to see "more openness" to such discussions. However, her home group had other priorities, and this was discouraging to Talitha in terms of her unique ministries and service as a disabled Christian. Other participants experienced resistance to their activism in their churches. The service of educating churches on disability issues and pushing for change was important to several participants, emerging from their activist or social model perspective on disability, but this approach was not always welcome in their churches.

For other participants, resistance came when they tried to share their gifts with churches in ways that were accessible to them. Members of Faith's (focus group 2) online support group of disabled Christians wanted to share their unique opportunities for service with churches, offering to be involved with prayer ministry from their homes, but were not taken up on this:

> [T]he group that I'm in contact with, because we're house-bound we tend to pray a lot. And I think the church doesn't recognise that as a gift.

Deirdre had offered a similar gift to her church, of the time and opportunity that she had to pray, from her unique position as someone who was permanently at home due to her illness, but again her church had not accepted her offer.

Nonetheless, in some churches, participants were able to persuade leaders and committees to allow them to share their expertise on disability issues. This sometimes required a shift in power relations in churches, away from a pastoral model framework. Mims (individual interview) spoke about trying to become involved with her Anglican church's disability advisory group:

> I actually wasn't on that group because when I first started. The priest that was in charge…couldn't—wouldn't—see mental health as a disability….I actually had to go to a meeting and literally go through the history of the mental health movement….But it was actually quite a convincing argument….We went in one meeting from them not really believing that mental health was a disability to a week later me being asked to talk at the next meeting and it mainly being about mental health [laughs].

This lack of familiarity with mental health and distress as a disability rights issue, rather than a pastoral issue, is not uncommon for people who experience mental distress (Mulvany, 2000). However, once Mims had undertaken emotional and intellectual labour to argue her point, she was able to help shift her church's representation of people with mental distress from the pastoral context to a social justice context. The church was eventually able to see Mims as an expert, not just in her own needs but also in those of other disabled people.

However, it seemed from some participants' experiences that it was not always necessary for churches to abandon pastoral model approaches in order to make use of disabled members' ministries and service. For Susanna (individual interview), opportunities to share her service came because the pastoral support she received was positive and individualised, making space for her to participate, including in service. In a direct contrast with Faith's situation, her house group had used her ability to pray in ways that she found helpful, setting up prayer ministry in which she could participate:

> The prayer ministry is something that is really important to me because one of the few things that I can do as part of a Sunday service is I can pray. Our house group was thinking and praying about this, and we developed a prayer ministry for Sunday mornings.

Susanna's experience suggests that there might be a number of ways for churches to approach disabled people that resist or remodel traditional pastoral approaches, enabling people to share their gifts more fully. Nonetheless, in churches where participants met with more resistance to their offer of service through disability expertise, an inflexible pastoral model view of disabled people was often the dominant framework for approaching disability.

Furthermore, the hierarchies and power imbalances inherent to the pastoral model were often revealed in participants' resistance to it, when they attempted to offer service in their churches. For Rhona (focus group 1), as a Methodist local minister who is visually impaired, barriers to sharing her service were illustrative of power struggles in churches and impacted on her ability to serve in her community. She related an incident where she had asked repeatedly in advance to be given large print and other accessible copies of materials, but found that her request was not acknowledged:

> [T]his very senior man, I went up to him very nicely before the meeting. There was no un-gracefulness in me whatsoever. I said, "Hello, it's good to see you."…And, "I'm just wondering are you doing a presentation today, can I have a copy? Have you managed to [get me] a copy…beforehand?" And he looked me up and down as if I was a piece of shit….And so the next issue is about power. If I am demanding somebody higher up, clergy or higher….If I'm demanding something that they're not willing to give, that means I've got power over them.

Rhona is here shown undertaking significant emotional labour with little response. Her interpretation of this exchange was that her request threatened pre-existing power structures. Asking for something from someone above her in the church hierarchy involved a power negotiation framed by the pastoral model, which positioned her as unable to make requests or to express expertise about her own access needs. The refusal of the church leaders to negotiate Rhona's needs with her had a negative impact on her ability to participate in lay ministry in her church.

Others described similarly difficult power negotiations in their attempts to share their service in churches approaching them from within a pastoral model structure. Sheila (pair interview 1), a wheelchair user, described an incident where she became very angry because her minister wanted to speak for disabled people, rather than allowing her to speak for herself and on behalf of an imagined disabled community. She interpreted this as presenting an issue because she did not play the role prescribed for her by the pastoral model:

> Interestingly, there was one time I was in a meeting with [the vicar]. He started talking about something about disabled people and how they've got to be treated pastorally and they can't do anything or something, and I just said, "Excuse me, but as a disabled person myself, I think I would like to speak for disabled people. I don't think you can speak for us." I thought: Oh dear me, I've really said the wrong thing there….I suppose I'm a bit stroppy really, aren't I? It's my nature to be a bit stroppy….You kind of get a bit sensitive, you know. When anybody's going to be making comments about disabled people and you feel strongly about it….I think he probably couldn't cope with it….I think disability was just difficult for him to go with actually because I was—I don't know, I didn't put myself in the frame of—I've just got to sit there and be looked after, I can't possibly do anything.

Sheila's internal conflict centred on whether she would allow herself to be framed by a pastoral model which she found limiting and frustrating. She was unsure how to resist and challenge this pastoral concept of herself appropriately in a formal church context. Other participants, including Zoe and Katie, also spoke about having to tread carefully when resisting their prescribed pastoral model roles, even as established ministers. Unequal power dynamics were often central to the pastoral model concept of disabled people in churches, with negative impacts for those offering service and ministry.

Zoe and Katie (focus group 1) believed that it was important for churches to understand the expertise and passion of many disabled people about their own needs and disability access and inclusion more broadly. However, they were wary of common responses to disabled people who asserted their own agency over their own needs and access in churches:

> Zoe: We become our own expert don't we? And that's the biggest message isn't it in terms of access? If I leave nothing else with the churches I'm working with, it's how about asking people in your church how you can help them? Quite simple but massive.
>
> Katie: Yeah. I know me better than you do.

Zoe went on to describe how being discouraged from asking for access solutions could lead to the silencing of disabled people. She believed that the result of such silencing was a feedback loop, with churches continuing to make assumptions about disabled people's needs, rather than asking them. To come to a disabled person and ask about their needs may involve relinquishing power, offering disabled people the agency to make choices about their needs, in defiance of a pastoral model that defines disabled people’s needs for them. Conversely, to make assumptions about access is to cling to power conferred by a model that constructs disabled people as passive and in need of others’ service. For Zoe, one answer to this invalidation lay in the resistance that disabled people could enact in churches, modelling change by insisting on taking on ministries: “that’s something we have to be doing ourselves so that people realise that it’s all right.” She represented disabled people’s resistance as creative misfitting, taking on active roles even where structures position them as passive, and demonstrating an alternative disability paradigm for churches.

4.2.2 Underestimating disabled people's abilities and gifts

As discussed, the pastoral model expectation that disabled people will be objects of care, rather than agents of ministry, was a direct barrier for many participants who wished to offer service to their churches. For a number of participants, this barrier involved an underestimation of them as people, and of their abilities and gifts. Many found they had to confront these devaluing pastoral attitudes directly in order to be taken seriously in their own service and ministries. This was often true even for those who had otherwise positive experiences of church. Sheila (pair interview 1) had been involved in several ministries at her church, including prayer ministry, and generally felt very included there. However, she still felt that she had to struggle, at times, to be seen as capable enough to be involved in such service. Speaking about an interregnum at her church, and her difficulties participating in congregational decision-making at this time, she said:

> It’s interesting how little they involve disabled people like me in church things in general. You know…the politics of church. You know, there are some people who are the bee’s knees, they think, and they’re invited to be on this that and the other committee, and there are people like me who are never going to be invited I feel, despite the fact that I’m not unintelligent….But you know, I think being in a wheelchair does, even in church, sort of lower me down the people [who] are able to do things.

Sheila’s thinking on this subject was somewhat paradoxical: she linked the issue to “the politics of church” initially, then said that “even at church” these responses to wheelchair users existed. Sheila may have expected attitudes to disability to be better at her own church where she had often felt included despite her impairments, than in wider society, a response she had in common with other participants, as discussed in

Chapter 3. Sheila's language about her role in church ministries tended to be conditional:

> Surprisingly enough, I'm allowed to do healing. Sitting in the wheelchair, I do healing. I can tell that…some people think, you know, can I possibly be the person who's doing the ministry? You know, I'm in a wheelchair—what on earth are you doing, doing healing? But people get over it and I do it and I'm allowed to.

Here Sheila commented on a pastoral model attitude that assumes that wheelchair users could only have a passive, receiving role in healing ministries, being served rather than serving others.[4] Her repetition of the word "allowed" implied that, given her position as a wheelchair user who would more conventionally have been seen as a receiver of healing ministries, she needed permission from church hierarchies to break out of a pastoral model role into a less conventional ministry role for a disabled person.

Such underestimation was particularly experienced by participants who had impairments that were visible or obvious. A number of these participants found themselves confronting pastoral model expectations about their own impairments and abilities when they were involved with lay service and volunteering in their churches. Emily (focus group 3), who has cerebral palsy and a speech impairment, experienced underestimation based on expectations of what she could achieve and offer in church, especially from people who did not know her well:

> [I]t depends on the person and my relationship with them. So, I think a lot of people wouldn't—they don't know anything…about me, but they assume certain things because of how I walk and how I talk. Once I get to know people it's like: Oh, she's got a brain.

While she was studying theology at a high-ranking university, she experienced this underestimation of her abilities more directly:

> I always remember a story at my church. It's a well-to-do man, and I walk past with my [university-branded] hoodie, and he was like, "You don't go to [University A] do you?" And I'm like, "Yes and I study theology." In your face!

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[4] While this attitude is likely to be constructed in part through norms and beliefs around healing and the body, as explored further in Chapter 6, it also relates to pastoral model expectations about the roles of disabled people in ministries. Sheila's experience may suggest a reciprocal relationship between healing beliefs and the pastoral model in churches.

Emily was aware of the pastoral model framework that her fellow congregants were using to relate to her as a disabled person, in these encounters of invalidation and underestimation. Similarly, Talitha (pair interview 4), who also has cerebral palsy and a speech impairment, had largely positive experiences with her church, which she described as having been very welcoming to her. However, she sometimes felt uncomfortable in her volunteer work for her church's hospitality team:

> I do quite a bit with the hospitality team….[T]he easiest thing for me to do is welcome, on the first floor on the way into church. So yeah, some people wonder why I'm sat there [laughs] looking lost….I have to work hard to display my team badge and say, "No, I'm here to welcome."…I guess it's not right, but…not everyone accepts that we [disabled people] can actually do things like that.

Talitha had to use compensatory strategies and emotional labour to pass as someone with her own ministry to offer. Reflecting both on her own experience and that of her disabled friend Pauline, she commented that, while they do both need help to access church, they also wish to give back to the church community:

> [S]ometimes I think—I don't like dissing them, but—we need help, we do, but they think we need help and we can't give anything back.

Talitha's description of her situation reflected the inflexibility of the pastoral model. Nonetheless, she believed that it was possible for disabled people both to be served by their churches, and to minister in churches themselves.

Some participants were discounted as leaders because churches focused on the disability barriers that they encountered in church, rather than on their talents and gifts. Victor (pair interview 2) was discouraged from informal Alpha course leadership in his church, in part as a result of the practical barriers he faced in accessing church:

> I've done leader training but I've not finished it….I wanted to lead a group in Alpha. But the person who was running Alpha…came up with all the negatives. You know like, "Think of all the things that could be difficult and wrong." …It wasn't like, "How could you get around this?" So I just, you know, once the barrier was up I just said no. [In Alpha] you get into a group. And all the person does is—you know, you start the conversation off and try to keep get people involved to speak. Because they're all new and they're not Christians. So it's your job to pose questions and start a debate. And I can definitely do that. They were thinking more of the dinner times, serving tea.

Victor's comment "once the barrier was up, I just said no" was telling: he saw this discouragement as a signal that the church would not support him in his ministry.

While sharing food is part of the Alpha experience (Hunt, 2005), Victor did not see it as essential to the course. If the church had enabled him to bypass this element, he felt that he would have been able to lead. The unwillingness of the church to adapt its culture was an attitudinal "barrier" for Victor, a term that carries weight in disability activist contexts with which Victor is involved. He perceived that, rather than the church considering ways to restructure or overcome the barriers, these were the focus of decisions around whether he could lead. There were some other occasions where Victor and Hazel felt more supported in attempts to be actively involved in church life, but this support was precarious and not always available. Their active involvement in their church was dependent on other congregants knowing them as people, and thus being able to see past pastoral model expectations and view them as people with service to offer, rather than as in need. A shift away from the pastoral model might have enabled Victor to use the potential leadership gifts that he was keen to offer to the church.

A few participants became aware of this underestimation of disabled people's gifts and service through an imagined community of disabled Christians. In these cases, the underestimation was not directed at them, but at others. Brianna spoke about other disabled people in her congregation who were discounted for more active involvement in the church, because fellow congregants perceived them as objects of care. Similarly, Mims (individual interview) encountered an attitude towards older people that implied they needed help, rather than being valued sources of wisdom and experience:

> [E.] has become a really close friend. A sort of mentor and agony aunt….I get really angry because several people have said to me, "Oh you're so good, you're going to visit [E.], aren't you good?" Almost like I am doing her a favour and it is kind of like—I go because I get so much from her, you know?

Mims creatively misfit against other church members' pastoral model interpretation of her friend. She used an alternative paradigm to interpret her friend's ministry, reinterpreting age as a positive source of service, as much as it might also involve impairment. For Mims, allowing her friend to offer ministry meant not expecting it to be available through formal church structures, but visiting her at home. In this paradigm, the location of the friend's ministry moves to the places where she is enabled to offer it, indicating the kind of structural change that could accommodate disabled leaders as they are.

However, despite ongoing difficulty for many participants in sharing their gifts in churches, a number described ways in which their subject positions as disabled people were a source of their service to churches. Zoe (focus group 1) discussed this in the light of her deanery and church's response to issues of disability in their community, including healing and becoming a "dementia friendly" church:

> [A]ctually, for most of us the gifts are our limits. Because I have increasingly found that when I have got better at saying, "Can you help me with this?" I sort of see it as what my ministry is, to sort of make it all right for people to be limited. And because then if you start by saying "I could really do with a hand with this. Do you mind getting that for me? Oh, and let me know if there's anything I can do for you," it's incredibly empowering. But in a really different way to society. The Kingdom of God is meant to look really different to a well-run organisation. You know Jesus, our king, rode on a ridiculous unbroken donkey. He looked like a fool. And therefore that's our model of power.

Katie and Zoe went on to discuss the potential impact that a theology of limitedness could have for churches, beyond disabled people. Zoe considered that those who did not have such an awareness of their own embodied limits would be less able to offer such a gift in service to others. There is an echo here of limits theology, as discussed in Chapter 2. However, where limits theology often emphasises that both non-disabled and disabled church members alike are limited, Zoe's disability theology here is about the gifts inherent in disabled people's *distinctive*, located limitedness. This theology of gifts and limits was expressed by a number of participants for whom, rather than being an inherent barrier to service, disability was itself a source of gifts that they could bring to churches.

4.3 Ordained Leadership and Disabled People

Thus far I have argued that the pastoral model positions many participants as objects of care and service, rather than as agents of their own ministry and service to others. As I have discussed, this was evident in the experiences of many participants, although not all, who wished to be actively involved in church ministries as volunteers and as lay leaders. However, the problem with the pastoral model was most apparent among the participants working in ordained ministry, or other, similar formal ministry, or who wished to be ordained.[5] These participants faced three main barriers to their work as ordained ministers and church leaders, centring around the normative ideal of the non-disabled minister: (1) the built environment; (2) the cultural practices of churches, sometimes arising from the built environment and the normative ideals it constructs, although not solely; (3) structural occupational barriers specific to the profession of ordained ministers. As in Chapter 3, these barriers often overlapped. In all three areas, it is apparent that churches' views of ordained ministers or church leaders, and what they expect from them, are often influenced by a pastoral model concept of disabled people as objects of care, rather than as potential ministers.

4.3.1 Positioning disabled people as laypeople not ministers

A number of participants who attempted to serve in ordained ministry or church leadership positions, particularly those who were physically impaired, encountered church buildings which positioned disabled people as laypeople, rather than ministers. This required them to negotiate their ministry around their poor fit in church environments that privileged normative bodyminds of clergy. Most commonly, ordained participants related this to the serving of communion. Isabelle, Zoe, Katie, and Rhona all spoke about negotiating ways to preside at communion in church buildings which did not easily accommodate them. These included buildings with steps up to altars, with no ramps for wheelchair access. Whilst lay participants usually had alternative, if inadequate, options for receiving communion without having to negotiate steps, ministers found the situation much less manageable. Church architecture created an expectation that they would offer communion in inaccessible parts of the building. A number of ordained participants, and those training for ordination, had met with concerns about how they would offer communion at inaccessible altars, as Isabelle recalled (individual interview):

> I mean one of the guys keeps saying, "Well how are you going to do communion?" "Well we'll just move. We'll get rid of [the raised platform]. We'll just put the table out the front."

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[5] The concept of ordination is only relevant to some liturgical denominations. In this study the concept was relevant to ordained ministers in the Church of England and the Methodist Church. However, there were also participants in leadership and ministry in other churches.

In these cases, not only did buildings restrict these participants' offering of communion, it also conveyed a symbolic message about what disabled ministers could and could not do. By extension, it communicated an expectation of compulsory non-disability for ministers. All the ordained participants had developed strategies for serving communion and for other practices where they were limited by church buildings. These strategies ranged from Helen's request to her congregation that they tell her when they were last in the queue to receive communion, as she could not see them, to Katie and Zoe's use of a seat or stool at the altar. Yet despite these coping strategies, assumptions were still made about what many of these ministers could, and should, achieve. These expressions of ableism were constructed and reinforced through church buildings and practices.

In some cases, church practices grew out of buildings which constructed a non-disabled ministerial ideal. These practices were also often based on pastoral model assumptions that ministers and church leaders would be non-disabled. Katie (focus group 1) considered that church practices were based on a "physically able way" of doing things in churches, which assumed—and privileged—normative ministerial bodyminds:

> So, it was that kind of construct that says things can only happen if you do it in an able-bodied way. Like prayer ministry, having to stand up. And to preach you should be in the pulpit really, because that's what we do in our church. No, I can preach from the floor thanks….And that certain things can only be done in a certain way which is the physically able way. And you want to say: Ah, it's not necessarily true.

However, the expectation of normative bodyminds in hypothetical ministers was expressed not only in the building of churches with raised pulpits with steps, but also in church cultural practices surrounding preaching, which was expected to take place at the pulpit. Similarly, among participants who were ministers in churches without altars, assumptions were still made about whether they could offer communion in standard ways. In Rhona's case (focus group 1), this was because of how communion had always been shaped by the congregational layout of her church.

> I [assist with] a communion on a Wednesday morning sometimes which means going round with the individual little glasses…on the tray. And

> somebody again high up in our circuit said: Well, you can't do it. Why? Well, you can't see to walk round with it, can you?[6]

In these cases, the building communicated and created the expectations of the congregation and other ministers, and church culture followed those expectations.

Conversely, for other ministers, church practices which constructed an ideal non-disabled minister had little to do with the structure of the built environment, and more with the cultures of churches. Some participants spoke about the ways in which disabled clergy and their access needs presented particular challenges for their non-disabled colleagues. Zoe (focus group 1) described her work in the deanery where she has responsibility for disability issues, and a church within that deanery where she served as a minister for a month. She was delighted by a refurbishment of this church to create better disability access, as a result of which she could serve communion from her wheelchair at the altar. However, clergy at the church were resistant to suggestions of change to the way that they offered communion, despite the new flexibility offered by the refurbished building. Zoe gave them three months' notice of the disability access needs that she would have as a minister there, but she still met with resistance when she attempted to negotiate her access needs. While disability access was important to this church's clergy in relation to their parishioners, they could not conceive of making changes to their practices to accommodate disabled ministers. Zoe related this to the issue of power and disability in churches:

> [I]t was absolutely [about] that power dynamic. And when it came to being there for a month and assisting with the Eucharist. But you can stand to do that can't you? No. But you can stand to do this can't you? No. Well, how will you read the Gospel if you're not going to stand? And all of that. And then we got to the chalice and it was: Well, don't bother. And I had to, because of the power, sit there and say, "It's really difficult I know, but that is what I've been ordained for." He was saying that parishioners were going to find it difficult. And it really wasn't the parishioners. I ended up saying, "Do you know what, I do this every week somewhere else in this deanery. Your church ain't that different." I'm trying to keep that dynamic of: It's all right, I'm not taking away your power. But I'm also not yielding. You've got no choice about this….And it went very well, the month there. And it's changed things. But…it was just so explicit, about that giving of power.

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[6] Rhona emphasised that she only assists with "extended communion" in her Methodist circuit, as she is not ordained to offer full communion.

Zoe argued that fellow ministers were more willing to make changes for disabled parishioners than for disabled ministers. The former was in line with the pastoral model, as a way of offering support to disabled people. However, giving up power and control to disabled ministers was, Zoe considered, much more difficult for these clergy. This may have been in part due to their liturgical theology and practice, which Zoe called their "high view of the priest". However, it was also impacted by their pastoral model approach to disability. Zoe had to undertake careful negotiation over accessibility and power relations, because she misfit in the church's pastoral model framework as a disabled priest. She was forced to do emotional and practical labour, finding a careful balance between respecting the church's practices and not "yielding" her ministerial rights and power. Isabelle and Katie (focus group 1) had similar stories of needing to offer communion differently, and meeting with challenges and resistance. Katie's congregation agreed to accept communion differently from her—she, too, offered it from a seated position—but did not accept her suggestion of continuing this practice when other priests were offering communion:

> I've got a retired lady who comes and does communion for me now and again which is lovely. And if she's doing the mid-week communion I can guarantee there'll be rail down, kneelers out and they'll do it properly. Even though she said: I want to keep doing it Katie's way because that's how we do it at this church. But other people kind of go: Oh no, seeing as Katie is not here we can do it properly….If they've got a theological reason for flipping the rail down and putting the cushion out and doing it that way, that's great. But…it's—this is how you do it properly.

Katie referred to this idea of receiving communion "properly" several times, suggesting that, for some congregants, it was a challenge to receive from a disabled priest because it did not meet their expectations of what was liturgically and theologically acceptable. However, Katie challenged the idea that receiving communion from a disabled minister had any real theological impact for communicants.

Many participants who were ministers experienced a subtle expectation that they would, and should, pass as non-disabled or minimally impaired, as a result of pastoral model expectations. While Zoe and Katie asked churches to accommodate them as disabled ministers, and did not attempt to conceal their impairment effects, some ordained participants had the opposite attitude: they were concerned about not wanting to appear to misfit in their churches, and not wishing to draw attention to themselves as disabled ministers. Helen (individual interview) had concerns about not wanting the service to be aesthetically "rickety" and negatively impacted by her impairment effects and access needs. She carried out significant emotional and practical labour to ensure that her status as a blind minister was not a focus:

> You really do have to prepare very carefully and know what you're doing….I also found that I always rang my readers to find out that they really were coming. And that I didn't say, having looked at the rota, "Well, now John's going to read our first lesson," and then you get a woman's voice because John has swapped with Mary….That sort of thing, I think, needs careful checking. Otherwise the service becomes either an embarrassment, or very rickety. And I don't like services to be rickety. Because if they are, instead of relaxing into the worship, people are thinking [gasp] "Helen's got it wrong." Or "Poor girl." So, I don't want that. I want to fade into the background.

Similarly, Isabelle was concerned about her aesthetic effects on worship at her Anglo-Catholic church, aware that attention was drawn to her if her wheelchair made noise in the service. Her church's leadership had considered ramping the altar but found it would be architecturally difficult, so Isabelle had been presiding from the front of the altar. She was concerned about disruption for the church if they put in the temporary ramp that was being proposed, which she worried would be noisy. While the church building was limiting Isabelle's ability to participate in the same way as other ministers, her concerns were particularly about presenting a good fit as a minister, and not drawing attention to herself as a disabled person. She also had some concerns about the practical issues that her access needs would have on her ministry, including not being able to wear robes. Both she and Helen wished to present a good fit and to pass successfully, as ministers who are not *too* disabled to serve. There may be echoes here of a pastoral model which does not make room for disabled ministers to appear disabled in front of congregations. What Isabelle called "disruption," relating to very obvious impairment effects and access needs, would draw attention to disabled ministers as disabled people, and the pastoral model only makes room for them as receivers of ministry and service, not as providers.

Nonetheless, a number of ordained participants challenged the pastoral model requirement that ministers be non-disabled, or be able to pass as such satisfactorily, in order to offer service to others. A number considered that confronting these normative assumptions about the ideal embodiment of priests could have a positive impact on churches. Both Katie and Zoe (focus group 1) insisted that the accessibility-related changes they made to communion were only aesthetic, not theological, and that churches could be persuaded to accept them:

> So in the same way that my gender, from the Church of England point of view…doesn't affect what God does to the bread and wine, neither does my disability. It is just about logistics. It doesn't say anything bad about theology. But of course for a lot of people they struggle with that. And I gave them the choice, because they've got to make [it]: Oh crumbs, what would I rather do, have it done properly or have it from the priest?

Katie was aware that, as she presided over communion, she was compelling her congregants to reconsider their pastoral model and theological objections to receiving communion differently from a disabled priest. Furthermore, both Katie and Zoe suggested that their presence as disabled ministers, in situations like these, led to changes in attitudes. Questioning assumptions of the normative, ideal non-disabled priest was positive for the churches in which these disabled ministers served. As a result of the accessibility changes that they required, their churches had to consider what was theologically, and what only aesthetically important about communion. This was one of many ways in which the presence of disabled ministers had the potential to expand normative assumptions of the ideal minister.

The concept of the ideal non-disabled minister also created structural barriers to ordination or entering leadership. Like Isabelle, Helen was similarly limited in the ways in which she was allowed to serve as a minister: as a blind minister, she had been required to find a post in an Anglican church that would accept her before she was allowed to train for ordination. Although this occurred in 1981, and the landscape of ordination seems to have changed for some of the participants since then, it does not seem to have changed for others. Charlotte (focus group 2), who has a chronic health condition and works as a spiritual director, felt that she was discouraged in her questions about training for ordination, in part because of concerns over whether she would physically be able to do the work:

> I'm exploring where I am going—you know, where God wants me. And I had a conversation with the vicar, who…was also the Diocesan Director of Ordinands in our diocese....And I said, "I'm considering whether I have a call to the ministry in the church." And she seemed quite dismissive of it because of my pain and fatigue. And it seemed almost…as if the Church didn't want people with pain and fatigue issues because we're more complicated....but it may have been that she felt that I wasn't right at that time. And so—and I've spoken to other people and they said that's not the case, that's not the Church's position. I think…it's a case of waiting and seeing where God

> wants me. And if it continues to come up, you know, challenge it. But I…know some ordinands with disabilities, some of them have fatigue issues. So it can be done.

Here, Charlotte was in a difficult position regarding whether she should challenge negative attitudes to her potential ordination. Selection of candidates for ordination is a religious choice, and not simply an occupational decision. Accordingly, questioning a decision or concern regarding training for ordination is a theological matter, which goes beyond simply arguing about one's suitability for a job. Charlotte understood decisions theologically as representative of God's will for her in ordination, and seemed reluctant to criticise her denomination and its ordination directors. However, she made contradictory statements over whether the situation might be a disability access and equality issue. It was clearly very difficult for her to challenge the power of her church hierarchy on the issue of her ordination, even when she suspected the possibility of disability discrimination. Charlotte herself linked this attitude to pastoral approaches in churches, in terms of assumptions about what disabled people can do. To counteract this, she suggested that encouraging part-time work might enable more disabled people to serve as ordained ministers. Here Charlotte demonstrated the difference between disability, where barriers are social and can often be remedied, and the *inability* that she felt was sometimes ascribed to her, arising from perceptions of her impairments. In contrast, she mentioned a wheelchair-using priest she knew whose barriers were more easily identified and remedied, who was being enabled to serve by his church. She argued that because accommodating her was potentially more complicated, the Anglican Church could not imagine how this could be done. In her condition of variable chronic illness, Charlotte presented a significant challenge to the compulsory non-disability required of ministers as a result of the pastoral model.

Zoe (focus group 1) had faced similar barriers to her ordination, and had to push to be allowed to train as a minister in the Church of England:

> My sister asked me when I told her I was—great news, they had said I could do stipendiary ministry and full time training and all of that, after going through very stealthily with some very strategic advice from white men in power actually. But it did work. And she said, "Oh, it's really nice of them to pay you for a job you can't do, isn't it?"

Here Zoe underlined the low expectations of those around her—that she would not be able to do the job—and how she had to bypass these with advice from those embedded in the hierarchy of the Anglican Church. Underlying her comments here is shared background knowledge, with the rest of the focus group, that the pastoral model limits what disabled people are imagined to be able to do in churches. In all these cases, the pastoral model created structural barriers for participants who were seeking, or had sought, ordination and training for ministry.

In other cases, churches' and denominations' models poor understanding of disability had been limiting for some participants who were interested in ordination. Shona is deaf but not a member of the Deaf community, nor a user of BSL. Responding to Katie, who was talking about the Church of England's Committee of and Among Deaf and Disabled People, she had asked, "Why [are] Deaf and disabled separate terms?" (focus group 1). Katie's response was that financial and personnel issues likely affected whether it was possible to allow for one committee or two. Shona then expressed related concern about the inclusion of deaf Christians who are not part of the Deaf community:

> Shona: So when I've been in situations when I've talked to people about the possibility of pursuing ordination in the future and they say: Oh there's this Deaf church in such and such place, would you like to go there? They're generally the people that are within the Deaf community….
>
> Katie: So you'd be more disabled going to a Deaf church than going to a hearing church?
>
> Shona: Exactly.

The structural barriers that Shona encountered when considering ordination related, in part, to churches' models and perspectives on disability, and towards her specific impairment. She met with little understanding of the difference between the Deaf community and deaf people who do not use BSL. The suggestion of segregation was an easy structural solution to Shona's problem, in an echo of discussions above and in Chapter 3. In fact, this was of no use to Shona, who would not have been accommodated in Deaf churches. Shona's structural barriers were not solved by a segregationist approach, but this approach seemed embedded in the pastoral frameworks of those with whom she had raised the possibility of ordination.

In denominations other than the Church of England, other participants also faced structural barriers to entering church leadership, particularly Andrew (focus group 2). He was frustrated that he felt he had gifts in preaching and teaching, but that he could not use these gifts because of disability access and cultural barriers. As discussed in Chapter 3, Andrew had been personally impacted by the cultural practices and structures in his churches that excluded him as a deaf person. However, these did not affect him simply as a congregant, but also as a potential leader. He did not meet with direct discrimination, but rather with structures that prevented him from leading:

> [In] the past I was like a trainee church leader. So I preached, not every week, but I would preach occasionally….I felt my particular gift was in teaching, whether preaching or in a small group or small seminars….I don't remember negative attitudes. I always found the church to be very accepting of me….[I]t was only when I got so deaf that I couldn't follow that I found suddenly, it wasn't that they didn't want me. It was like, I just didn't fit into the way that they did church. I just didn't fit into the way that Christians did things when they got together….And I think they were disappointed to see me step down from leadership.

Andrew specifically linked structural barriers to his inability to serve in church leadership. He could not continue preaching and leading because of the church's environment and culture. He understood this from both an individual model and a social model disability perspective: the problem, in his estimation, was *both* that his impairment effects had deteriorated, *and* that he "didn't fit into the way they did church." Yet many of the barriers he faced were structural, and his statement allowed for the possibility that churches could have created a better fit for him as a leader.

However, for some participants, the ordination structures of their denominations allowed them to participate as ministers in more imaginative, inclusive ways, with support from churches. Isabelle (individual interview) had a positive relationship with her church. She felt that being known by the congregation meant she was accepted and welcomed. Isabelle was about to begin training as a local minister, which she explained was an ordained version of the licensed lay minister role. I asked whether she would prefer to be a paid minister:

> I can't do that physically….I've retired from full time work, and I have some part time paid work and I'm drawing my pension early. So that's due to my health….It is an assistant type of role, which suits me fine because that's what I want to do….So that's not a restriction…due to my disability. I think, yeah, it's just what I chose to go with and helped with in terms of time and energy levels and what I can do….I suggested it, and it was received very positively….I thought people would think: Oh, you know, why can't we have someone healthy doing it? But actually there hasn't been. And they were told that I'd been accepted on Easter Sunday and the whole church erupted into clapping….It was really affirming.

Isabelle insisted on and claimed her power to choose the form of ordination she pursued, despite her occupational disability-related restrictions. She expected resistance or barriers to her suggestion, because of her access needs, but did not encounter this. However, Isabelle clearly had a supportive church community where she was valued as a potential minister, rather than meeting with underestimation, as many other participants did. This church support was key to her experience of finding an ordained role in which she fit.

A minority of participants had faced fewer barriers in formal ministry. One such case was Helen (individual interview), discussed above, who said she was the first blind female minister in the Church of England, and had had a long career in ordained ministry. Not all her experiences of attitudes to her ministry had been positive, however. The Church of England had initially raised concerns about whether she could succeed as a blind minister. Nonetheless, Helen primarily understood her role in ordained ministry in terms of her faith. Her concept of God’s provision and purpose had been the most important factor in her approach to underestimation or resistance from others. Her faith had empowered her to advocate for herself in response to the attitudes she had met:

> And I think… it’s just been a question of thinking: Well, if God wants me there, he'll have to do the fighting. Because as I say, I am not a crusading feminist, not at all. And…he's provided me with wonderful colleagues, who have never made a fuss.

Helen’s description of herself as “not a crusading feminist” points to the overlap, in her experience, of gender and disability. She was ordained soon after the 1992 Church of England policy change allowing women to be ordained as priests. Helen was aware of potential and actual limitations placed on her ministry, but she believed that God would provide, such as by placing her with colleagues with an understanding of disability. The alternative, of being politicised as an activist for change, was not compatible with her values. Nonetheless, she had clearly been quietly assertive and persistent when she met with barriers to her ministry. Helen’s personal faith gave her the confidence to remain convinced that God wanted her to be a minister, and was a strategy of resistance to structural barriers to her ministry.

However, for most of the participants who were ordained or working as church leaders, structural and attitudinal barriers were inherent to the role of minister, leading to ministerial marginality (Aune, 2016) for many. These barriers will be discussed further in Chapter 6, in the context of the spiritual capital that is required for church leadership, and what might prevent disabled people from acquiring that spiritual capital.

4.4 The Pastoral Care Model vs More Radical Care Models

The limitations that the pastoral model place on disabled members of churches is evident throughout this study. For Pattison, as outlined in Chapter 2, much pastoral care in churches today is individualistic. In part, this is a consequence of the individualism prevalent in late capitalist society today, within which context church pastoral care operates and is influenced. However, it also points to a fundamental orientation of the pastoral model, and of Christianity itself. The "analgesic function" of much pastoral care is, Pattison suggests, often more focused on "making the suffering bearable" than remedying that suffering, by addressing its sociopolitical causes (1994:208). While his analysis is primarily of the churches' work in secular contexts, this study suggests that churches may also need to reconsider how the pastoral model affects and limits disabled congregants.

In contrast, there are radical, less individualistic models of care in disability studies which may offer guidance to churches interested in adapting the pastoral care model, so that it is less disempowering for disabled people who wish to be agents of change, rather than objects of care. Margaret Price's (2015) feminist disability studies concept of participatory care is one example. Price argues that "care must emerge between subjects considered to be equally valuable…and it must be participatory in nature…developed through the desires and needs of all participants" (2015:279). In contrast with the often-paternalistic model of care in church pastoral settings, this model is participatory; it involves a sharing of power and agency, both on the side of those offering care, and those receiving it. Price cites the maxim, "If you can't go, then I don't want to go" (2015:279) as central to this model.[7] Such an approach might result in a transformed model of pastoral care where, for example, a congregation decided not to use an inaccessible altar location for a service. In this situation, *care* has been understood to mean the full participation of all, and the needs of disabled people are prioritised as an essential part of the "all" of the community. For Price, using language that resonates with limits theology, "care

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[7] Price credits this maxim to disability activist Mia Mingus (2010).

means moving together and being limited together" (2015:279). There is precedent for such an approach of shared power in a number of mainstream theologies, including that of the Church as the body of Christ, based on Paul's reference that all parts of the body matter (1 Corinthians 12:12-26).

One alternative to individualised and disempowering pastoral care models is for churches to look more closely at the social issues underlying pastoral problems. Pattison suggests that churches need to examine whose side they are on in their provision of pastoral care, "to self-consciously choose where they are going to situate their care in the conflict of interests between powerful & powerless" and to adopt "socio-politically aware and committed pastoral care, rather than inequality" (1994:266). As argued in my Introduction, the concept of "whose side" an institution or ideology takes has been central in disability studies. Furthermore, Pattison places an emphasis on encouraging people to find their own voices. Allowing marginalised social groups to name the models that will best serve their needs, he suggests, may be one way of achieving this. In disability studies terms, this approach could be conceived of as a shift towards user-led and user-informed models of pastoral care, such as the model of interdependence discussed above. Such a shift may require that disabled people are enabled to reclaim the power of symbology and theology for themselves. I explore this theme in Chapter 6, where I examine participants' theologies, as created, owned and expressed for themselves. A move towards disabled people's ownership of care models and theologies may create opportunities for them to redefine themselves as agents of service and change in churches, in contrast with their current representation as objects of care.

For disabled people in this study, such redefinition and reclaiming of their role as agents of service in churches was a recurring interest. However, while participants may have frequently wished to become "willful guests" (Ahmed, 2014) in churches, they did not always have the resources to engage in this kind of creative resistance against a disempowering pastoral model. In the chapter that follows, I analyse the data discussed in this chapter and Chapter 3, in relation to concepts of willful guests and conditional hospitality. I reflect on the extent to which participants were satisfied with the practices and models that they encountered in churches, and the ways in they resisted these practices and models when they were not.

Chapter 5. Discipl(in)ing Bodyminds: A Conditional Welcome for Disabled People in Churches?

This chapter provides an analysis of the participants' stories presented so far, in order to establish the extent to which participants were integrated into church communities, assessing in the process whether their churches underwent transformation to make space for disabled people. McRuer considers the issue of "a place at the table" for disabled people, which he calls "integration into society *as it is*" (2006:112). Such integration forces disabled people to attempt to fit into an untransformed and often segregated society, without examining what happens at the "table," how it happens, and for whose benefit. In contrast with simply offering disabled people a place in an untransformed society, the Freireian concept of "conscientisation" proposes a cultural transformation in systems and institutions (Peters and Chimedza, 2000; Ware, 2016). In a church context, conscientisation implies transforming social and cultural "ways of doing church" (Andrew, focus group 2), so that these are no longer built solely around non-disabled people's access needs and preferences.

In the sections that follow, I theorise more concretely the implications of inaccessible church built environments, and how these produced certain kinds of misfitting for participants. I then consider the institutional power expressed when church cultural norms are maintained. Next, I consider churches' social norms of friendship and presenteeism, as represented by participants, and the ways in which many participants misfit against these social norms. Reflecting on Garland-Thomson's (2011) argument that misfitting can lead to resourcefulness and adaptability, I then look at the resistant and compensatory strategies that participants used to cope with and challenge their exclusion from normative church environments and cultures. Finally, I examine theories of pastoral care and relate these to the experiences of participants in their churches, asking whether they were enabled, through church transformation, to be active agents of ministry and service in their churches. The chapter ends with a theoretical reflection on conditional hospitality and the politics of participation in churches.

5.1 Misfitting in Buildings and Practices: Landscapes of Power

Disability theorists, particularly geographers, have argued that architectural designs can marginalise bodies which fall outside the parameters of normalcy. Imrie and Edwards describe the geographical concept of landscapes of power (Lefebvre, 2014; Zukin, 1993) as "characterised by geographies of exclusion" (Imrie and Edwards, 2007:626). They contend that architecture which marginalises disabled bodies cannot be considered in isolation from societal systems of normalcy and ableism. In their production of idealised bodies, architectural designs and spatial organisation iteratively produce *and* are influenced by normalcy:

> That such bodies are core to architects' conceptual schema is indicative of societal and aesthetic projections of moral and/or ethical spaces, characterised by places that are rarely sensitive to disability and the impaired body.
>
> (2007:626)

Kitchin refers to this iterative working of spatial power on disabled people's bodies as "the disablist writing of space" (1998:349). The built environments of the churches that participants described in this study offer examples of the entanglement of architectural landscapes of power with normalcy, expressed in aesthetic and moral projections. The architectural design of many participants' churches was influenced by institutional and denominational structures, as in the standard design of an Anglican church. However, participants' experiences demonstrated that church design and use is also influenced by normative concepts of the bodymind of the ideal worshipper and minister.

Disabled people disrupt church environments when they misfit against normative architectural design. For Patsavas, this disruption reflects the interconnectivity of all bodyminds in the social environment, and the ways in which impairment "leaks" into communities encountering disabled people:

> When we recognize the leakiness…of pain, we can begin to conceptualize bodies, desires, and experiences (painful, shared and otherwise) within a system of connectivity. My experience of living with pain leaks onto those around me....Any borders that do exist are as much a product of active negotiation as they are flesh.
>
> (2014:214-5)

For many of the participants whose stories were shared in the preceding chapters, attending church involved many such "active negotiations" with fellow congregants and church leadership as a result of the fitting and misfitting of their bodyminds in church environments. For some, this involved confrontations and struggle against institutional structures and hierarchies. The discipl(in)ing of participants' bodyminds was one result. Another was the self-exclusion of disabled people from church spaces which marginalised them, which reinforced the power of these landscapes. Participants either stopped looking for churches they could attend comfortably, or moved between churches, searching for built environments that would better sustain them; there were no similar consequences for the churches in which they misfit.

Furthermore, as power is enacted through architecture and disabled people misfit in church environments, their presence and absence shapes church practices through the use of these spaces for worship. In many cases, participants were segregated in churches because of the negative impacts that their bodyminds would otherwise have on liturgical practice, ritual, and order of worship. Katie (focus group 1) talked about "the mainstream people who make all the decisions and build all the buildings," referring in part to specific decisions made by church leaders within the Church of England. However, her statement also references broader normative projections, in Imrie and Edwards' terms (2007), of an ideal bodymind. This maps onto assumptions of an ideal worshipper, who is accommodated by seating configurations, positioning, facilities, and other architectural features in churches; the ideal worshipper is, in turn, also produced by these environments. When a worshipper falls outside of these norms, discipl(in)ing of their bodies results, in the form of segregation or other marginalisation within church buildings.

However, it was not only pre-existing church architecture which marginalised participants, but also the ways in which that architecture was used. Worship cultures emerged from church buildings that had been designed for a normative range of bodyminds. One example is that of communion rituals, where participants' divergent embodiment regularly disrupted the aesthetics and order of worship, where they were unable to fit successfully into the landscape of power built around communion practices. In these cases, communion and other worship practices arose from, and interacted with, buildings and their design, as these were put to use during worship. Other participants proposed that spiritual aesthetics were another reason for church building uses which excluded non-normative bodyminds. In their disruptive impact on practices designed for the aesthetic uniformity of an anticipated norm, disabled people do not always "look nice," as Rhona (focus group 1) said. When they deviate from norms and misfit in church environments, disabled people challenge the aesthetics and practicalities of worship styles and ritual order, designed around these environments. They expose the precarious norms that underpin the associated practices and cultures.

In a few cases, architectural barriers were not a prominent issue for participants with physical access needs. Stephen, for example, was happier in a community where he was individually welcomed and supported than in a fully physically accessible church environment where the community was less inclusive. However, for most participants whose impairments had physical dimensions, it was important that their church's building was accessible to their needs, and many considered good disability access to be an embodied form of welcome to that church. This included not only access to ritual spaces, but more everyday accessibility and facilities too, such as accessible toilets and after-church coffee facilities. Some had left their churches, and others were considering leaving, because of poor access, for example where they were reliant on the help of leaders and volunteers. Furthermore, even among those whose impairment was not physical, church environment and design affected inclusion, as shown in the experiences of some participants with autistic spectrum conditions who needed quiet spaces.

A number of participants were dissatisfied with church institutional responses to buildings in which they misfit. Within church landscapes of power there was often evidence of disciplinary power at work on disabled bodyminds in churches. Participants' access was not always a straightforward matter of buildings or facilities. Neither was the problem simply a lack of money or permission for building alterations, in most cases. Instead, securing disability access tended to involve negotiations that reflected power relations between disabled participants and members of church hierarchy who controlled building use. For many participants, negotiating access to churches for their divergent bodies involved carrying out emotional labour and encountering psycho-emotional disablism in return. Where the "leaky bodies" of disabled people impacted church practice, disabled people were required to discipline their bodies, to make them fit practices and environments better. Discipl(in)ing of bodies was the response when disabled people's alien-being-in-the-world[1] was out of place, and thus a potential threat to the order of ritual in

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[1] Paterson and Hughes' concept of alien-being-in-the-world (1999) inverts Csordas' concept of the body as being-in-the-world. In this schema, the body "dys-appears," i.e. is foregrounded in the experience of a disabled person through intercorporeal and intersubjective encounters which

churches (Douglas, 1966). This affected whether participants could forget their body and allow it to recede into the background. Csordas (1994, 2002) proposes that ritual allows bodies to recede into the background of a person's awareness, as "the somatic mode of attention" (1994:67) to the body is reduced, through the person's integration into community. However, through the dys-appearance of the body (Paterson and Hughes, 1999)—the socially-mediated foregrounding of the body that disabled people often experience—the misfitting body may instead remain an impediment to ritual and worship. Zoe (focus group 1) found that she could never "forget" her impairment and needs because of buildings and practices that marginalised her. Conversely, when her body was not made a spectacle or segregated from other congregants, it was less likely to dys-appear. Attempts to make participants' bodyminds fit in inaccessible Christian buildings and practices, to discipl(in)e them in the Christian community, led to their alienation. However, when participants' bodies were allowed to exist *as they were*, participants experienced empowering equality in church. Finding ways to allow participants to fit better in churches, to participate more fully on an equal footing with non-disabled fellow congregants, offered them improved embodied experiences of Christian life and worship.

The theology of church buildings also needs to be considered in any study of how disabled people misfit in church built environments. Liturgical exclusion and segregation was a particularly symbolic form of exclusion for some participants. Garland-Thomson describes segregation of disabled people from public spaces as a "casting out" (2011:594), echoing the Levitical prohibition of certain disabled priests from the holiest spaces in the Temple, as explored in Chapter 2. Although no participants literally encountered Levitical-style prohibition from church spaces, they were cast out of the "inner sanctum" in subtle but no less noticeable ways. Sometimes this involved physical exclusion from the holiest spaces in churches. Brianna was particularly aware of her exclusion from cathedral spaces with liturgical significance; for her this was not routine exclusion, but specific to the holiest ritual and liturgy of her church. The experience of being cast out also included, for some, the segregation of wheelchair users at the back of the church, separation from family or peers, the prevention of participants from accessing buildings and church services

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recognise and expose the disabled body as different, and through barriers in the physical, cultural and social world.

without support, difficulty in attending social and Bible study groups, restrictions on taking communion in the ways that participants wished to, and, for a few, being prevented from attending church at all. While these barriers are unlikely to have been overtly theological in motivation, they carry uncomfortable echoes of Old Testament prohibitions on Temple access. Exclusion from the most liturgically significant areas of churches conveyed a symbolic message, for some, that they were unwelcome.

The parallel co-constitution of buildings and liturgy as spaces of segregation and exclusion also speaks to questions of who is idealised as a minister or confined to the position of worshipper only, as we saw in the previous chapter, and as analysed below. However, lay participants were also affected by the theological implications of architectural spaces. The original design of the high altar in an Anglican church or cathedral will in part have been intended to represent the relationship between God and the congregation (White, 2003). In a number of the church environments described by participants, the space of God and the clergy is prioritised, but less priority is given to the encounter with God by disabled church members. The space in which clergy function and separate themselves from the congregants is a key aspect of this demarcation and prioritisation of certain types of space. The most sacred place in the church, in this respect, is especially removed from disabled churchgoers, as much as that may be an unintended effect of the use of space.

For Garland-Thomson (2011), misfitting occurs in and through processes of meeting the material world, moving within it, and negotiating access to it. In this study, it was evident that many participants misfit in the environments of their churches, where their divergent bodies were considered deviant and disruptive and were discipl(in)ed. This affected the welcome that participants experienced in churches, their inclusion in worship and social events, and the ways in which they experienced institutional power. The impact of buildings will recur throughout the rest of this chapter's analysis, particularly in the discussion of participants' social experiences in churches. I now theorise the ways that institutional power was also enacted through church cultural and spiritual norms.

5.1.1 Institutional power and church cultural norms

The churches in this study, as described by participants, exemplify Foucault's theorisation of pastoral institutions. Foucault argues that these institutions partly operate through hierarchical power structures, but they also function as communities and for the benefit of their members, through "systems of social networks" (1982:793). Pastoral institutions operate techniques of governance such as surveillance, as well as

> traditional pre-dispositions, legal structures, phenomena relating to custom or to fashion (such as one sees in the institution of the family); they can also take the form of an apparatus closed in upon itself, with its specific loci, its own regulations, its hierarchical structures which are carefully defined, a relative autonomy in its functioning.
>
> (1982:792)

"Traditional pre-dispositions" and "phenomena of culture" are embedded in the cultural norms of the churches described by many participants, particularly their worship cultures. For participants, fitting into these norms was often a challenge. Many of these norms arise from tradition or theology, such as communion practices or the expressive worship of charismatic churches. However, participants' experiences reflect on other church norms as more arbitrary aspects of a church's culture. The structure of most church services, particularly the sermon, reflects normative assumptions: that congregants will be able to sit still, stand when required, listen for extended periods, and understand and follow a lecture. Long, audiocentric, speaker-led sermons arise from the privileging not only of a hearing culture, but also of learning and intellect in churches. This audiocentric culture excluded not only participants with hearing impairments, but also those with learning difficulties. Similarly, sitting and standing conventions are guided by the structures of a church tradition or denomination, structured around liturgy and worship, but they are also governed by the cultural norms of each church. Invisible conventions of practice communicate norms of bodily acceptance to participants, but these may not be an essential aspect of worship. Other worship and cultural frameworks of churches also affected disabled people's bodyminds, such as the modern trend in many churches to move towards more informal worship, where informality created norms that were difficult to achieve. Furthermore, not all the norms inherent in church practices are purely Christian norms. As Zoe said, many normative practices in churches are influenced by wider society's attitudes to disability, which interact with and influence Christian theologies and practices.

In order to present a better fit into church cultural practices and limit potential disruption to worship practices, many participants disciplined their own bodyminds. For some, this involved passing as non-disabled or less disabled. Not all participants had this aim, and I will consider participants' various strategies of resistance in the following section. Some grappled with whether the self-disciplining of their bodyminds was necessary, deciding it was not, such as in Susanna's acceptance of her embodied and performative differences in worship through an affective commitment to God. Others were offered alternative ways of participating in worship that allowed a better fit for their bodyminds. However, for many, churches expected them to fit their bodyminds into church cultural expectations, despite the discomfort it could cause. Here we see again how many participants' bodies were "leaky" in these community situations, provoking resistance from their churches to the disruption caused by their access or impairment needs. Misfits with divergent bodyminds, who need to accommodate those divergences performatively in worship, are a challenge to fellow congregants and church leaders.

Such cultural norms in participants' churches were often enforced through volunteer members of church hierarchies, affecting the precarious informal support that participants received in their churches. Churches are often sustained by volunteers from the congregation[2] and participants' churches were no exception. They described how lay volunteers were crucial to the operation of church activities and services. Institutional cultural norms were often enforced through the actions and attitudes of these volunteers. For some participants, the attitudes of individual volunteers, such as vergers and communion servers, directly affected their access to church. For others, experiences of psycho-emotional disablism came mainly from volunteers. Many were dependent on the goodwill and informal support of volunteers for access to communion, and some found their bodies discipl(in)ed publicly when volunteers were unwilling to accommodate their needs. Churches often assumed that informal support would be sufficient for disabled congregants' needs. However, such support is precarious, and many factors may affect its

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[2] Members of the study's RAG stressed this point. The Church of England does not collect full statistics on volunteering within churches, as opposed to volunteering with external church-run community initiatives. However, its research shows that more people do unpaid work with churches than with any other organisation (Church of England, 2014).

availability, as explored in more detail below. To create institutional change so that disabled people are consistently better supported in churches requires profound changes in church cultures and structures, including examination of church reliance on volunteers and how this impacts disabled churchgoers. This would have potential implications for the training and engagement of volunteers and other congregants, a point to which I return in the thesis Conclusion.

Institutional discrimination is not usually the result of malicious motives, but of unyielding normative structures. Neil Thompson (2010) notes that discrimination often arises from the ways institutions work. Further, institutional discrimination can "set the context for everyday life as experienced by disabled people and very often pass[es] without remark" (Cameron, 2014:45). Cameron's comments reflect the routine institutional disablism faced by a number of participants, who regularly confronted barriers arising from the cultures and structures of their churches. It is likely that this exclusion was a result of institutional practices designed unconsciously to suit the majority, which churches failed to adapt when these practices caused misfitting. Nonetheless, in resisting critique of cultural and structural discrimination, participants' churches passively communicated: We've always done things this way, so why should we do things any differently to suit the needs of a few? Institutional change and conscientisation in churches, in contrast, involves scrutiny of cultural practices. It requires churches to communicate and demonstrate that they will do things differently to allow a better fit for all members.

However, some participants acknowledged that their churches were undergoing institutional and cultural change, to various degrees, towards more complete inclusion of disabled congregants. Changes in church culture and buildings allowed more consistent access to worship and social activities. Some participants' churches considered and codified aspects of church culture that impacted disabled people, for example, by signalling that standing was not required of those who found it difficult. For some participants, such communication of expectations indicated a church's attitudes towards disability. For example, Clare felt that her church's deliberate approach to disability inclusion, signalled in such codification of expectations, informed fellow congregants' responses to her access needs. Together with other participants' examples of deliberate cultural change in churches, this suggests that is possible for churches to begin to dismantle structural disablist barriers. However, many participants' experiences suggest that this involves active work, rather than being a passive process of rhetorical welcome for disabled people. This study shows that many aspects of church cultures impede the access of disabled worshippers and require proactive labour.

As discussed in Chapter 3, the social culture of churches was a particularly challenging framework of cultural norms for many participants, to which I now turn to theorise in more detail. I consider the structures and functions of church cultural activities, and participants' normative encounters there, through the lens of theories of presenteeism and concepts of interdependence.

5.1.2 Belonging, presenteeism and friendship

Church social groups and events—small group fellowship, post-church coffee, and informal social activities—reinforced church normalcy for many participants. Participants' churches often assumed that a feeling of belonging and shared identity would develop in communities through the committed, regular attendance and involvement of members. This is a form of presenteeism. In occupational studies, presenteeism relates to the level of an employee's "face-time" (Johns, 2010: 206) which actively demonstrates their presence at work. In terms of disability, research has considered the relationship between theories of presenteeism and

> concepts of what constitutes the "ideal worker," identifiable in managerial and workplace discourses and practices, also incorporate assumptions about ableism: where non-disability is viewed as an organizing norm.
> (Foster and Williams, 2014: 2)

Some scholars suggest that the requirement to be present and active in churches is deeply embedded in their cultures. In churches that expect people to take responsibility for their own spiritual growth, they must be *seen* to do this, through social and ritual involvement in church structures (Harvey, 2003). Robert Wuthnow interviews a pastor at a large church who considers that "A person in a small group is going to be growing….God designed us to be in a group like that of some sort" (1994:277). For this pastor, God requires small group membership and normative social involvement. There seems, for participants in this study, to be an ideal church member, who is present and able to join in, a parallel to the concept of the "ideal worker" (Foster and Williams, 2014). This ideal is constructed around a non-disabled, socially active norm. In churches, as in the workplace, this ideal involves ableist assumptions. Many participants desired to fit visibly into church culture, including its social cultures. However, those participants who could not maintain a normative level of church presenteeism, due to impairment effects or barriers in churches, often found themselves excluded from church life.

Prescriptive church social norms were a source of exclusion for several participants. Anthony (individual interview) was particularly concerned about the requirement to be social in churches. His experience was of a church normative assumption that to be social is to be human, and that “there is something wrong with you” if you cannot or do not want to be social, or if your preferred ways of being social are different from the church norm. If the purpose of small groups and social activities is in part to encourage a sense of belonging, particularly in large churches where it is easy to feel anonymous, what happens to disabled people when they are unable to—or prefer not to—participate in these social structures? Relatedly, many churches’ insistence on regular and frequent attendance was a difficult expectation for many participants to manage, often due to impairments that impacted their ways of being social. While not all participants found church social cultures as oppressive as Anthony did, the sense of normative social assumptions and pressure to conform to church social practices was shared by many.

In a related concern, many participants were impacted by churches’ focus on growth, which sometimes negatively affected the pastoral care and support of disabled church members. The church growth imperative, which Marion Maddox (2012) argues is characteristic of churches in late capitalism, had a negative impact for the inclusion of a number of participants in their churches. The aim of church growth may need to be examined in churches where friendship, welcome and support for disabled people are valued. The normative social structure of home groups, with their implied presenteeism and tendency to serve as compensation for large church size, was a cultural barrier to church social life for many participants, affecting their sense of belonging. Some participants’ experiences of not being able to opt out of a home group, where involvement was expected for all church members, suggests that the cell church structure is not always flexible enough for disabled people who need alternatives. For other participants, the cultures of home groups and other informal church activities were inaccessibly audiocentric, or privileged neurotypical social norms that they could not easily access. Yet, for most participants, self-exclusion from church activities was not the answer. Their exclusion from these groups impacted their sense of belonging at their churches, creating a sense of isolation or of distance from church community.

Furthermore, many participants faced issues with disability access to the social gatherings where friendships were developed in their churches. Access was not only relevant to worship spaces: it was important for people to be able to access the social gatherings that can be significant to a Christian's sense of belonging in churches. Where small groups or coffee spaces were held in inaccessible settings, attitudes were communicated to participants about how they were valued and included in churches (see Imrie, 1998). In contrast, an accessible building can communicate inclusion on the level of a perceptual shift of a community, manifested in the environment. As Clare (individual interview) said, people "shouldn't have to ask" for the facilities that enable them to participate fully in church, whether the church activity is worship-focused or social. If disabled congregants find that access to worship spaces is considered more important than access to coffee, it may communicate that their welcome in churches is incomplete and precarious.

For those who were not consistently excluded from small group cultures, the smaller size and relative flexibility of home groups could be a useful pastoral compensation for the problem of large, anonymous churches, which some participants found had a negative impact on disability access. This reflects Balmer's (1993) conclusion that small groups can have a positive impact on pastoral inclusion in churches. Nonetheless, this cannot be taken for granted among disabled people: small fellowship groups are not, as this study shows, a straightforward solution to access issues arising from church size. Many participants met with significant disability barriers to joining in with church activities. Enabling a disabled person to become fully involved in a church may involve many complexities of access that are not simple to resolve, and which are unlikely to be achieved solely through rhetorical and interpersonal welcome, or reliance on informal community support.

5.1.3 Resistance: Challenging disablism and its effects

As we have seen, the disabled Christians in my study used various adaptive strategies, in Foucault's terms, to challenge normative practice and expressions of church institutional power. For Garland-Thomson, the concept of misfitting allows for agency, where disabled people use resistant acts of misfitting to challenge the environment and the ideologies on which its construction is based:

> [A]lthough misfitting can lead to segregation…it can also foster intense awareness of social injustice and the formation of a community of misfits that can collaborate to achieve a more liberatory politics and praxis.
> (2011:598)

There were a number of examples in this study of such creative and activist collaboration between disabled Christians, although many of the participants were isolated in their experiences of misfitting in churches. However, participants often expressed a sense of a broader imagined community of disabled Christians, which some considered relevant for working together towards change in churches. Participants demonstrated a range of creative coping strategies and ways of working around their misfitting, from their positions of divergent embodiment. I will consider this in relation to a number of individual participants and their strategies for achieving a better fit in their churches.

For a number of participants, the sense of an imagined community led them to undertake activism and resistance in their churches. However, activism was not always successful; its success depended on the frameworks used by participants' churches to understand and address disability. Brianna's personal experiences of exclusion gave rise to her activism around accessibility at the cathedral. Yet it was difficult for the cathedral hierarchy to understand that Brianna's position on disability access and inclusion was an activist one, over and above a personal complaint. The cathedral's framework for approaching disabled people was primarily pastoral, while Brianna's was activist; the cathedral's model of disability was individual, while Brianna's was social. As a result, they could only see her campaigning as relating to her, rather than to a wider disabled community. Other participants had more success with activist approaches, where churches worked within frameworks of disability that made space for social or activist models. However, for many, churches had mixed or negative responses to activism and campaigning on disability issues. As explored in the previous chapter, this involves a clash of disability models and frameworks—between churches' pastoral model and some participants' social model or legal models of inclusion. It can be argued that this mismatch will be difficult to overcome, based as it is in attitudes inherent to much Christian theology, which often paternalistically represents disabled people as recipients of care and healing, rather than partners in structural change. This mismatch of models of disability limited many participants who wanted to represent disabled people as having rights of access and inclusion in churches.

For some participants, in contrast, it was important to fit in church as much as possible, and they used a range of compensatory strategies to achieve this aim. The theory of misfitting, with its space for many kinds of strategies used by disabled people living in a society that privileges normalcy, allows for acknowledgement of these active compensatory strategies that aim for a better fit. For Helen, it was important to work towards appearing normal, and not to stand out as disabled. Similarly, James felt that the social difficulties typical of Asperger Syndrome were something to strive to overcome, and gave this his own theological framework. These self-adaptation strategies were active choices on the part of participants, and they used them to feel more included in church contexts.

However, sometimes participants' acquiescence to the disciplinary forces of church institutions negatively affected their bodyminds. At times, Brianna attempted to shape a misfitting bodymind around a cathedral environment that was not built for her or intended for her use, for example, by walking to the high altar despite the pain it caused her. She described being watched without an offer of help as she moved chairs for herself so that her wheelchair would fit into a space that was not officially sanctioned for wheelchair users. As Brianna's example shows, some participants simultaneously wished to fit more seamlessly into church cultures or environments, and continued to struggle against norms and circumstances that were not designed for their divergent bodyminds. Nonetheless, Brianna also resisted misfitting, reframing apparently compliant practices as activism.

A few participants adopted more complex strategies to deal with more direct forms of disablism and negotiate with power. Rhona was regularly involved in difficult negotiations to secure her access needs, which involved self-surveillance and emotional labour on her part. She reframed much of her engagement with psycho-emotional disablism as a response of "graciousness," which gave her agency in these situations, through a Christian theological framework. Brianna negotiated power through emotional labour in relation to her most basic and physical needs, and had to self-police both her affective responses and the timing of practical requests in order to continue to ensure her own welfare and access. Such forms of interaction management can be coping strategies for those negotiating psycho-emotional disablism (Reeve, 2012). Brianna's ability to resist power was dependent on how much she would continue to need bodily support from each different member of the cathedral hierarchy in the future. Similarly, her comment "they're only steps" in relation to having to walk to the high altar, suggests an attempt to rationalise the resulting affective dimensions of the disablism she experienced. Such acquiescence to a certain level of embodied and psycho-emotional disablism was part of her resistance to the normative gaze of cathedral staff. From her disempowered position, Brianna's continued survival within disablist power networks seemed to necessitate working within those structures, rather than fully resisting them. This was the case for a number of participants, who had to engage in emotional labour in response to psycho-emotional disablism when negotiating for essential access to their churches.

For those who wished to do more in their churches than simply be looked after, resistance could require negotiation, involving psycho-emotional disablism and emotional labour. In Zoe and Katie's analysis of power imbalances in churches, they argued that it was important for disabled people to disrupt pastoral norms by modelling active service in churches. Such reclaiming of the right to offer service is a resistant approach to the power dynamics inherent in the pastoral model, where it precludes disabled people from taking on service or leadership roles. However, such resistance places much of the responsibility for pushing for change onto the disabled people who already lack power within this structure. Such a strategy also requires disabled people in churches to become more visible and more confrontational in their interactions, where the pastoral model is at play. As noted above and in previous chapters, this is likely to be particularly difficult for many disabled people in ministry who must pass as non-disabled—or at least, minimally impaired—in order to minister. Such creative misfitting against the pastoral model's expectations of disabled people is one strategy to effect change, but it is likely to be very difficult for disabled people when they are not also supported by structural change within churches.

Furthermore, resistance may be extremely difficult for disabled Christians facing psycho-emotional and other disablism. Clare had no immediate method of resistance when she was asked whether her health condition was "real." Anita Ghai (2003) argues that such epistemic invalidation is frequently experienced by disabled people in a society that values normalcy, where disabled people are expected to allow others to define them and control their behaviour. Behavioural control was in operation through pastoral power in many participants' churches. Resisting such power is often ineffective in this context, as Ghai notes: "the expression of resistance is likely to be interpreted as unrealistic. It will, on the contrary, be constructed as lack of acceptance, unnecessary bravery, compensation or simply ignored" (2003:39). Brianna's concerns about disability equality were dismissed in this way, as unrealistic, irrelevant to church life, and on one occasion, as "brave," an interpretation of an action—walking to communion at the high altar—that could instead have been seen as resistance to power. This patronising response by cathedral staff did double, complementary work: it failed to recognise the structural oppression which required Brianna's bravery, and it re-inscribed a pastoral model interpretation onto the scene. Such pastoral invalidation was an imposition of normalcy that attempted to bring participants' divergent bodyminds into line with church cultures and environments designed for congregants with a more normative range of embodiment. As Clare's experience showed, a single example of psycho-emotional disablism could have a devastating effect on future participation in churches. As a result, while resistance against such disablism was possible, it was often very difficult.

Where resistance to power and disablism in churches became too difficult for participants, one final resistant strategy was to seek another church. Many did not make this decision lightly; they were often very committed to their churches and were sad or frustrated to have to leave. However, it was sometimes the only strategy open to participants. In this situation, participants' access needs were often their priority when looking for a new church. Maria prioritised churches with good toilet provision and other access facilities that suited her needs. When Lucy was seeking a new church, she deliberately avoided returning to those whose worship cultures were stressful for her. Settled in a church that was only partly suitable for her needs, she appeared to feel stuck, unsure whether another church would be any more accessible than her current one. The spiritual marketplace (Finke and Stark, 1988; Roof, 1999) was limited for these and other participants, whose choices of church were, of necessity, based on disability accessibility and cultural inclusion, rather than on other features such as the denomination or theology of a church.

There were a number of other resistant strategies in use among participants. While some resisted normalising environments and cultures of churches, many were daunted by the difficulties of doing so. Self-exclusion was therefore a recurring strategy, with a number of participants withdrawing from church activities where these could not be extended or changed to better include them, or withdrawing from church entirely. A number leaned towards strategies of forgiveness and patience.

However, responding thus was often very challenging, particularly when exclusion continued. Self-adaptation to church settings in which participants misfit was the most common adaptive strategy, used in situations of inadequate access, psycho-emotional disablism, and encounters around the dys-appearing body. Such self-adaptation around misfitting can be a creative resistant strategy. However, Reeve argues that when disabled people force their bodyminds to behave "according to cultural norms of able-bodiedness rather than being free to adopt any mode of behaviour and movement that is 'normal for them'" (2012:88), they remain in a vulnerable and precarious position that exacts a psychological and physical toll. This appeared to be the case for many participants. Nonetheless, for many, the creativity inherent in conscious and resistant misfitting meant that they were able to impact the attitudes and approaches of those around them in churches, sometimes leading to structural change for them and other disabled people in their churches.

5.2 Pastoral Care and the Pastoral Model in Churches

The paternalistic approach of the pastoral model to disabled people had a number of problematic effects for participants. Many of the examples outlined above show participants struggling against the unacknowledged power differentials that resulted from the pastoral model. As already noted, churches' pastoral approaches to disability often clashed with independent living models or disability rights models. For some participants, the pastoral model resulted in inappropriate pastoral care which was overly focused on individual issues rather than structural barriers, as described by a number of those experiencing mental distress and others. For many, the pastoral model's shaping of pastoral care for disabled people in churches resulted in reliance on others. This marked the difference between the interdependency that non-disabled fellow worshippers experienced, and disabled people's forced dependency on pastoral support that was not always forthcoming. In the following section, I consider the implications of the pastoral model at work in church pastoral care, and the ways in which it impacts disabled people's participation in churches, through the lens of disability theory.

5.2.1 Effectiveness of church pastoral support: Dependency and interdependence

There was often a difference between the ideal of pastoral support within church communities, and the reality of this for disabled participants. For many participants, the reality of informal support at their church did not meet their expectations of support in the church community, or met only some of their needs while leaving others unaddressed. Furthermore, for some participants, pastoral care structures were counter-productive for their inclusion. Some experienced well-meaning but obstructive support in their church. Others were concerned that some church pastoral care was actively damaging, for example, for those experiencing mental distress. For many others, pastoral care was insufficient to their needs, and left them unable to participate fully in church.

Some churches met participants' needs through segregated provision of disability support. Such groups may be relevant as additional support alongside church attendance, when church structures do not provide a positive or fully accessible experience for people with some impairments, as WAVE Church's ministry demonstrates. However, it was notable that most of the participants in this study were critical of segregated groups. Groups run by non-disabled people for particular populations of disabled people did not constitute a full experience of church for these participants, and often did not allow them to serve others, only to be served. Segregated groups also further entrenched some participants' concepts of disabled people as objects of care and objects of service in church, rather than its agents. In both Helen and Liz's schema, disabled people were recipients of care and service, while their own self-concept was that they were "ordinary" people who were capable of offering service to others. For them, being *unable to see* did not necessarily make them *disabled*, and this seemed in part to relate to their perception of disability from a pastoral model perspective. Although they were both aware that they had faced some disability-related barriers in churches, they were more focused on the individual factors and qualities that influenced their inclusion in service and ministry, rather than on structural issues. The dichotomy of disabled people as objects of care, and non-disabled people as potential ministers, had an impact on the self-concept of a number of participants who wished to be more active and offer service in their churches.

For many participants, forced dependency in churches was ubiquitous as a result of churches' pastoral model approach to disability. It involved frequent frustration with "having to ask." It may not always be apparent to non-disabled people in churches that disabled people *have* to ask for help, since they do not occupy this subject position within churches. However, participants were particularly aware of the imperative of dependency through their subject position as people made dependent by their churches. To draw on Csordas' theories, their somatic modes of attention remained focused on their bodies, which could not recede into the background even if this is what they wanted. Aware of their marked bodies, they could not pass simply as worshippers, but were instead conscious that they were misfitting, *impaired* worshippers. As a result of this vulnerability, created by inaccessible environments, participants were forced into precarious negotiations with church power in order to secure access to their churches. Here, a fundamental incompatibility between the pastoral model and an independent living access model was revealed. This resulted in clashes of approaches, between disabled people who wanted equal access to churches, and the leaders of their churches, who expected pastoral care to be sufficient to meet the needs of all members.

Some participants' churches aimed to meet their disabled members needs through familiarity and friendship with those individuals, using models of interdependence in churches, which were predicated on the availability of informal support in church communities. In some cases, individual change appeared to follow in churches where churches got to know disabled members as people. This was important to several participants. A few related their positive experiences in their churches to the fact that, because they were personally known there, their impairment needs were understood and met, often informally, by the community. However, as already noted, church cultures of friendship and informal support did not always lead to structural change that better accommodated participants' needs. Rhona, for example, noted how she often felt more welcomed outside her home church than within it, where she was known for repeatedly asking her church to accommodate her needs as a visually impaired person.

Moreover, it is unclear whether positive contact with disabled people led to deep structural transformation in churches, and whether some participants' positive experiences of community support would translate to similar experiences for other disabled people who were less well-known in these churches. Positive attitudes towards an individual disabled person, which lead to better inclusion for that person, are potentially positive only for that individual. Some participants discussed the effectiveness of interdependence in churches, focusing on the structural barriers that pastoral models of informal support did not address. Their reflections suggested that interdependence achieved solely through familiarity and informal support is unlikely to meet the needs of all disabled church members.

Where participants were left dependent on other church members, this led to discussions of theologies and models of interdependence in churches, often designed around non-disabled Christians whose bodies are already sustained by church environments and structures. Where churches create hostile built environments and make normative decisions about their use, the consequence for many disabled people will be vulnerability and dependency in churches. However, participants' own alternative theologies addressed these structural and social barriers; their subject positions as disabled people allowed a clear perspective on the specific ways in which they were made vulnerable in churches. What Katie (focus group 1) called "good models of interdependence" might, she felt, be possible in churches which developed a good understanding of disabled people's needs and marginalisation. She suggested that reducing the misfitting of disabled people in churches would lead to better theological models of interdependency, in which all are dependent on each other, but no one is so dependent that they are left without support. As Katie described it, an alternative model of interdependence would involve "mainstream people [becoming] more aware beyond their own ability," and developing a better understanding of the ways in which church buildings and practices can marginalise disabled Christians. The apparent paradox here is that, in this model, greater independence for disabled people would allow for a more authentic model of *inter*dependency. Rather than the forced dependency of some people on others, it would allow for genuine mutual reliance among all people in churches, without creating a divide between those whose needs are met by the environment and disabled people, whose needs are not.

5.2.2 Disabled people's ministry and expertise: The power dynamics of the pastoral model

For a number of participants, one result of the pastoral model was their silencing and marginalising where they wished to offer lay or volunteer leadership in their churches. The pastoral model in churches is dependent on a non-disabled gaze (Reeve, 2012), which stigmatises participants' non-normative bodyminds in churches. While this is also the case in secular contexts, in many participants' churches a pastoral model lens more specifically positioned participants' disabled bodyminds as objects of care, precluding the offering of service. For some, this involved self-devaluation of their own potential. Hughes posits that disabled people experience ontological invalidation of disability as “a worthwhile existential status” (2007:681). Such ontological invalidation is inherent to the pastoral model, which represents disability as an issue of need and remediation. Meeting with underestimation, some participants either limited themselves, or found it difficult to break out of their prescribed roles as passive receivers. This effect of psycho-emotional disablism had, for some participants, “a cumulative negative impact over time on their self-esteem and self-confidence” (Reeve, 2012:82; see also Thornicroft, 2006). My study shows that disabled people were rarely seen as experts in their own needs by their churches. Zoe discussed this ontological invalidation and devaluation; she described a model in which disabled people are further disempowered in church contexts, where their needs are traditionally met within professionalised pastoral model structures. Examples of this ontological invalidation could be seen in many of the participants’ church contexts, where the pastoral model reinforced some participants’ views of themselves as receivers of service, even if many others resisted and continued looking for ways to serve in their churches.

The difficulty of the pastoral model in adapting to the concept of disabled people as experts in their own needs involves questions of power in churches, and who is able to exercise it. This was evident in the reception by churches to those participants who asserted their own expertise. Participants found they had to manage interactions closely; they were required to do emotional labour (Reeve, 2012) even when they had the necessary expertise. However, disabled congregants who made their own access decisions and requests, rather than allowing church leadership to define their needs, were clearly resisting their prescribed roles within the pastoral model. This could necessitate a relinquishing of power by church hierarchy to disabled people, which was sometimes resisted by churches. Such power relations were at the centre of the difficulties faced by many of the participants who wanted to define their own access needs, educate their churches on disability access or disability theology, support other disabled people, and otherwise share the expertise that they had developed from their subject positions as disabled Christians. The power dynamics of the pastoral model overwhelmingly positioned disabled people as objects of pastoral care, shaping the ways that churches understood and related to disabled people as individuals with the potential to offer ministry and service. In many cases, this potential was overlooked or actively blocked.

In the case of participants with expertise in disability access and support issues, discounting this specialist expertise sometimes left their churches with incomplete or poor disability access. For many participants, their social locations as disabled people were the basis of the unique gifts that they wished to offer to churches as service. However, their churches rarely took advantage of this offered service. Participants' churches appeared ignorant of the wealth of knowledge and skills available to them among their disabled congregants, because they positioned them only as beneficiaries of service and support, rather than as capable of offering it. Participants, in turn, were disempowered by the failure of churches to gain from their knowledge on disability access and inclusion. For some, reliance on pastoral support persisted as a result. Instead, if churches had positioned these participants as people with service to offer, they would have gone on to contribute to improved access and inclusion for other disabled people.

However, despite the barriers to offering service that many participants encountered, a number had unique ministries and service that they could offer to their churches *because* they were disabled. Through creative misfitting, many participants carved out a resistant space in which they could offer their expertise to churches as service and ministry. They showed that they were capable of offering service to their churches, not only in spite of the barriers they encountered, but often in ways that were shaped by and around these barriers. Such creative misfitting is a way of returning the non-disabled gaze (Reeve, 2012) and resisting the resulting ministerial marginalisation that disabled people encounter in churches.

A few participants expressed a recurring theme that "the gifts are our limits" (Zoe, focus group 1). For Zoe, this was key to her theology of dependency and interdependence: a subject position of limitedness *as a disabled person*. This is a specific and different kind of limitedness from that encountered by non-disabled people, rooted in her subject position as a disabled person. Zoe linked this limitedness to the unique ministries and gifts of disabled people in churches, which they could offer as service to non-disabled members. Zoe here offered a new, disability-focused perspective to limits theology, explored further in the next chapter, in which disabled people are active agents of this theology's development in churches. Disabled people's embodied subject positions offer them gifts and perspectives that cannot be experienced by non-disabled people. Non-disabled church members *need* disabled fellow congregants, in order to understand the disabled perspective on limitedness in churches, as much as the disabled people in churches *need* non-disabled people for other insights. This model of theological interdependence, then, reveals disabled people as essential and necessary in churches, with their own active ministries that arise directly from their experiences as disabled people.

5.2.3 Disabled ministers, compulsory non-disability and the pastoral model

If disabled laypeople misfit in churches, this was even more the case for disabled ministers, and yet they were required to maintain a better fit in churches than laypeople. In a number of ways, these ministers and leaders challenged concepts of an ideal cleric who fit into the structures of churches as they are. For many, the result of this misfitting was ministerial marginality (Aune, 2016), where disabled people were less enabled to train and serve as ministers than their non-disabled colleagues. Disabled ministers encountered structural barriers inherent to the occupational and cultural structures of their churches or denominations, because of the idealisation of non-disabled clergy. A number encountered these barriers when considering ordination or training for church leadership, or in churches where it was not understood how they could be ministers. In examples of ontological and epistemological invalidation, these disabled ministers' ways of being and knowledge of their own needs was undermined. Some encountered pastoral model "solutions" to barriers to ordination, which were unhelpful. One such solution suggested to Shona, that she serve as a minister in a Deaf church, was based on pastoral model tendencies towards meeting disability needs through segregation, thus disavowing churches' structural barriers. For others, no potential solutions were forthcoming, as in the example of Andrew, who had to discontinue his training for leadership because cultural barriers impeded his access. Some participants were able to overcome barriers to professional ministry, with support, as in Isabelle's case, or through their own adaptive and compensatory strategies, as in the case of Helen and others. However, many continued to face significant barriers throughout their ministry.

Across the narratives of many of the ordained and professional disabled ministers in this study, the common thread is the expectation of compulsory non-disability (McRuer, 2006). The pastoral model expects that ministerial bodyminds should meet the expectations of a cultural "tyranny of perfection" (Hughes, 1999:159). Ministers should be, or at least appear, non-disabled, not only in order to embody the perfection of God, but also to fulfil adequately the role of pastor to those who receive service. The pastoral model requires professional and other ministers to be physically capable of offering service, and not to require it from others; the reverse can be seen in the narratives of disabled laypeople, explored above, who were only expected to receive the service of others, and not to offer their own. The expectation of compulsory non-disability impacted disabled ministers' embodiment in a number of ways. As noted above, the disabled body in society is a dys-appearing body, a body which is constantly foregrounded where others' bodies are privileged through a better fit, and allowed instead to disappear. In encounters and situations where the disappearance of the body may be considered a spiritual ideal, such foregrounding of the disabled body had clearly limiting effects for disabled ministers. It is through intercorporeal social encounters that the disabled body becomes the focus of unwanted attention (Paterson and Hughes, 1999), in the places where it falls short of the cultural ideal of bodily invisibility. My participants' narratives show how, in the context of these churches' pastoral model, the minister's body was not permitted to be a focus. For these disabled ministers, their dys-appearing bodies continually reasserted themselves, leading to conflict.

In these ministers' narratives, this conflict was often enacted in the buildings of ordained participants' churches. This was especially true of liturgical churches, whose architecture required that ministers be positioned above the congregation, in a space symbolically closer to God than the congregation. Those who could not negotiate steps, or could only enter these spaces with difficulty, misfit against this requirement of ministerial embodiment. However, it was not only architectural spaces that caused the dys-appearance of the ministerial body; cultural and ritual practices in churches had a similar effect. For example, communion practices privileged sighted ministers over visually impaired priests, and physically mobile ministers over wheelchair users. While church buildings were one of the most common sources of misfitting of ministerial bodies, restrictive church cultural practices also constructed the ideal of the non-disabled minister.

As such, many of the participants presented a challenge to this ideal of the non-disabled minister, in churches where disabled people were expected to be receivers of ministry and service in the pews, rather than offering their own ministry from the front. As Katie (focus group 1) said, when disabled people misfit in church traditions and customs, they can be "agents of change," disrupting the idealisations assumed in practices such as communion. In some churches, this led to clashes with power and authority, requiring a standard of fit which not all participants could achieve. Some disabled ministers' insistence on doing things differently meant that those around them had to challenge their own preconceptions of the ideal. However, for many of the ordained and church leader participants, frameworks of compulsory non-disability meant they simply could not fit as leaders. For some, this meant leaving church leadership; for others, it entailed regular emotional labour, negotiations over access needs, and challenging the framework of compulsory non-disability that was ascribed to their position.

Moreover, disabled ministers in this study were often required to pass as non-disabled, or as less disabled than they actually were, in order to maintain an acceptable fit and thus fulfil pastoral model expectations of non-disability. Reeve (2012) argues that passing is an embodied performance which is often the only option available to disabled people: it diverts the non-disabled gaze, protecting disabled people from stigma and invalidation. In the case of some of these disabled ministers, passing as non- or less disabled was a way to deflect attention away from themselves where they did not fit pastoral model expectations. They were able to present an appearance of bodyminds that achieved appropriate disappearance, rather than disruptive dys-appearance. This is certainly not the only possible interpretation of their attempts to reduce the impact of their impairment effects on the congregation: disabled people pass as non-disabled, or less disabled than they are, for a number of societal reasons (Brune and Wilson, 2013). However, it was one factor in their passing efforts. Nonetheless, such passing is stressful, with negative emotional and physical consequences for those disabled people who attempt it (Reeve, 2012; Thomas, 1999). It creates ongoing social expectations of performing a fit, which can be impossible to maintain. In this study, ordained participants often found they were not able to pass consistently, while passing was stressful and even untenable for others. Others chose instead to ask for their needs to be met, even if, in the process, they became known as disabled ministers, with attendant negative consequences. Nonetheless, many disabled ministers in the study felt the need to pass to some extent, highlighting the compulsory non-disability inherent in the pastoral model, and its division between those who offer service and those who receive it.

However, because of the way that the pastoral model constructed the ideal of the non-disabled minister, the impact of disabled ministers for churches was sometimes more significant than that of disabled laypeople. A number of participants described congregants and other ministers learning to “do church” in new ways which challenged the ideal of the non-disabled minister, as a result of their presence and its influence. These participants interrupted expectations of what disabled people can do in churches, and in so doing, resisted the divisions of recipient and provider of service inherent to the pastoral model. They showed that disabled people are capable of offering—and can be enabled to offer—ministry and service to others, even while they are simultaneously its beneficiaries.

Nevertheless, given that pastoral model expectations of ministers were inherent in church environments and practices, the ability to minister was often dependent on attitudes and informal support. Support was needed only from participants’ colleagues and superiors, but also their congregants, all of whom had to adjust their pastoral model expectations and normative behaviour in church in order to accommodate disabled ministers. Some of the narratives discussed in Chapter 4 suggest that congregants are not always willing to do church differently for the benefit of disabled ministers. However, once congregations became more familiar with disabled ministers, there was sometimes more willingness to create change to accommodate them. The pastoral model is inherent not only to church hierarchy, but to the entirety of church structures and cultures. It may be easier for fellow congregants to make changes to church practice and accessibility for the benefit of disabled lay church members than to adjust to disabled ministers, if their expectation is that only non-disabled people can minister.

In my Introduction, I drew on disability theory to argue that the disability industry, through segregation, surveillance and definitional control, disempowers the disabled people with whom it works. A non-disabled professional disciplinary gaze uses these technologies of power to render disabled people’s bodies docile. Parallel structures can be seen in churches, where the power to include or exclude ministers’ impaired bodyminds is concentrated in the hands of church hierarchy, operating through the expectations of the pastoral model. The disabled ministers in this study faced significant structural barriers to accessing their profession, which continued after their ordination. Discussing her denomination's ministry to disabled people, Katie (focus group 1) emphasised the ways in which normalcy is reinforced through the persistent image of a church leader or ordained minister as non-disabled, white and male, with a lifestyle that reflects standards of normalcy. The structural barriers that exclude disabled people from leadership thus also underpin the normalcy of church leadership, in a self-reinforcing cycle. In failing to address the wider social barriers that prevent disabled people from becoming involved in church leadership and ordination, churches maintain the status quo of the non-disabled hierarchy, preventing change to the normative ideal. These frameworks for the social and other barriers faced by disabled ministers will be further discussed in Chapter 6, particularly in terms of the spiritual capital required to become part of church-based networks of theological and practical knowledge and power.

5.3 Welcome Guest or Willful Stranger? Politics of Participation and Transformation in Churches

In Chapter 2, I argued that much current theology of disability invokes concepts of welcome for disabled people in churches. The concept of welcome rests on that of hospitality, the welcoming of the stranger into another's space. In her book *Willful Subjects*, Sara Ahmed deconstructs the word *welcome* in its Old English form into its constituent parts, which combine *will* with *guest*, to argue that "Welcome originally implied a guest 'whose coming is in accord with another's will'" (2014:53). Accordingly, Ahmed contends, a guest must "will in accordance," or risk being seen as a "willful guest" (ibid.) who abuses the hospitality with which they are provided. Here, Ahmed draws on Derrida's concept of "hostipitality" (Derrida and Dufourmantelle, 2000); he combined the terms *hostility* and *hospitality* to illustrate the conditional welcome of the stranger, arguing that hospitality operates on the terms of the host, not the guest. Ahmed illustrates the power imbalance inherent in a system where the host holds the power to welcome the Other into their space:

> [I]n being welcomed the "you" is positioned as not part of the "us," or should we say not yet part. What does it mean, what does it do, for the participation of some to be dependent on an invitation made by others?....If certain people come first—such as hosts, but also parents or citizens—then their will comes first.
>
> (2014:53-4)

In this context, the will of the hosts has precedence over that of the guests, and power lies not with the guest who is welcomed, but with the host.

Disabled guests can only participate in churches as far as they are enabled to by non-disabled hosts. For Ahmed, the welcomed outsider is a stranger at the door, a figure of alterity and liminality. The welcome of the stranger can be performative, where “the stranger becomes a commodity fetish that is circulated and exchanged in order to define the borders and boundaries of given communities” (2013:150). In this context, the welcome of a stranger reinforces “an economy of difference” (2013:151), bolstering existing communities by reinforcing boundaries and barriers of “us” and “them,” and concealing values around who is welcomed and who is not. Peter Melville describes such performative hospitality as a “politics of reception,” also using the image of a door:

> The door…enforces itself *as a limit* by guaranteeing that there is and always will be an outside and that what and whoever is permitted to pass through will be sheltered from the storm…concealed, guarded, and protected from what and whomever is imagined to pose a threat to the safety and integrity of the household….The "open" door…must declare its openness—dis-close, reveal and un-cover itself—time and again to each stranger who happens to arrive and stand hesitantly before it. Forever producing itself in an undisclosed act of disclosure, the “open” door advertises its own impossibility. It must forever speak and re-open itself.
>
> (2003:27)

The protection of the community from threats—including the need to change—can be seen in many of the stories of welcome and unwelcome in this thesis. The concept of the liminal stranger, and the power relations at work in opening or closing the doors to them, is familiar in disability studies, where the permanent liminality of disabled people has been explored (Murphy, 1987; Willett and Deegan, 2001). The performative rhetorical and theological welcome of disabled people into churches, while certainly not intended to be insincere, nonetheless involves politics of participation where non-disabled hosts—church leaders and congregants—control the access and inclusion of the disabled worshipers, who are thus permanent guests.[3]

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[3] Judith Still (2010) argues that hospitality is necessarily temporary, and that there is no such thing as a permanent guest. However, disabled people are permanently liminal members of society (Willett and Deegan, 2001). In this sense, participants’ ongoing dependence on their church hosts, as a result of perpetual misfitting in inaccessible church environments, led to their permanently liminal status as guests, rather than full and equal members of churches.

Many of the participants discussed here experienced such conditional hospitality: a welcome where access and inclusion in church congregations was dependent on the conditional will of their hosts, the overwhelmingly non-disabled leadership and congregation of churches. However, this was not always the case; for some, their experience of inclusion involved church spaces and communities that were reshaped around them to create a better fit for them. In these cases, they were no longer guests, but became part of the "us."

Furthermore, in my view, the pastoral model gives this conditional hospitality a Christian and ecclesial context that further entrenches the role of host and guest, of "us" and "them." I have argued in this chapter that the pastoral model shapes and limits the inclusion of many of these disabled participants, as objects of ministry, contrasted with its agents, who are assumed to be non-disabled. Behind this is an ontological invalidation of disability, rooted in the pastoral model, that rejects disabled people as sources of expertise, activism, change, or ministry. Derrida suggests that the outsider is questioned with specifically *paternal* authority (Derrida and Dufourmantelle, 2000; Still, 2010). Such paternalism is seen in the pastoral model's dichotomy of the active *welcomer* and the passive *one who is welcomed*, the host with agency as compared with the guest who is only partially accommodated. In contrast, models of full membership and enabled participation through transformation may instead move disabled church members from a pastoral position, where they can only receive hospitality, to a role of belonging and co-creation within churches and communities.

As explored in Chapter 2, the pastoral model of inclusion demands that all are compelled to come to the banquet table. However, to return to McRuer's contention, a place at the (banquet) table does not always mean a transformation of the banquet so that all can fully participate. Disability theologian James Metzger draws on the Parable of the Banquet, where guests were "compel[led] to come in" (Luke 14:7-14), to reflect on some of these issues with welcome. As I discussed in Chapter 2, this parable is often quoted as encouragement to bring disabled people into churches. As we saw there, Metzger reverses this common interpretation of this parable, arguing that, in being coerced to come in to suit the whims of the host, "the poor and disabled are stripped of agency and autonomy, an experience not unfamiliar to them" (2010:236). Similar experiences of disempowerment can be seen in many of the participants' stories, for example in their frustrations when their needs were ignored and their expertise invalidated in their churches. Rather than a call for transformation, Metzger sees this parable as representing a form of welcome for disabled people predicated on being required—“compelled”—to come in. This form of welcome requires survival in a church environment that is not designed for disabled people’s bodyminds, in which they misfit. Metzger’s interpretation opens up a new critical space to allow such conditional welcome to be questioned, and to call for alternative, more transformative approaches to church accessibility. When churches aim to include disabled people within *their* spaces, how far do they transform their cultural norms to accommodate others' differences? Pastoral concepts of conditional welcome often focus on bringing people into spaces that are already designed to sustain only a normative range of bodyminds, rather than transforming institutions to make room for diversity.

The church norms described in many participants’ narratives are both spiritual and cultural. They arise from both the built environment and the practices that take place within it. They are often so deeply embedded into church cultures that they are invisible to many, creating subjugated knowledges that are then not always taken seriously within those churches. The church normalcy discussed by participants is precarious, as are all expressions of normalcy (Mallett et al., 2016). Church cultures “sustain” normative bodies (Garland-Thomson, 2011); disabled people’s bodyminds are challenging and disruptive to the way churches operate. As this chapter has shown, the creation of docile bodies, which do not impact churches’ priorities, is thus one way in which church normalcy maintained. As participants’ bodies were discipled by churches, they were *disciplined* by them. This was often an effect of attempts to reduce disabled worshippers’ impact on the aspects of church life that were prioritised: liturgy, worship, or other key activities, dependent on the cultural focus of each church. Church life and culture was easily disrupted by the impact of the “leaky bodies” (Shildrick, 1997) of many of these participants. Any church designed to allow a limited and normative range of bodyminds to enter will face challenges in making more room for human diversity in its environment and culture.

Furthermore, the concept of misfitting shows how such normative environments result in the creation of vulnerability, which is not inherent to bodies, but dependent on whether an environment supports a bodymind, or renders it a misfit. Misfitting is inherent not to a body, but to the socio-political and material worlds that constitute institutions, such as churches (Price, 2015: 273). Unable to fit well in their churches' environments, many participants described finding themselves reliant on the precarious informal support and goodwill of leaders and fellow congregants. Garland-Thomson's theory highlights ways in which, where environments cannot accommodate disabled people and precarious support fails as a consequence, the end result is often the segregation of disabled people. In "the co-constituting relationship between flesh and environment" (2011:594), these buildings and environments give rise to marginalising practices.

Rather than pastoral concepts of welcome and inclusion that are rooted in the theologies and experiences of non-disabled hosts, an alternative model would involve *transforming* churches—their spaces, practices and culture—to encompass the needs and situated knowledges of disabled church members. Addressing church cultural norms may involve significant change for churches in the way that they "do church." Participants' stories suggest that norms in need of transformation may include church service structures, the use of technology in services, sitting and standing during services, sermon delivery and structure, the aesthetics of the service, how post-service coffee is shared and conducted, and the way home groups operate. These structures and practices are bolstered by physical and architectural landscapes of power. Underlying them is church institutional power, expressed through traditional and cultural norms, and church social norms of belonging, presenteeism and particular expressions of friendship. To challenge the materiality of segregating practices may also require cultural change at an institutional level. Furthermore, disability exclusion in churches, as in all institutions, is mediated through social relationships, where built and social environments are used in ways which exclude disabled people. Transformation of church institutional structures will require confronting these power relations wherever they are expressed. More than simply asserting that the gospel is intended for all, a transformation of churches may be able to make the gospel *accessible* to all. Such transformation would require churches to look closely at their practices, asking how far those practices exclude people, and how this could be reversed. Freire's concept of conscientisation is aptly Christian in its metaphors: conscientisation requires new birth, an "Easter experience" (1972:30) where majority society can be transformed by the oppressed.

Thus, drawing on McRuer's theories (2006), conscientisation in churches will involve disabled people demanding access, not simply to the old, currently inaccessible order, but to new and transformed churches. In this study, many participants demanded access to transformed churches, resisting disabling structures and misfitting creatively in them. However, without adequate responses from churches, this was unsustainable, causing frustration for many and inciting some to leave. The conditional welcome into untransformed churches that they experienced was not enough. Instead, the conscientisation of church communities would aim for "extraordinary" and radically changed churches, in McRuer's terms (2006:198), where oppressive cultural, traditional and spiritual practices are disrupted. The result would be churches in which disabled people would no longer be required to fit, or *misfit*, around disabling social and spiritual norms which negatively impact their bodyminds, simply so that they can attend church. Instead, church social and spiritual norms would be questioned and redesigned for the benefit of all, where "all" explicitly includes disabled Christians.

In Part C I argue that such cultural change in churches will only occur if the perspectives and theologies of disabled Christians are taken seriously as resources for transformation. I suggest that listening to disabled people in the churches is central to engaging with disabled people, as "prophetic" voices (Hull, 2014:97), in the transformation of churches. Hull posits that this will involve "a change in the church's understanding of itself and its mission", becoming no longer "a mirror of normal society" (ibid.) but a transformed model of community that is changed from within by disabled Christians. It will also entail allowing disabled people to have their own "distinct ministry" in churches (ibid.). The next chapter will explore some of the ways in which disabled people can be such a resource for transformation in churches, through their own ministries, theologies and active participation in congregations.

Part C: Disabled Christians' Theological Perspectives

Chapter 6. Disability Theologies

This chapter argues that disabled people are capable of being agents of theology rather than its objects, while also considering the barriers that impact their entrance to the theological conversation around disability. To open, I outline the ways in which religious and spiritual capital affect participants' engagement in the theological conversation, in order to identify the institutional and social barriers that prevented participants from thinking about their faith and sharing their ideas about Christianity in theological terms. Second, I consider what disability theology can look like when constructed by disabled people themselves, based on examples drawn from interviews with participants. These include their social theology of the "upside-down Kingdom of God" and reflections on the Bible from positions of identification. Finally, drawing on the theories of liberatory theologians, I reflect on participants' theologies to argue that it is important that disabled people are given the tools to think about Christianity and express their experiences of faith. Problematising the lived religion/elite theology binary, I argue that, because of disabled people's social location, disability theologies will not always be found in seminaries or academic theology books. Accordingly, spaces may need to be created where disabled people may develop their own theologies. In a parallel to Marcella Althaus-Reid's argument that theologians should have looked for queer theologies in salsa bars, I end by considering whether theologians of disability have a responsibility to seek out disabled Christians' perspectives and give priority to disabled people's own theologies.

6.1. Marginalised Lived Theologies: Spiritual and Religious Capital

In Chapter 2 I introduced the concept of the difference between disability theologies and theologies of disability. Where *disability theologies* emerge from disabled people's socially located positions, disabled people are more often objects of *theology of disability* than its agents. As I will outline, Christian discourses dominated by non-disabled people have often spoken about disability, but few disabled people's voices have been heard in this conversation.

Participants reflected on the barriers they encountered that prevented them from developing and sharing their theological perspectives. These barriers were impacted by their religious and spiritual capital: their religious and theological skills and resources. Laurence Iannaccone, drawing on Bourdieu, defines religious capital as: “The skills and experience specific to one’s religion includ[ing] religious knowledge, familiarity with church ritual and doctrine, and friendships with fellow worshippers” (2001:299). Lay consumers are dispossessed of religious capital and thereby inculcated with a particular religious habitus. The laity possesses enough capital to articulate its religious needs, but not enough to participate in the struggle over monopoly and legitimacy (McKinnon et al., 2011:359) in the “competitive symbolic economy” of theology and church (Verter, 2003:150). Both religious and spiritual capital are necessary for entry into the fields of church hierarchy and academic theology, where theological thought is developed and controlled. These concepts overlap, but religious capital is generally described in terms of proficiency in the institutional context of churches, while spiritual capital is about personal mastery of spiritual competencies including “theologies, ideologies and theodicies” (Verter, 2003:159). In this chapter I will primarily be discussing participants’ spiritual capital, or their lack of it, as a set of personal theological competencies in a social context.

Spiritual and religious capital do not exist in a vacuum. Acquiring these forms of capital is predicated on access to other capital, including economic and educational capital. Verter highlights “the fluidity of exchange between economic and spiritual capital” (2003:178) arguing that material and financial resources are needed to engage in religious activity. Bourdieu referred to this as the reconversion of capital (Bourdieu and Boltanksi, 1978). It is well-established that disabled people generally have lower economic capital than others in society, and lower levels of educational achievement are also likely to impact disabled people’s access to theological education. Disabled children leave school with fewer academic qualifications than non-disabled children (Barnes et al., 1999), and there is significant exclusion of disabled people from higher education at all levels (Barnes, 2007b; Morris, 2001; Ralph and Boxall, 2005; Tinklin et al., 2004). Educational capital is thus a relevant barrier for other disabled people with ambitions for entry into the fields of churches and theology. Theological education is an important prerequisite for entrance to church and denominational ordination and leadership, where disabled people may currently be under-represented (Wallman, 2001).[1] Elite economic and educational capital play interrelated roles for those appointed as bishops in the Church of England (McKinnon et al., 2011). More generally, formal theological education has been shown to be a particularly important source of religious capital for religious leadership in some denominations, where seminary education enables ministers to acquire religious and social capital distinct from that of laity (Finke and Dougherty, 2002). Active religious involvement, especially religious leadership, has also been linked with other forms of social capital (Wuthnow, 2002). Limited educational and economic capital are likely to limit disabled people's ability to access theology and other religious fields, as I explore below in relation to participants' experiences.

Furthermore, spiritual capital is embodied;[2] this is relevant to discussions of participants' experiences as they attempted to acquire spiritual capital in order to develop and shape theologies. In Bourdieu's terms, symbolic forms of capital impact the *habitus*, which is a disposition towards the world, an internalised mode of being in a particular field. As Verter describes it: "Internalized and naturalized as a mode of thought and behaviour, the habitus precedes conscious thought, ordering one's choices and structuring one's activities" (2003:154). Thus, the habitus of disabled people may resist shaping into religious habitus. Acquiring symbolic capital into a habitus involves work: it cannot be instantaneously transmitted (Bourdieu, 1986). In churches and in the field of theology, disabled people's religious habitus will be impacted by pre-existing access to other forms of symbolic and economic capital. This has already been seen in the environmental and social barriers that prevented participants from engaging fully in a religious habitus in communion and other worship practices; it is also evident in the discussion below.

In Foucauldian terms, knowledge and power are closely interdependent. In this chapter, I contend that, while the *discourse* of theology limits disabled people's participation, the *field* of theology also functions to exclude disabled people from contributing to it. Given the close relationship of theology and church practice, this

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[1] It is difficult to be certain of the level of underrepresentation of disabled people in church hierarchies, as many denominations do not collect statistics data on numbers of disabled clergy. The Church of England, for example, collects statistics about their ministers' age, gender and ethnicity, but not disability (Research and Statistics, 2018).

[2] In Bourdieu's theory, capital has three states: the embodied, the objectified, and the institutionalised state (Bourdieu, 1986; Verter, 2003).

exclusion from the field of theology and its discourse is likely to impact disabled people’s participation in churches, as already explored in in previous chapters. The relationship between theology, practical church inclusion for disabled people, and spiritual capital will be explored at the end of the chapter.

The concept of *lived religion*—an understanding of religious thought and practice that makes space for those with less spiritual and religious capital—is also central to participants’ ways of thinking about Christianity. Participants developed their theological perspectives often, though not only, in response to the ideas expressed about disability by legitimated sources of theology: ministers, church representatives, writers of theological books aimed at churches, and sometimes academics. Yet their social location was far from that of elite theologians. Meredith McGuire uses the category “lived religion” to discuss the expressions of religion which are lived in practice, by individuals and groups, in contrast with the “prescribed religion of institutionally defined beliefs and practices” (2008:12). Similarly, in the field of academic theology, William Dyrness (1992) uses the term “vernacular theology” to describe the ordinary theologies that people incorporate into their practice. These, he argues, may always not be recognisable as theological frameworks, particularly to those who expect theologies only to emerge from academic institutions and church leadership settings (1992:31). These concepts allow for the inclusion of participants’ sometimes-different ways of thinking about and doing Christianity. However, while the examination of ordinary life as theological is relevant to many of the experiences of this study’s participants, creating such a distinction could itself create an elite/populist hierarchy (Tanner, 1996). This may risk representing disabled people’s religious perspectives as less valid than academic or ecclesial theologies. I reflect on this theological dichotomy, as the background for the valuing or undervaluing of participants’ religious knowledge, below.

Nonetheless, in my interviews, the “lived”—embodied and experiential—theologies created by participants often reflected their socially located positions as disabled people. Following Rachel Muers and Rhiannon Grant (2017), I will go on to theorise participants’ perspectives as *theologies at thresholds*. In the next sections of the chapter, I consider participants’ spiritual capital and its impact on their ability to explore and shape disability theologies rooted in their social location, as well as the barriers they faced to forming and sharing these theologies.

6.2 Disabled People's Theologies and Perspectives on Faith

Finding any Christian teaching and theologies on issues of disability was extremely difficult for many participants. For others, it was difficult to find such materials that were relevant to their church background or accessible to their needs. As a result, some participants were beginning to form their own disability theologies. However, many encountered obstructions to these efforts, and to their attempts to find resources for their theological explorations.

Many participants felt that not enough research had been done into disabled Christians' theologies or experiences. Many were pleased to see that this research was taking place, as a result. In response to my study's research questions, Clare (pair interview 1), for example, said "I think it's just so good to hear somebody asking the question." Her perception was that not enough research had been conducted on inclusion for disabled people in churches, as compared with research into other churches and other social issues:

> I was saying to my housemate, who's older than me and has begun a PhD, and saying this isn't a topic that is spoken about and it's not a topic that I think has been researched about. And it should be….It's the idea that there are groups of people who are struggling mentally—they've researched into that. There are people who have got family and social problems—they've researched into that. But no one's really ever looked at how positively we can include [disabled] people better. That's mad.

Likewise, Helen (individual interview) said that it would be interesting to participate in the research because "it's not something you get many people's views on." Jean (individual interview) said, "that's something that nobody's thought of before," when she encountered the research proposal; this was her reason for taking part in the research. Rhona (focus group 1) said, "Thank God. About time somebody did," of the need for the research, echoing Clare's emphasis on the lack of research on the topic in comparison with other social issues. As a result, some were keen that the results of the research should reach other Christians, so that more could benefit from a process of sharing and developing disability theologies. Clare, for example, suggested that the research should not "stay in the thesis" but should reach churches and disabled Christians. This fits with the aims of this research study: more research on disability and churches, and theologies of disability, should be accessible to disabled Christians. However, while fieldwork suggested that research and other ways of networking of disabled Christians could be sources of spiritual and religious capital, few participants in this study had access to such networks.[3]

Consequently, interviews suggested that it was often difficult for participants to find external resources, such as books, to aid their own thought and theology on disability and Christianity. Some, such as Deirdre, were seeking teaching on living as disabled Christians, and could not find any. Even Katie, as a minister, could not find theologies of disability which resonated with her, and she established a disability theology group as a result. A few were aware of some theology or church teaching that explores issues of disability. Hazel had read Joni Eareckson Tada and was aware of Marilyn Baker, who presents a programme about disability on Premier Christian Radio, because of a childhood friendship with her. Zoe referenced the “disabled God” and appeared to be drawing on Eiesland’s theology (1994) at several points in focus group 1’s discussion; she is a minister with theological training. The majority, however, had encountered very little formal theology or church teaching on the subject of disability at all, while some could not find theology that resonated with their own church backgrounds and wider theological positions. It is likely that much theology and teaching on disability, written for academic audiences, was not accessible or available to many participants. Furthermore, for some, theology and teaching on this and other subjects was not accessible to their disability access needs. Issues of disability accessibility of teaching materials were a factor in Deirdre’s dissatisfaction with Christian teaching on disability, given that she needed audiobooks in order to be able to read, due to impairment effects. She had found very little theology of disability available on audiobook. This was also clear in Lucy’s case, as I discuss further below, where much Christian teaching on a range of subjects was inaccessible to her needs relating to Asperger Syndrome.

Furthermore, a number of participants expressed dissatisfaction with the content of Christian teaching or theology of disability, when they could access it. Mims (individual interview) was unsatisfied with the theologies of mental health that she had encountered. During a discussion about mental health difficulties and theologies of demon possession, she reflected on some theological books she had read, some of which she felt could make church situations worse for people

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[3] As I describe in my Introduction, there is some activity around disability theologies created by the disabled Christian community, for the disabled Christian community. However, these activities and their theologies had not reached most of the participants.

experiencing mental distress. She critiqued the trend towards an uncritical focus on friendship in theologies of mental health and illness:

> When you read the theology, it is really lightweight.…It is all about not being afraid of people and being their friends and being on a level with them and stuff. It is all very nice, but it is very twee. It doesn't get down to any of the—you know.

As a solution for her dissatisfaction with theologies of mental health, Mims proposed more "open discussion" about the range of issues faced by people with mental health problems in churches. This concern about biblical interpretation on the subject of disability was shared by other participants. Speaking particularly about healing theologies, Susanna (individual interview) expressed unease about church preaching on the subject, which she felt "has not always been the best interpretation" of disability.

In part because of such dissatisfaction with teaching on disability, several participants had looked outside of orthodox teaching, and even outside the boundaries of Christianity, to find other theologies or philosophies of disability. For George (Skype text-based interview), Christian teaching on disability was sometimes a constraint that limited her thinking on the subject. In response to one of my questions on healing in heaven, she said:

> [T]hat's exactly the sort of thing I want to be discussing, my entire concept of heaven is based on Christian theology, I think if I understood other religions' concepts of the afterlife that would help me to think outside the constraints of doctrine about what the concept of heaven means for me…but I can't really express this to people at church because it just sounds like I'm drifting away from Christianity in search of some other faith.

For George, the dearth of Christian teaching on disability was her impetus to explore other religions and philosophies. Similarly, Liz (individual interview) wanted to go beyond the "basics" in her understanding of God, and was exploring a pantheistic theology through a local spiritual centre. She was finding ideas there that she had not encountered at her church. However, other participants were seeking more accessible ways to engage with spirituality in teaching or practice from other religions. George felt she was able to connect with God better through Buddhist mantras, in part because they were like a "verbal stim," where "stim" is a term often used by autistic people to describe a sensory-stimulating activity that is calming or comforting. For George, this more interactive Buddhist practice was more accessible to her, as an autistic person, than Christian forms of prayer. Mims was also seeking in interfaith contexts, and found Islam and the Quran relevant to her spiritual framework in a way that she could access.

A number of participants were taking the initiative to look in other new directions for answers to questions on disability and faith, including in secular contexts. Susanna had taken a course on disability studies and had conducted her own research on disability and churches. Encountering a lack of resources on the subject, for Katie (focus group 1) the solution lay in a combination of social and theological approaches. Having spent a long time failing to find what she considered "good" disability theology, relevant to her interest in the social gospel and liberationist perspectives, she eventually co-founded her own user-led disability theology group with friends. One of the aims of the group was to provide opportunities for other disabled Christians to encounter and form their own disability theologies. Here, Katie was drawing on models of engagement from the broader disability movement, departing from the current model of theology of disability developed only in academic settings or for church leaders. Katie specifically noted that she did not have any desire to write a book, saying that "[B]ooks go on shelves and get mentioned in bibliographies and that's the end." Instead, the aim of her disability theology group was to engage with churches and to help disabled people to create disability theology together.

In both the focus group discussions and the one-to-one interviews, theology was constructed *in* and *through* the group discussion, often through participants' reflection on their own experience. The framework of focus groups allowed for in-depth construction of disability theology: participants asked each other questions, recognised diversity in theology among different disabled people, and developed their ideas together. A number of participants said that taking part in this research was their first opportunity to reflect on disability and faith. The value of community in the shaping of disability theology was clearly important to some participants, but few had access to groups where they could discuss these issues. This impacted the ability of some to explore questions of disability and faith as Isabelle (individual interview) noted:

> It's very difficult because I tend to think by discussing things…you can talk about how everybody's bodies are different, but their *characters* are different and that's how it tends to interact. And therefore, it's not a subject

> that you tend to discuss. So, you know, you don't really get the chance. So it's just your thoughts going round in your head.

Likewise, participants often asked to share contact details in focus groups, or to be put in touch with other disabled Christians, and others said it was useful to have an opportunity to meet and share experiences and discuss ideas with other disabled Christians, as part of the research. Miranda (individual interview), who said she was not "heavily into theology," was nonetheless keen to hear the results of the research so that she could hear others' theologies, and she said that talking through the interview questions had helped her to frame her own ideas on disability, faith and churches. Susanna, too, said she had not had the opportunity to consider some issues of disability and faith until she encountered the research questions. Clare (pair interview 1) was particularly pleased to have been able to meet another disabled Christian from a "similar but different church background" for the first time. Outside of the interviews, many met barriers to creating disability theologies together. However, some were working to address lack of contact with other disabled Christians: Faith, for example, was in the process of forming her own discussion and prayer group online, given her difficulties with leaving her house and her subsequent awareness that this situation affected other disabled Christians too.

Whether participants were able to access theology and teaching was often a structural accessibility issue. Lucy (individual interview) had difficulty accessing any teaching and theology at all because church structures did not accommodate her learning difficulties and Asperger Syndrome, which made her feel "like I'm always stuck at the new Christian kind of level of understanding." Lucy was unsure whether churches could do anything to make teaching more accessible to her, perhaps because she had never experienced other forms of teaching. Her access to theologies and confidence in expressing them was affected as a result, though this did not stop her from forming her own disability theologies. For other participants, physical access impacted their access to Christian teaching and theology. In this sense, some surprisingly practical issues became theological. Two participants shared how they were better enabled to access church and teaching through the provision of accessible toilets. As discussed in Chapter 3, the accessibility issue of toilets had a significant impact on Maria's access to Christian teaching and theology. Similarly, Katie (focus group 1) shared a story about how practical toilet needs related to her perceived theological needs, at large events associated with the *New Wine* evangelical network:

> And you think: Oh, need the loo. So you get up on your crutches. You start to walk to the toilet, and all the prayer ministry people are going: Oh, we can pray for her for healing, hurrah. And they all come swamping you. And you're like, no, the biggest need I have right now is a toilet. You can pray for one to come to me.

Here Katie highlighted the absurdity of thinking of miraculous physical healing as a more immediate need than access to a toilet. The structural issues preventing Lucy, Katie and Maria from accessing theology, in the case of churches and Christian festivals, were very practical. This is rarely reflected in theologies of disability.

Other participants' access to theology and teaching was restricted by the social impact of disability. Rhona discussed the social impact of poverty, another structural disability issue that might prevent some disabled people from accessing the settings where theologies of disability were being developed. She was hoping to attend a Methodist conference on issues of mental health, but could not afford to. For Rhona and Katie (focus group 1), the barrier of poverty was central to the access of disabled people to the field of theology:

> Rhona: How much are the tickets? Residential—now bear in mind clergy who are going probably get paid for it, but the laity, you know. So anyway, £150. Now you've got me, who's obviously on benefits. Therefore I haven't got the money. Therefore I can't find £150 up front. But I can pay a deposit and then pay it up in instalments....[They said] No. Absolutely not….I said: Well, you know you realise mental issues often go with low earning potential. Therefore you're going to penalise the very people—unless you want it all to be the professionals. The white middle class intelligent professionals....You've got the double problem of poverty with disability I think.
>
> Katie: …There is a bias in all of these things that actually the people who are going to be able to come to these, because they can afford to, or are able to do it without too many hoops, are the fit, healthy, able, middle class, probably white men....And who can then go back and minister to these disabled people and mental health people. Rather than it being the very disabled people themselves turning up—
>
> Rhona: Who have got their own stories to tell that would probably be more beneficial than any lecture.

In Rhona and Katie's view, disabled people were being excluded from disability theology not just by the social structures of disability, including poverty, but by the unwillingness of churches to recognise these barriers and remedy them. The churches, in this picture, are complicit in the social oppression of disability that prevents disabled people from creating their own theologies. The group here began to develop a socially-located theory of disability poverty and its impact on disabled people's access to disability ministries and theologies. This theory formed part of the group's broader thought on the "upside-down Kingdom of God", as I explore further below. This was one of several discussions about the impact of the social location of disability on access to the contexts of theologies of disability. This impact is relevant wherever such theologies are developed: in academic settings, in professional conferences and training, or in seminaries and by ministers who have been trained there. Yet, as Rhona and Katie asserted, if the stories of these disabled people can be heard, as contributions to disability ministries and theologies, they may be "more beneficial than any lecture" from professional non-disabled people. Social location matters to disability theology, they argued.

Participants widely varied in confidence levels in developing disability theologies, as a result of the issues explored above. A number had explored or even created alternative disability theologies, but were not sure how to relate these to orthodox theologies. However, some participants were much more confident in expressing their own theological views. Most often, assurance in sharing opinions on faith was seen from those with theological training and ministers. However, confident critiques of churches and theologies of disability also came from some laypeople and those without theological training. This included Anthony, who critiqued churches' approaches to autism, and Mims, in her concerns about theologies of mental health. On the whole, however, many lay participants seemed nervous or reluctant to express their divergent or original theologies. Yet they were often capable of forming theologies, despite this lack of confidence, especially when encouraged by open discussion with other participants. One example was Lucy (individual interview) who offered an original idea about healing in heaven in relation to autistic identity:

> I have thought about [healing in heaven] actually. I didn't work out what the answer was. But I think I came to a middle where I thought that there'd either be healing or it wouldn't be a problem. So, you know, other people's attitudes or whatever it is that gets in the way….I don't think all disabilities are necessarily a problem. So if they're not a problem, why would they be fixed? Because a lot of [diagnoses], it's just a word to describe something that's a bit more than your character, but it's related to that....It's more other people that—If other people's imperfections get in the way then it might be those that are changed.

Despite Lucy's lack of self-confidence, her theology of healing and transformation in heaven was shaped by a creative and adamant social model interpretation of eschatology. Similarly, Miranda made statements on the Bible and healing which formed coherent and resistant theology, though she expressed concerns about her right to interpret the Bible differently. A lack of confidence did not mean that participants did not have theologies to express. However, the range of social structures preventing disabled people from accessing theology seem to have affected some participants' *willingness* to communicate their own ideas about faith and God, or to frame them as theologies. This was especially the case where they perceived their theologies as unorthodox or different. Because theologies shape disabled Christians' lives, their own theological perspectives and strategies for forming them are important. The following sections of this chapter will explore two of these theologies: participants' socially located responses to the Bible, and their theologies of privilege and marginality.

6.2.1 The Bible and disability: places of identification and experience

Many of the participants expressed theological positions on the Bible, even though not all participants were confident in these. To some extent, this reflected these participants' relatively low religious and spiritual capital, explored shortly. Nonetheless, where participants were seeking theology relating to disability, they often looked for this in the Bible, searching for reflections of themselves that made sense of their experiences as disabled people. This was despite a lack of access to elite theologies, as discussed above, and was often because of dissatisfaction with the teaching on disability that they had heard from pulpits or read in Christian books. Many participants drew on their own experience as a source of reflection on faith, especially where they had little familiarity with academic theologies of disability. The result was a range of different responses to the Bible, all embodied and experiential.

Participants often sought images in the Bible to which they could relate from their social location as disabled people. Participants had creative and resistant approaches to biblical reading: they spoke back to the ways in which the Bible had been used to define their experiences of disability. In these interpretive approaches, participants often communicated some awareness that current hermeneutic and theological representations of disability were of limited use to them, while still acknowledging the power of the Bible in their lives. In Chapter 2 I argued that the Bible has been interpreted and used in modern churches and theologies using a "normate hermeneutic" (Wynn, 2007:92). These biblical interpretations reflect and reinforce modern social norms and concepts of disability, even though the concept of disability is anachronous to the contexts of biblical texts. Many participants had encountered normate hermeneutics used to justify certain healing practices or to spiritualise disability as an object lesson in church teaching, and wished to express divergent views.[4] Betcher argues that, despite Christianity's longstanding use of disability as a metaphor "to think with" (Betcher, 2007: 59), this does not mean that Christianity represents disability; rather, it uses disability as a representational tool to communicate spiritual messages—as a narrative prosthesis (Snyder and Mitchell, 2006), as I discussed in Chapter 2. In contrast, many participants sought alternative, authentic models for their lives a disabled Christians, finding them in their own interpretations of the Bible.[5] Eiesland calls this process *resymbolisation*: the active reclaiming of biblical symbols that have been used to represent disability in the past, and the search for new symbols to represent the experience of disability. Three key strategies for resymbolisation in biblical interpretation emerged in interviews. Following Elisabeth Schüssler Fiorenza (1992), these strategies can be identified as: imaginative identification with disabled characters, the examination of biblical ideological inscription on disability, and resisting normative readings by making disability the centred subject of biblical interpretation. In imaginative identification, interpreters tell stories in new ways, identifying with marginalised characters—in this case, with disabled characters. In examination of ideological inscription, normative ideologies and social relations in the Bible are uncovered. Resistant readings shift the subject of biblical interpretations, focusing on the effects of the text on marginalised groups—in this case, its effects on them as disabled people. While participants did not name their strategies of biblical reading in this way, they

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[4] Participants' general theological approaches to the Bible varied, sometimes as a result of Christian tradition or denomination; for example, they expressed varied levels of biblical literalism or liberalism. However, their socially located readings led many to perspectives on the Bible which were not always predictable by church background.

[5] While a few participants took the rejectionist view that the Bible was not relevant to disabled people in late modern society, as discussed below, most took redemptionist or historicist approaches (Avalos, 2007b) as a starting point for their own hermeneutics. While Avalos' tripartite structure of disability biblical interpretation (see Introduction) is relevant to theologies of disabled participants, few were limited to only one of these perspectives. They were more often engaged in socio-political readings of the biblical texts, using strategies such as redemptionism to support these readings.

often engaged in these critical reading processes. In what follows I discuss how participants used these creative and resistant strategies towards the Bible, and the barriers to doing so, for some.

Most participants engaged critically with the Bible and its uses and representations of disability, to varying degrees. Some participants took a broadly rejectionist strategy towards the Bible's representation of disability, influenced by their social location as disabled people. Lucy (individual interview) highlighted the vast difference between her life as an autistic person in late modern society, and the stories in the Bible. I asked her whether she found anything useful in the healing narratives, as an autistic person:

> It was a really different time when the Bible was set, so…I don't want say not relevant because that's not what I mean, but…I don't think it's that helpful to now because it was a really different time and people now wouldn't have the kind of problems that people then would have as much. I don't mean the physical problems. I mean, you know, access to stuff. And a lot more people can live for themselves now, whereas then they'd be completely reliant on other people….So I just don't think they're relevant now.

In Avalos's terms, Lucy here used a historicist strategy towards representations of disability in the Bible. She was not arguing that the Bible *as a whole* was irrelevant to her, but that it was rarely socially relevant to her position as a disabled person in late modern, Western society. Similarly, Miranda, who was familiar with the Bible as a Franciscan Tertiary, felt the Bible had little to say about disability, or to disabled people. Other participants' rejectionist approaches to the Bible involved criticism of its use in churches without considering the weight of ideological inscription. Mims challenged uncritical uses of the Bible to represent mental health problems, in some churches, which she considered dangerous. It was difficult for these participants to identify with the Bible from their socio-political location as disabled people, since its historical explanatory models differ from the models and social contexts of disability with which they were familiar.

Some participants expressed concern about the way that Bible passages have been used and interpreted on the subject of disability. Here, imaginative identification with biblical characters often allowed them to uncover disablist biblical ideological inscription, including the spiritualisation of disability as a "metaphor to think with" (Betcher, 2007). Hazel (pair interview 2) reacted to a particular use of blindness as a spiritualised metaphor:

> Well funnily enough, the end of the sermon this week was about Jesus healing a blind man. And I had to laugh because [the minister] said, "You've got to remember this man was blind and what trust he had. He threw down his cloak. He was never going to find it [again]. The man was blind." There's me and [my husband] sitting there....I just sort of laughed, you know, and I said, "Well, you'd be surprised."

For Hazel, this interpretation's spiritualised illustration of disability was irrelevant to her experience as a blind person. Hazel's response was embodied and experiential: as a blind person who is able to function in the world, she recognised the misrecognition of Bartimaeus' situation. A number of other participants also found it difficult to relate to over-spiritualised use of biblical narratives to their real experiences of life as disabled people. Victor said he always wondered how they got the paralysed man up to the roof in Mark 2, when the man was severely disabled; Miranda had a similar imaginative identification with this figure. The paralysed man's *access* as a disabled man became the subject of their interpretation, in resistance to the mainstream interpretations they had encountered, which merely used him as a spiritualised metaphor for Christian experience.

To reclaim biblical texts for the use of disabled people, participants often shifted the subject of interpretation towards disabled biblical characters. As part of this process, participants examined the effects of the text on themselves as disabled people, and sought alternative models for disability. For example, Katie and Zoe (focus group 1) used biblical texts to critique the ways in which biblical narratives have been used as models for healing. Their interpretation of Acts 3, Peter's healing of the lame man at the Jerusalem gate, soon after the ascension of Jesus offers an example:

> Katie: When Peter and thingy go to the Jerusalem Gate after the whole Easter stuff had been going on....And they turned up and see a load of cripples sitting by the side of the road. So clearly Jesus did pass them....You know, he hasn't done anything, he's been useless. All those cripples left around—
>
> Zoe: Where physical healing was clearly not the objective otherwise he'd have had a far more systematic approach.
>
> Katie: Exactly—he'd have been far more thorough, wouldn't he?

Katie here signalled a shared insider space with Zoe in her use of the disabled community-reclaimed term "cripple." A creative, disability-focused reading emerged through their shared social location, moving the subject of interpretation away from Peter the healer, to the disabled characters who had not received healing. Later, Katie used another example where she again shifted the subject of interpretation to the experience of a disabled character, this time to make the theological point that physical healing, for disabled people, is often partial and difficult: "Jesus didn't heal everybody he met. And in fact [with] one guy he had to have several goes at it because something wasn't right." This original, experiential reading of the biblical text (Mark 8: 22-26) was informed by her encounters with churches which focused on miraculous and biomedical forms of healing, resulting in an encounter between Katie's socially located reality of disability and what she perceived as the unreality of the Bible's representation. In traditional readings of this biblical narrative, the presence of disability in the story is often used as a narrative prosthesis: the disabled man's purpose in the text is simply to be healed, as evidence of God's power, or as a metaphor to show how Jesus' disciples moved from ignorance of God into enlightenment (Hull, 2013: 25-6). Katie's imaginative identification with the healed man allowed her to resist this normative ideological inscription. In communal readings of the texts as alternative models for disabled people's experiences today, these participants used biblical healing narratives not just as parables, but as theological models for disabled people's experience. In reclaiming agency for these overlooked subjects of the biblical text, they became theological agents themselves.

In the search for alternative models for disability in the biblical text, other participants also positively imaginatively identified with the story's protagonists. They represented biblical characters not as metaphors for spiritual messages, but as real disabled people with parallel experiences to their own. Mims (individual interview) sought to identify the voice in the Psalms and the writer of Job as figures experiencing mental distress, with whom she could identify:

> I also find Job really helpful, you know—what he has to go through and comes out with....Some of the Psalms as well… there was clearly distress, anguish—you know, there is a real anguished voice in some of the Psalms that I find real comfort from.

She also identified with Jesus on the cross:

> I think with mental health, one of the very special things is that Jesus can't

> have been on the cross and not had a mental health problem. When he says, "Father, Father, why have you forsaken me?" That is a bit of paranoia that he is not there anymore isn't it? You know? That is a sentence of paranoia.

In her interpretation, Mims' experience paralleled that described by Hull in his "open letter to Jesus" (2013:13), in which he reflects on places in the Gospels where Jesus' experiences of crucifixion intersect with his own experiences of blindness. This opportunity for identification with Jesus was clearly important to Mims, signalling her resistant willingness to identify with potentially-disabled characters from biblical narratives in defiance of their more common use as narrative prostheses.

Not all participants were interested in resymbolisation or resistant readings of the Bible in relation to disability, preferring to affirm mainstream or normate hermeneutics in their reflections on the Bible and disability, and taking a more literalist approach to the Bible than other participants. However, even those who read the Bible more conventionally used strategies such as redemptionism with these readings, centring interpretation on figures from biblical narratives that spoke to them as disabled people. For example, James (focus group 3) imaginatively identified with Moses as an example of God's care for all people including disabled people:

> What I found interesting actually for me, like in Exodus when God is speaking to Moses from the burning bush. When Moses is saying: I can't do it, I can't go to Pharaoh and tell him what you're asking me to tell him. And the Lord actually says through the burning bush: Who made you? Who made death, life etc?[6] There's so many different ways the Lord could have said that. But he chose to use that specific example….Because, you know, it does show that God is actually proud of all his creation. He doesn't set the limit anywhere. He says: Look, I care for all of these people, so you should too.

While James often reaffirmed literalist readings of the Bible, in his imaginative identification with Moses here he interpreted against the grain of common readings of the Bible and disability, to make a counter-normative argument that God values disabled people as they are.[7] His other readings of the biblical text tended to reaffirm disability's teleological origins in the Fall and the importance of healing. Such complexity of biblical interpretation, with each participant holding a range of views

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[6] James asked me to clarify that he was citing Exodus 4:11, which in full reads, "Who gave human beings their mouths? Who makes them deaf or mute? Who gives them sight or makes them blind? Is it not I, the Lord?"

[7] Nonetheless, in post-interview communication about the interpretation of his words, James asked me to reaffirm here that he believes the cause of disability is the Fall.

on disability and the Bible, was not unusual among the participants who discussed the Bible. Participants' complex social locations, as disabled people but also as Christians and encompassing other identities, was often reflected in the ambiguity of their interpretation.

However, the extent to which participants were willing to engage in resymbolisation strategies was often determined by their varying levels of confidence in their approach to the Bible. On subjects where a hegemonic theology had shaped the views of the non-disabled people they encountered, such as on the subject of miraculous healing, a number of participants were anxious or insecure about their own positions. They did not always trust their own theologies as much as external sources of theology and hermeneutics. However, they nonetheless often held confident counter-normative positions on the Bible. When Miranda (individual interview) reflected on what she personally believed the Bible says about healing, she was confident in expressing her divergent views: “Are we sure about this? How do we know?….[W]here does it say in the Bible? I'm not convinced it says in the Bible, we will all be healed when we get to heaven.” But when describing how she tried to discuss the Bible and healing with her friends, she expressed a lack of confidence in expressing the right “answers”: “But no, I just—the healing bit—I suppose I could get panicky over it when people—and I'm not good on the answers.” While Miranda seemed intimidated by those with different views on the Bible from hers, she was clear on her resistant reading that she would “still be in my wheelchair in heaven”, challenging the normative hermeneutic expressed by her friends. Lucy (individual interview), similarly expressed a lack of confidence in her knowledge of her faith. Yet she too was able to express resistant readings of the Bible in her argument that she would be autistic in heaven, as discussed above. Both resistant readings protested what Hull calls “eschatological visions towards the singularity of the average” (2013:68). Lucy and Miranda were both able to express their own opinions on the Bible, but they were hesitant to do so, in part because of their awareness of their lower religious and spiritual capital as compared with some other Christians.

6.2.2 Disability theologies of privilege and marginality: The "upside-down Kingdom of God"

I was talking about this upside-down Kingdom [of God] and how we meet Christ in each other and usually in the places we'd rather not look. In the margins.

Zoe, focus group 1

In the context of disability and beyond, many participants discussed issues of power, privilege and liberation for the oppressed. However, these were not usually represented as purely secular issues. They were most often placed in the context of the Christian tradition of the social gospel and Christ's concern for poor and marginalised people. Zoe coined the term "the upside-down Kingdom [of God]" for this concept of a society organised according to God's values. The phrase was echoed by others, often in relation to disability specifically.[8] This social gospel, with its impact for disabled people, was discussed by participants from several denominations and across evangelical/liberal divides. However, it was explored in particular detail in focus groups 1 and 2, where longer interview lengths and group discussion allowed for deeper theological reflections. These groups discussed how, in their perception, their churches were not challenging social values and hierarchies. They related their alternative theologies of brokenness and of the upside-down Kingdom to churches and their practices. Some participants proposed alternative models of church and theology, which they felt would lead churches to address privilege and transform wider social values. In this sense, they saw disability as only one part of a broader social system of privilege and oppression in which churches were implicated.

It was particularly in the context of the "disabled God" image (Eiesland, 1994) that focus group 1 reflected on this "upside down Kingdom" social theology.[9] In the extract below, the group members can be seen developing the theology of the disabled God in new directions:

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[8] Participants often drew on a social gospel and liberatory theologies to explore this issue, although not all of them had access to academic liberatory theologies. A few were able to relate their social and liberatory theologies to other classical theology. Andrew spoke of encountering Martin Luther on the "suffering Church" and the "invisible Church" (focus group 2). Few participants were able to make such connections to theology, however. The ability to draw on academic theological models depended on participants' social and educational capital, such as knowledge of church history.

[9] The phrase "upside-down Kingdom [of God]" was coined by Zoe, in focus group 1, with input from Rhona, Katie and the other members of the group. Not all participants had encountered Nancy Eiesland's theology of the disabled God; several who explored models of the wounded or disabled Christ did so without explicitly knowing about similar critical disability theologies.

> Katie: I'm 40, and it only occurred to me a year ago that when Jesus comes back from the dead and knocks on the locked door and walks straight through it and goes, "Hi, surprise, don't be afraid"—
>
> Rhona: They were enjoying a nice Chablis—
>
> Katie: That's right, having a nice Chablis and a quick chat upstairs. And…he comes back with all the wounds. He comes back as God.
>
> Zoe: Disabled God.
>
> Katie: To the extent he can say "Stick your hand in my side."
>
> Rhona: The marks were still there.
>
> Katie: So he comes back with all the wounds still on his body. He comes back disabled.
>
> Zoe: And the revelation of God as Christians believe it—I think we forget, it was not—the book isn't the revelation, it was a person, and somebody with hideous wounds. It was a broken person with the revelation of God. We like to jump to the resurrection…the resurrection is meaningless unless the crucifixion has happened.

It is significant here that the focus group cooperate in a re-telling of the embodied encounter of the disciples with the risen Christ (John 20:19-29). This is in contrast to the way the image of the disabled Christ is used in some academic theology of disability, using the image of a scarred Christ already ascended to the throne of God (Epperly, 2003; Swinton, 2011; Yong, 2007), distant from humanity and, accordingly, perhaps more difficult to identify with as a (disabled) human being. Instead, this interpretation is comparable to the disability theologies of Eiesland (1994) and Hull (2003a), who explore the image of the scarred Christ in his newly risen encounter with the disciples. The focus group's interest in the disabled Christ similarly focused on his embodied, human encounter with ordinary people who can touch his scars. For Zoe, this is the revelation of God to his people: an unambiguously "broken person" who was nonetheless divine.

Later, the group discussed their interpretation of a resurrected-yet-broken Christ as a resistant reading of the biblical text, against the grain of the Christology that they had encountered in many churches:

> NJ: Do you find that [disabled God theology] reflected at all in things like sermons?
>
> Katie: No….Most sermons that I hear are generally very upbeat and very, 'God is good'. And not many deal with—they skip straight to the resurrection really. The gloriously risen, ascended, glorified…

> Zoe: Well, I think the triumphalist stuff is so—Hymns or songs. So much of it is triumphalist, victorious, imperial. And I have a real problem with that as well.
>
> Katie: Yeah, the power of Jesus which isn't in brokenness. It's in defeating death.
>
> Zoe: Well, and you know, all the iconography that we have…it's shiny, it's perfect, it's robed in gorgeousness.
>
> Rhona: But you need that as well to lift your eyes. So it needs to be a balance.
>
> Zoe: …Yes you have to walk the whole road….But if we don't talk about all the other stuff as well, it's meaningless.

Katie's central juxtaposition here was of the glorious, risen Jesus versus a broken, more human Jesus. For Zoe, this was more than just a Christological difference. Speaking back to theologies which represent the risen Jesus as traditionally powerful and physically perfect, she asked whether God's power could also be encountered in the brokenness of Jesus. It was *in* the brokenness of the crucifixion that these participants encountered Jesus' divinity, in an imaginative identification from their social location as disabled people. Yet, particularly for Zoe and Katie, their experience was of churches that "skip[ped] straight to the Resurrection," rather than taking a "journey" through the crucifixion. Their challenge was for churches to confront a wounded, marginalised and disempowered, yet still *divine*, Jesus. This was a Jesus in which they saw their story, as disabled people, reflected.

Through a story about an incident while she was preaching, Zoe (focus group 1) explored this "triumphalist" theology further, representing the "upside-down Kingdom" as its opposite:

> I used some of the images of Jesus...*The Christ We Share*…[10] And I tried really hard to not go too mad on the disabled—but I deliberately chose different ethnicities of Jesus....But there was also an angry Jesus. And because I was talking about this upside-down Kingdom and how we meet Christ in each other and usually in the places we'd rather not look. In the margins. And as I finished I had a full on heckle, I had a "Rubbish" shouted from the back. And then after the service a man came charging up to me. "Not one word out of your mouth. It's all about you isn't it..." But the idea of the Kingdom of God being that journey....Beauty for brokenness. And the opposite of empire. Oh, and I'm going to continue to upset that man every time I preach in church….we will always disagree, it seems. It was upsetting.

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[10] *The Christ We Share* is a resource pack for churches created by the Methodist Church (2004).

Zoe used the images to suggest that Christ could be met in the margins and among unfamiliar, Othered bodies, creating a *rapport de face à face* (Levinas, 2011 [1985]) with these marginalised Others through Jesus. She gave these images further authority by including an angry Jesus, representing Christ as both the face of the Other and the face of the judge of those who marginalise others. She seemed already aware of the potential for resistance to this theology, and its association with her own social location, as suggested by her half-statement that she tried to avoid the over-use of disabled images of Christ. In this encounter, there is a suggestion that it may be difficult for a disabled person, in particular, to challenge imperialistic theologies, due to their social location, a point I return to shortly.

However, participants did not just stop at a purely theoretical consideration of the "upside-down Kingdom." For a number of participants, theologies of liberation and brokenness spoke to their social experience of disability in the world.[11] Andrew and Faith (focus group 2) developed a practical social theology of non-disabled privilege in churches:

> Andrew: Deaf people talk about hearing privilege. So the church is very much a hearing dominated—and the way it's structured. Like we talked about small groups, preaching—but there's a hearing privilege there which if you're deaf you don't have....What I feel the church should be better at is understanding people who aren't in positions of privilege and seeking to address this....But my observation is that quite often the Church follows what the privileged society wants….What people in privilege do, they set what's normal for society and everyone else has to fit around that. But privileged people don't see it because it's just normal. They don't think about it. And I feel the Church tends to swallow privilege. In the sense that most people seem to be blind to it. So I always feel that's something that reflects poorly on the Church. I think if Jesus was here I don't think he would be going along with what the privileged did. I think he would be interested in people who are on the margins of society. You know, people who haven't got privilege.
>
> Faith: Because he went to people's homes, didn't he? He didn't stay in one place all the time.

Both Andrew and Faith reflected on privilege in churches from their social and embodied location as disabled people. Faith's comment reflected the systemic barriers that she herself was facing, unable to find a church because she was rarely

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[11] Liberatory theological frameworks were applied to social experiences of disability both by the small number of participants who had explicitly encountered academic liberationist theologies, and by a larger number who had not, but were still aware of a social gospel.

well enough to leave her house. For her, Jesus's ministry to the oppressed was radical in literally meeting people where they were. From Faith's perspective, the privilege of mobility, which enabled Christians to reach the location of worship, was a privilege that churches were not addressing. This perspective was rooted in her direct experience of disability, a perspective which, as Andrew said, could be invisible to those in churches with privilege. Furthermore, Andrew associated privilege with prosperity theologies and the church growth imperative, and was concerned that churches were not seeking alternatives to paradigms of expansion and material success. He linked these prosperity paradigms to church healing ministries, critiquing these as an attempt to change bodies rather than addressing social inequalities and barriers:

> [T]hey want to solve your problem. But…actually I believe that the church should be, not trying to pull people up so we're all in the same privilege but actually should be finding a way of…breaking down those barriers really. Whether that's a physical access barrier, whether it's a cultural barrier or a language barrier. But that doesn't seem to be—the Church is more about numbers, you know—the new building.

Andrew saw a lack of challenge in the churches to compulsory ableism, in ideas that parallel disability theories (Davis, 1997; Goodley, 2014; McRuer, 2006). Andrew's alternative to prosperity theology was a Jesus of the social gospel, concerned with marginalised people and providing a counter-cultural alternative to hegemonic social structures that promote compulsory ableism.[12] Andrew's contention that privilege is unseen by those who have it, cited above, highlights the importance of socially located disability theologies, centring the perspectives of disabled people. Similarly, for Charlotte (focus group 2), spotlighting the social locations and perspectives of disabled people was a Christian principle. She used the biblical model of Christ as authority for this approach:

> Christ often asks: What would you like me to do for you? Does the church ask us what we'd like the church to do? Not so much.

For Charlotte, while Jesus centred the needs and interests of disabled people—took their side, to use a disability research concept—churches do not always do the same. She and a number of other participants presented a theological model of Jesus's

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[12] Andrew did not talk about Jesus' ministry to the "poor," where biblical and late modern concepts of poverty could be too easily conflated, as I discuss in the final section of this chapter. Instead, his focus remained on the modern social concept of privilege and the systemic barriers it creates.

concern with the perspectives of disabled people, which was influenced by disability studies and activist paradigms, but was also uniquely Christian and theological.

Charlotte considered social norms of disability together with other, broader social norms, opposing these to Christian values:

> My church has just written a Lent book [with contributions] from each member of the congregation. And the reading that I was given to write about was a bit from Deuteronomy…where God says, "I give you a choice between life and prosperity and death and austerity." Not austerity, I can't think of the word….Anyway, death and really terrible things. In my reflection I was saying: Well, in society then people would look at that as, sort of, being wealthy….And I'm not sure that God does see it that way. Maybe God's prosperity is different….I think it's more about love and empathy.

Charlotte set up a binary opposition between different models of prosperity, contrasting society's focus on wealth with God's different form of prosperity. Her lexical shift, from "that says" to "God says," emphasises the authority of God in this opposition. For her, God is on the side of the marginalised, in a sense that reflects Liberation Theology's prioritisation of the poor. Furthermore, like Andrew, Charlotte contrasted God's counter-cultural values with church growth models. In response to Andrew's discussion of the evangelical church growth imperative, I asked whether Anglican participants felt the Church of England was less concerned with numbers of congregants. Charlotte responded:

> Yes, though there are bits of the Church of England in some of the reports that have come out recently. They're talking about successful churches being about great numbers and things. But I don't think it's necessarily the case. I think if you look at the Gospels and what Christ is saying. Christ is there for the poor or the marginalised….I really think that it's important to be alongside people where they are, and not to conform to society's norms. To be counter cultural because that's what the gospel is. I think there's a great danger in the prosperity gospel in that it makes people think: Well, if things are going wrong in my life it must be because I'm not worthy of God's love and God doesn't love me anymore....And I think that's a really dangerous thing.

Again, Charlotte drew on theological knowledge to represent an opposition between the values of a prosperity gospel and the position of the marginalised.[13] Like

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[13] Charlotte's access to such concepts as the social gospel and Franciscan theology came from her experience as a Franciscan Tertiary and chaplain. Theological experience was a commonality between participants who discussed the "upside-down Kingdom," more so than evangelical or liberal theological perspectives, or church denominational backgrounds. Access to academic and ecclesial theology was particularly important in being able to express broader theological issues relating to marginality and the social gospel in churches.

Andrew, she associated both a church growth imperative and the prosperity gospel with the norms of society. She suggested that disabled people and other marginalised people might be excluded from churches with a focus on growth and prosperity.

Many participants did not wish to stop at theory, but wanted to see practical church applications of the social gospel and theologies of the "upside-down Kingdom." Some were interested in the social hierarchies of churches, and how the values of a social gospel could be reflected there. Rhona (focus group 1), drawing on James 2 on giving honour to certain members of the synagogue, argued that disability should be received in a way that was consistent with her understanding of a social and liberatory gospel:

> So for disability it's just part, for me, of the whole theology of the Church. That Jesus came to turn values upside down with the Beatitudes. And therefore the church needs to be turning their theology upside down. That Jesus came for the broken. Not for the rich and the able.

Some participants embedded their practical recommendations for churches in a broader theology of the difference between the values of society and (what they each perceived as) Christian values. In common with Charlotte, Susanna (individual interview) similarly conceived of a Jesus who would wish to live alongside and support the most marginalised and oppressed in society, despite her evangelical background contrasting with Charlotte's more liberal church background. However, she experienced this theology in a practical sense, in her church and its community focus:

> I think, generally, it's the feeling that if Jesus was living here in this community in this age, he would be with the people that don't have anything to eat, with the people being sanctioned from benefits and are having to do without, with the people aren't able to work, with the people that aren't able to get a bank account, and with the people that are lonely and need somewhere to go. That's where Jesus would be, who he would be with and who he would be ministering to. So, as a church, those are the people that we should be honouring and the people that we should be ministering to. I think that's very biblical. I think that's very right, and I love that about the church.

In Susanna's understanding, Jesus was interested in those who were experiencing poverty specifically as a result of social oppression, as contrasted with the sometimes-catachrestic use of the concept of the "poor" in churches and theology, as discussed further in the final section of this chapter. She, too, embedded biblical models in her reasoning, including the requirement to honour the least and the poorest (from James 2, echoing Rhona). Susanna's social location as a disabled person was implicit but present, as she related some of the social oppression faced by disabled and other marginalised people.

For many of these participants, their creative theologies, and the proposed applications of these, were rooted in their social locations as disabled people. Here it is relevant to note again Andrew's contention that privilege is often unseen by those who have it. Participants were often the only ones aware of the ways in which they misfit in their churches, and what would be needed to create truly inclusive communities where they fit. Theologies and biblical interpretation were central to many participants' ensuing concepts of transformation in churches. These were voices with theological agency, calling for new interpretations of theology and the Bible as the basis for a distinctively Christian form of inclusion for all, including disabled people. In the following section I explore further the barriers disabled people confronted in participating in the theological conversation in churches and beyond from their marginalised theological positions, and what this might mean for disability theology more generally.

6.3 Disabled People as Agents of Theology

In this study, participants demonstrated that disabled people are capable of creating diverse and resistant disability theologies. Yet many reflected on the barriers they encountered when they attempted to think about their Christian faith, and to share their own ideas about it. For example, they often found it difficult to find out about other disabled Christians' theologies, or to find theology of disability that made sense to them from their socially located perspectives as disabled people. Although there were a number of reasons for their exclusion from theology and Christian teaching, participants' lack of religious and spiritual capital was often a significant barrier to their participation in theological conversations. In this final section, I will relate theories of spiritual capital to disability theology—by which I mean disabled people's socially located theological perspectives. First, in the light of the broad themes of participants' theologies explored in this chapter, I discuss how they were impacted by spiritual capital. I also consider how this research project created spaces for disabled people's theology that began to compensate for this lack of spiritual capital. Second, I look at the elite/lived theology binary, and how this contributes to the devaluing and silencing of disabled people's own perspectives on faith. Third, I consider why disabled people's perspectives matter as disability theologies and whether professional theologians have a responsibility to enable disabled people to speak about their faith.

6.3.1 Marginalised theologies and the elite/lived theology divide

As Verter's theory of spiritual capital emphasises (2003), a struggle for control of religious fields is expressed in a monopoly over spiritual capital, including religious knowledge and theological thought. The resulting ecclesiastical and academic monopoly over the field of theology is evident in the theologies of disability described in Chapter 2. As I have argued in previous chapters, the Christian pastoral model has represented disabled people as unable to act or know for themselves, but who must instead be taught, led and cared for. In contrast, this chapter has explored their activity as agents who are capable of theology. These participants developed subaltern[14] *disability theologies* that moved beyond simple *theology of disability*. They did not always talk about disability, but they spoke from their social location *as* disabled people. In other words, while they valued discussions of the body and disability oppression, participants also wanted to share other theological reflections developed through their experience as disabled people. They had often been told by others what they should think about their impairments, about disability, and about how these related to God, in theological terms. Yet they were capable of relating to theology and the Bible for themselves. Furthermore, they often wanted to engage with or contradict the theological positions that had been laid out for them.

However, disabled people's theologies are devalued theologies. Much recent scholarship has focused on lived religion and vernacular religious thought (Ammerman, 2007; Dyrness, 1992; Hall, 1997; McGuire, 2008), but scholars have not always considered the difference in the ways in which elite theologies are

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[14] Antonio Gramsci's concept of subaltern populations (2008) has been developed in postcolonial theory to refer to those who are located outside of hegemonic power structures, socially and physically (Ahmed, 2013; Bhabha, 1996; Spivak, 1988). Homi Bhabha's concept of subalterns as mass populations on whom the self-definition of the hegemonic majority is contingent (Bhabha, 1996) resonates with the work of disability liberation theologians and biblical scholars, who show how disability is objectified to maintain hegemonic theological perspectives (Betcher, 2007; Hull, 2014; Kelley, 2011). As this chapter shows, disabled people speaking back from socially located positions could further impact hegemonic theologies that objectify disability, critiquing and reclaiming some of the ways in which disability has been used as a spiritual "metaphor to think with" (Betcher, 2007).

privileged over lived theologies.[15] For Kathryn Tanner, these "theologies of ordinary people" (1996:101) are often theologies developed by people in marginalised social locations, who are "without formal training in theology" (ibid.) and have no institutional standing in churches. She argues that, in categorising these theologies as a separate category of lived or everyday religious knowledge, the result is a hierarchical divide between central elite theologies and peripheral marginalised theologies. Describing a spectrum of lived or popular theology, Tanner locates at one end the theologies of white, middle-class churchgoers who lack overt theological training but are often able to access elite theological thought in other ways. At the other end are located the theologies of those who are marginalised in both church and society, such as those of Hispanic women in the United States.[16] While the concept of lived or ordinary theology may provide a framework for taking seriously the lived thought and practice of lay people, it nonetheless continues to divide Christian knowledge into privileged "official" and marginalised local theologies.[17] In Althaus-Reid's terms, it is *hegemonic theology* which remains central and legitimate in this schema.

Such a privileging of intellectual thought rather than lay practice in theology, as discussed in Chapter 2, may marginalise the perspectives of those who are not knowledgeable in an academic sense (Goodey, 2011; Lowe, 1993); it also marginalises embodied and experiential knowledge (McGuire, 2008). There is little space for the habitus of disabled Christians within a system that privileges intellectual knowledge above embodied experience, as seen, for example, in Lucy's experiences when her ways of understanding were marginalised by the structure of church teaching. Where thought and intellect are elevated in elite theology, this is likely to disadvantage many disabled people. As I noted in Chapter 2, the

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[15] I follow Tanner's (1996) term "elite theologies" for those theologies that are developed in academic theology departments and in church settings by professional clergy. Echoing theories of religious capital, this concept emphasises the ways in which institutional religious knowledge is given priority over the religious knowledge and experience of non-elites in religious and theological settings.

[16] For example, Dyrness' postcolonial work on vernacular theology acknowledges the colonialist thinking behind the concept of exporting the "good theology" of the West to countries with "bad theology" (1992:19). However, his solution, to represent lived theologies as vernacular, risks continuing the divisions of theology into elite and peripheral, legitimate and less legitimate. Although Dyrness argues that Christian thought needs the renewal that vernacular theology can offer it, this latter knowledge remains liminal in comparison with sanctioned forms of Christian knowledge.

[17] McGuire has also critiqued the hierarchical divide between intellectual theology and the ordinary practice of religion, arguing that scholarly approaches to religion can privilege the former over the latter (2008:13). However, the "lived" moniker may maintain an implicit hierarchy between the two.

suppression of the voices and stories of disabled Christians has been linked by some disability theologians to disabled people's histories of social marginalisation (Betcher, 2007; Lewis, 2007), and part of this suppression of subjugated knowledges may be encompassed by this hierarchical divide between lived and elite theologies.

In contrast, rather than stratifying different forms of religious thought and practice, liberatory theologies acknowledge that theology is social. Theology not only describes Christianity, but it also shapes, and is shaped by, Christians' social locations. For Black theologian James Cone, theology is a "political language" (1975:35) and its expression is strongly influenced by our social location: "one's social and historical context decides not only the questions we address to God but also the mode or form of the answers given to the questions" (Cone, 1975:15). Broadening the examination of theology as social, Althaus-Reid comments on the effects of ignoring the social effects of theology: it can be either an "actuarial science" (2010: 29)—a hegemonic perspective on the relationship between God and the world—or it can be transformative, with material results for people in churches and society. This theme, of theology as transformative, also strongly emerges from the theological thought of some of participants in this study. Although participants did not always conceptualise their thinking as theology, they nonetheless formed socially located theological perspectives, which often reflected on social issues. The social character of much of their theology allowed participants to think about their relationship with God and churches *through* their embodied positions as disabled people.

If a schema that divides "elite" and "lived" religious thought is abandoned, the religious thought of disabled Christians is given space to be taken more seriously. Disabled Christians already hold theological positions: this was clear from my research. Yet, as I argued above, some participants found it difficult to recognise or value these theologies *as theologies*. As Dyrness argues, non-elite theologies may not be recognised as such—especially if a group is excluded from the venues in which theology is traditionally constructed:

> Often it is said that this or that group "has no theology." Now if this is taken to mean that this community has written no theological treatise, or has no theologically trained spokespeople, then it may be accurate. But if it is systematic understanding of their faith, it is clearly false….A theological framework ordinarily…becomes a part of the tacit knowledge by which we live our lives.

(1992: 31)

The exclusion, by academic theology, of disability liberatory theologies, and other theological perspectives that have emerged from the disabled Christian community, taken together with the necessity for religious and other capital in order to enter the field of theology, are reflected in this study: in participants' direct experiences of a lack of spiritual capital, and, more subtly, in some participants' reluctance to explore theology or recognise their own theological positions as theologies. This may illustrate the inequality that arises when a marginalised group is more talked *about* by theologians than talked *to*.[18]

6.3.2 Disabled people's theologies and spiritual capital: Creating enabling threshold spaces

In this study, connection with a community of disabled Christians was significant in enabling participants to create theology. Participants' levels of spiritual capital impacted their ability to reflect theologically on issues of faith and disability. Yet, despite their lack of spiritual capital, many participants nonetheless wanted to engage in theological thought and discussion. The creation of spaces where they could come together as disabled Christians, particularly in the focus groups, was important in enabling this engagement. For some participants, simply being asked the questions on links between disability and faith—often for the first time—helped participants to develop their own theologies. In this section, I discuss the ways in which the research project provided a setting in which some participants became more comfortable to enter the theological discussion.

As I noted in Chapter 1, focus groups and interviews do not simply capture participants' ideas, but construct them together with the researcher in a "collaborative learning" partnership (Peters and Armstrong, 1998:76). In this study's focus groups and interviews, theology was constructed through the discussions. On several occasions, significant theological discussions took place in the focus groups, where disabled Christians were able to talk together while controlling the agenda. Other participants were more actively looking for ways to compensate for their lack

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[18] Althaus-Reid argues that a similar situation exists in relation to Latin American people living in poverty. Although Latin American Liberation Theology often claimed itself to be based on research into people's experiences of oppression, very little ethnographic research took place among poor people there (2010:30).

of spiritual capital, and this too often involved connection with an imagined or physical community of disabled Christians. Many of the participants wanted to engage with other disabled Christians, discuss experiences, and develop theologies together. Some wished to meet other disabled Christians for face-to-face discussion; others were interested in reading disabled Christians' published theological and autobiographical writing.

When participants were enabled to develop disability theology together, their disability theologies touched on topics that most published theologies of disability do not. While some participants were content with the orthodoxies of the churches they had attended and the theological teaching that they had heard or read, many expressed divergent theological positions. The result was a tapestry of different theologies, often but not solely about disability, drawing on embodied experience and positional readings of the Bible. Furthermore, participants were often not content with abstract, purely intellectual theologies of disability. Instead, they reflected on the practical implications of power and privilege for the churches, such as an understanding of ableism as a system that cannot be disconnected from other social systems of oppression. All these theologies could be conceived of as disability theology, where disabled participants explored positions on the wider theological issues that had impacted their experience of Christianity and churches, speaking from their social locations as disabled people.

These highly practical and resistant theologies could also be seen as theologies of the threshold. They diverge from Muers and Grant's original concept of threshold practices as work done on the margins of a church or religious community's institutional life (2017), since these are not theologies emerging from an ecclesiastical or administrative context. However, these are theologies that address the ways that practical aspects of church, such as toilet provision and coffee, are theological. In particular, theologies of the threshold emerged where participants attempted to engage churches on these issues, from their marginal positions, either individually or when meeting together for theological and supportive discussion. These marginal spaces for threshold theologies included Katie's theology group, which aimed to create practical theologies and materials that went beyond books, and the user-led conferences organised by members of St Martin-in-the-Fields Church, attended by several participants, which involve theological and practical discussion about disability and churches.

However, despite participants' willingness to engage in theology when spaces were created in which they could do so, spiritual capital continued to play a role in how, and how far, they were able to engage. On the whole, those participants who spent most time creating disability theologies and biblical interpretation were those with the most religious capital, particularly ordained participants. As Iannacconne argues (2001), active participation in churches both requires and develops higher levels of religious capital. Accordingly, there was high participation in theological discussion from lay participants with some theological training or experience, and from those with other active roles in churches. Verter's theory that "spiritual omnivorosity" (2003:167) requires higher levels of material and spiritual capital was also borne out, to some extent, among these participants, with broad spiritual seekers including those with higher levels of education or who read widely.[19] It was certainly not the case that only those who discussed academic and biblical theology were those with higher levels of spiritual capital. However, some participants had fewer tools to participate in theological discussions. This may have limited the ability of some to discuss the Bible or academic theology directly, leading them not always to recognise their views as theological.

Embodied capital, Bourdieu argues, is signalled through acts of consumption (Bourdieu, 1984; Verter, 2003). In the case of theology, it is necessary to consume knowledge in order to participate in it. For these participants, consumption of theological and other Christian knowledge required not only education—both general and specialised—but also physical access to resources such as books and networks where relevant theological knowledge is shared. Not all participants had access to all these resources. Financial capital was also relevant: poverty limited some participants' engagement in the theological conversation about disability. Furthermore, structural barriers to knowledge were in place in churches. Given the "fluidity of exchange" (Verter, 2003:178) between types of capital, disabled people's lower levels of material, symbolic and financial capital leave them with fewer resources to convert into spiritual or indeed religious capital. As a result, there will

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[19] In this study, seeking in religions or denominations was sometimes more of an indication of the exclusion of participants from the Christian spiritual marketplace. For Mims, who showed a relatively high level of religious capital in her knowledge of the Bible, the Christian theology to which she had access did not adequately address her concerns about mental illness in churches. Her interest in other religions allowed her to seek out alternative theologies with which she could better identify. However, not all disabled Christians will be able to do this, particularly those with more limited educational capital.

likely continue to be exclusion of disabled people from theological venues, whether academic or ecclesial. Overcoming these barriers to the theological conversation will be a challenge for churches and theologians, as I discuss further below. Churches and mainstream theologians may be able to create accessible threshold spaces in which disabled people can engage with theology, and this may help some disabled people to overcome some structural barriers that impact that spiritual capital. However, a range of strategies will be necessary to address such structural barriers, if disabled people are to participate more fully in churches and theological discussion.

6.3.3 "What would you like me to do for you?" Socially located positions and peripheral embodiment

As I discussed in Chapter 2, while some theology of disability addresses the practical issues that disabled people may face when attempting to access churches, most is focused on more abstract concepts such as the concept of welcome (e.g. Swinton, 1997; Yong, 2011b). However, the majority of concerns from participants in this study were practical. Theology is social and practical, whether or not it is acknowledged as such (Goss, 2002). For many participants, their theologies were applied and socially located: there was no division between the reality of their daily lives, and their theologies and interpretations of the Bible. This contrasts with some theological perspectives that privilege inward-focused theology and private biblical engagement (Chopp, 1987; Lowe, 1993). If the theological conversation about disability does not consider the impact of, for example, toilet provision for disabled people's participation in Christianity, it may fail to have much relevance for the disabled people for whom this issue is paramount in their access to churches and theological teaching.

Participants' narratives in this thesis suggest that disabled people's knowledge is marginalised, their speech silenced, where churches and theologians could instead be actively enabling disabled people to transform the conversation about disability and Christianity. As fields where power is at work, churches and mainstream theological discourses participate in the social system of dismodernism (Davis, 2002; Mitchell, 2015). Mitchell is speaking primarily of secular society, not religious contexts, when he describes a late modern culture in which "[d]ismodernist universalism renders the practices of nonnormative populations peripheral to the project of living" without any interest in "meaningful systems change" (Mitchell, 2015:29). However, Christian theological discourse similarly relegates disabled people to positions of peripheral embodiment and peripheral knowledge. Disability theologies are consigned to the position of lived theologies, rather than seen as sources of critique of the power and influence of theology in the lives of disabled people. Elite theology's monopoly over spiritual capital allows it to control the terms of the theological conversation on disability.

To be constantly spoken about without the opportunity to speak about oneself is to be silenced (Muers, 2004). For theologians and churches, maintaining control of Christian models of disability is dependent, in part, on maintaining the silence of divergent disabled voices. Silence from disabled Christians may then be read as "an unmediated absence" (Davis, 1995:109) of both God and meaning: an inability to speak, rather than a repression of voices; a source only of chaotic, fragmented narratives of the body (Michalko, 2002) in need of remediation. As Althaus-Reid argues (2010), hegemonic theology takes advantage of such silences, revealing the social power of theological discourses as it does so.[20] The result is a theological discourse and church cultures that are shaped by a "hegemony of normalcy" (Davis, 2013:10). However, Muers argues that silence is not necessarily absence, and that, even for those who have had their lives "shaped by the silence imposed by another" (2004:24), silence contains within it the possibility of future theological speech. To draw on Michalko (2002) and Shakespeare (1996): for disabled people, creating theologies together with imagined and physical communities of disabled Christians, on the thresholds of churches, is an act of communal resistance against their silencing in the theological conversation. As Shakespeare argues, "it all starts with having a voice…our task is to speak the truth about ourselves" (1996:111). This argument returns us to the critical disability research paradigm and the importance of disabled people's participation in theology, as explored in earlier chapters.

This chapter has explored examples of the transformative power of participants' socially located theologies and biblical readings. Hull gives the term "frontier theology" (2014:91) to such socially located forms of disability theology,

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[20] It is also important to recall here Lewis's contention that, for audiocentric churches, "faith comes by hearing" (2007:76). Deaf people have a history of exclusion from church and Christian faith *because* of the societal devaluing of silence, in comparison with sound and hearing. Muers argues that God may be affirmed in silence (2004), drawing on traditions that value silence, such as the Quakers. The communication of those who speak in silence may thus be transformative for theology and churches. Indeed, Lewis argues that Deaf culture and British Sign Language shape very different theologies from those that emerge from normative forms of speech.

arguing that they can serve a prophetic role for the churches and mainstream theology. Participants' experiential and embodied theologies ranged from imaginative identification in biblical theology to new perspectives on the mission of churches with the least honoured people in society. Their socially located, prophetic readings could form the basis of alternative Christian models of disability for disabled Christians looking for theological guidance. Furthermore, in their discussions of marginality, brokenness and a disabled God, participants showed how subaltern disability theologies are also relevant to non-disabled Christians, and to other theological perspectives. Some participants concluded that disability oppression is just one part of a broader system of social oppression that, for many of them, did not reflect the values of God towards *all* people, where "all people" includes disabled people. These socially contingent theologies present a challenge to hegemonic biblical interpretations and theologies that claim be universally relevant, through the plural perspective of "a spirituality of various human worlds" (Hull, 2013:73).

Furthermore, it was not possible for participants to escape their social locations in theology and churches. Should disabled people be required to reject their bodies and experiences in order to be able to engage with Christian theologies? Swinton seems to ask this of disabled people, when he contends that disability theologies cannot be justified as theologies because they are not for all people, arguing that "If, for example, God loves all people...then how can Eiesland justify developing a theology and an image of God that is only for disabled people?" (2011:285). This argument prioritises universal theology over socially located, subversive disability theologies. Yet, as Hull argues, social location cannot be escaped, for "[t]he world we know is the world projected by our bodies" (2013:62), and the sharing of socially located positions helps to ensure "that the Bible reveals its riches to everyone and not just to the sighted" (2013:17). From this standpoint, universal theology is not truly universal if it does not include the perspectives of blind people. Neither is it unanimously held that socially located theologies are less theologically accurate than universal theologies, as Swinton suggests they may be. Schüssler Fiorenza suggests that universal theologies have political interests and motivations, just as socially located theologies do, but that in universal theologies these interests are obscured by claims to objectivity (1992:39). This argument has much in common with the principles of emancipatory research, as explored in the

Introduction and Chapter 1, which developed out of resistance to problematic claims of research objectivity which marginalised disabled people. In the same way, in order to be truly inclusive of all people, hegemonic theology of disability may need to examine its claims to universality and objectivity, asking whether such principles are fully inclusive of disabled people and their social perspectives.

In order for theologians to hear disabled people's voices in the conversation, it may be necessary to reach them in ways that move outside established theological fields and their associated institutions, moving into the marginal and threshold spaces in which disabled people are doing theology. Such an approach would also be inspired by the approaches of critical disability research, but is not unprecedented in theology. "Where would God be in a salsa bar?" asks Althaus-Reid in *The Queer God* (2007), where she argues that no Liberation Theologians "had thought about doing theology in gay bars, although gay bars are full of theologians" (2007:1). The same may be said of disabled people. Where is God in a disabled people's activist demonstration against government disability policies, or in a "special school" for disabled children? Where is the theology that reaches the homes of disabled people like housebound participant Deirdre, or that speaks to participants like Andrew, who could not find a church that was accessible to him as a deaf person? There have recently been a few research studies based in places where disabled Christians congregate, but very few. Furthermore, not all disabled people form physical communities in specific places, whether in Christian or secular contexts; theology may need to be brought to disabled people in the wider community, bringing them together to compensate for accessibility barriers and low spiritual capital. For now, elite theological institutions remain the venues in which legitimate theology is created, whether ecclesiastical or academic, and disabled people's access to such institutional settings is limited. For disabled people to participate in the theological conversation, it will be necessary to visit and create threshold spaces for this purpose, outside of the institutions in which theology is currently constructed.

A theological project that is inclusionist of disabled people, but not transformative by and with disabled people, may uphold individualistic models of disability rather than critiquing oppressive societal structures. This is particularly urgent in a society shaped by biopower—the technologies of power focused on life itself (Mitchell, 2015; Tremain, 2010). As Chapter 2 explored, hegemonic theologies of disability have not yet often focused on critiquing societal systems and their effects for disabled people. As such they are largely inclusionist, rather than transformative, and themselves draw on a neoliberal rhetoric of inclusion. For example, neoliberal society is dominated by a disability discourse that claims that we are all disabled, without examining the social structures that relegate disabled people to positions of peripheral embodiment. As I argued in previous chapters, this individualising discourse of the body is also present in current theologies of disability, for example in a focus on the limits of all bodies. Mitchell argues that such an individualising approach to the body is a "meaningless homogenization as an antidote to bodily stigma" (2015:29). He further contends that "There is not a level playing field that all bodies occupy, and calling for a universalizing recognition of insufficiency will do little to accomplish meaningful systems change" (ibid.). Such a universalising approach, which obscures societal oppression, does not constitute real engagement with disabled people's concerns, nor with their socially located theologies. In this light, the comment made by queer theologian Goss is poignant: that theology that is not "strategically and practically oriented towards human liberation" is "a waste of time and energy" (2002:25). This does not mean that only liberatory concerns should be a focus of theology, nor that all disabled people will create theologies of liberation. Their theologies will, like the disabled community itself, be heterogeneous. However, the theologies expressed by participants in this study are transformative disability theologies, which speak back to hegemonic theology and its institutions. Furthermore, they are socially located, rather than obscuring of their social origins and effects. This is what divides disability theologies from theologies that simply discuss disability.

The alternative is to ignore the experiences and needs of disabled Christians and other disabled people. Althaus-Reid has explored the reification and romanticisation that can result when theology ignores subaltern experiences (2010). When the minority world's commercialised "theological marketplace" sought a romanticised subject of Latin American Liberation Theology for its own purposes, the real experiences of Latin American people living in poverty were not heard; experiences of material poverty became spiritualised and oppression was obscured. In this way, hegemonic theology entrenches the marginalisation of subaltern theologies:

> Theological reflection which has not disengaged itself from hegemonic Christianity or the construction of sexual order and law (decency) which

> repositions people into subaltern political positions, impoverishes people's suffering which cannot find an authentic expression in theological sexual categories.
>
> (2010:28)

From this liberationist perspective, attempting to avoid such reification and catachresis in the theological discussion about disability will involve listening to the "authentic expression" of disabled Christians.

The disability theology expressed by participants in this study is heterogeneous. They held a wide range of views on disability and Christianity, with no false consensus necessary as a conclusion. However, many of the participants' interests diverged significantly from current themes in elite theologies of disability, where the values and priorities of theologies are different from those contained in many of the participants' theologies. The question, then, can be asked: what are the socially-impacted theological issues that really matter to disabled people? Further research will be needed in order to answer this question more fully, and to explore the socially located perspectives of disabled people in more depth. However, in this study, there was an overwhelming sense that practical matters are theological, not abstract.

In their valuing of socially located perspectives and socio-political readings, the subaltern theologies of these participants have much in common with emancipatory research models, especially where these challenge research that emerges from only one hegemonic academic context. Earlier, I discussed Charlotte's view that the churches are not always asking disabled people the right questions. Following the biblical model of Christ asking those he healed "What would you like me to do for you?" she felt that churches were not always asking this of disabled people. The question "What do you want us to do for (and with) you?" is a question about disabled people's theologies. If theologians and church leaders wish to include disabled people in the conversation about disability and Christianity, and in other theological conversations, it is important that they take people's socially located theologies seriously. This will necessitate making disability theologies more accessible to more disabled people, which requires a recognition that disabled people are likely to have less spiritual and religious capital than non-disabled people, and that this will affect their access to theology and their participation in theological conversations. It is therefore likely to involve creating spaces where disabled people are enabled to share their ideas, supporting them to network with imagined and physical communities of disabled Christians. This is also likely to involve a challenge to the privileging of elite theological fields and their institutions, and the knowledge that emerges from them. In this context, to ask the biblical question "What do you want me to do for you?" is to ask what matters to disabled Christians, as a distinct and important socially located group within Christianity. As the theologies of disabled people in this study have shown, asking this question, and responding to the answers, may require doing church and theology differently.

Conclusion

1. Research Conclusions

The participants in this research illustrate how the systemic marginalisation of disabled people in churches constrains their roles, as objects rather than as agents of theologies and ecclesial ministries. As cultural locations of disability, churches and the field of theology control discourses of disability. The form of welcome into churches for disabled people, proposed by much current theology of disability, is a welcome controlled by churches. Disabled people are thus silenced, prevented from creating their own theologies and challenging normalcy in churches. However, many participants called for the transformation of churches, their conscientisation. I have argued that the concept of theological and ecclesial agency for disabled people will be fundamental to such transformation. Disabled people's perspectives must be central, not just as potential recipients of care and charity, but as active agents of service and ministry, if transformation of churches towards more complete inclusion is to be achieved. Rather than discipl(in)ing disabled people's bodyminds, churches undertaking conscientisation in their approaches to disability would allow disabled Christians to name and own the ways in which churches could create environments—physical, cultural and spiritual—in which they do not misfit. While physical spaces and access to these are important, it is often spiritual space and agency that is overlooked in the conversation about disability in churches.

Part A of this thesis particularly addressed research questions 4 a) and b), which asked what constitutes the current and historical context of attitudes to disabled people in churches, and what activism is present among disabled Christians and what concerns it is addressing. To answer this question, I explored the theological and socio-historical landscape of disability as an issue in churches today. I argued that the pastoral care context of church disability ministries has created a representation of disabled people as objects rather than agents of theology and ministry. However, alternative ways of conceptualising disability in Christian contexts emerge from critical disability theologies and disabled people's alternative models of disability in churches. The marginal, practical theologies of this study's participants offered such alternative frameworks, as I summarise below. Alternative models of disability and church were also found in the user-led and user-involved groups that contributed to this study. These alternative models transformed pastoral approaches in churches by turning their focus onto the issues that concerned disabled Christians, including equal access to and transformation of churches, both physically and culturally.

In the Introduction, I argued that there has been a lack of research into disabled people's experiences and theological positions; theology discusses disability, but often without the input of disabled Christians themselves. Furthermore, there is a neglect of religion in disability studies, and a corresponding lack of critical examination of disability in religious studies and theology. There is also little ethnographic research exploring the experiences of disabled people in churches. I outlined the social context for disabled people in churches today, arguing that church work with disabled people is usually located in a pastoral, often segregated system. I argued that there are few models of self-determination for disabled people in churches within this system of church disability work.

In Chapter 1, I argued that, given this social and research context, with little input from disabled people, it was important that this research prioritise the voices of disabled Christians. My methods were thus based on a critical disability research framework, and I described how my research aims and questions were iteratively shaped, first by my work with the two disabled people's groups referenced above, and then by and with participants.

In Chapter 2, I discussed biblical interpretation and theologies that encompass disability. Setting recent disability theologies in the context of late modern theology, I considered some of the ways in which the Bible has been interpreted in relation to disability. Although disability as a late modern concept is anachronistic to the Bible, the Bible is widely interpreted as being relevant to disability and disabled people, in churches and academic theology. I contrasted theologies of disability, which use a lens of pastoral care to consider disability, with what I have termed critical disability theologies, which centre the perspectives of disabled people. Critical disability theologies challenge the normative assumptions that have arisen from many theologies of disability, with some calling for more engagement with disabled Christians. However, critical and liberatory disability theologies remain a minority approach in theologies that discuss disability.

Drawing on the work of critical disability theologians and disability biblical scholars, I then considered ways in which the Bible has recently been interpreted as relating to disability. Such discussions have argued that disability has often been used as spiritual metaphor, in the Bible and interpretation. Theologians have examined connotations of deficit in such uses of disability in the Bible, through such patterns as a sin-sickness conflation (Eiesland, 1994). Others have examined ableist bias in the biblical text. While many biblical scholars work from a historicist approach to the Bible's representation of disability, there is significant redemptionism of biblical texts in theology, used to argue that the Bible is positive towards disabled people. However, some theologians are rejectionist in their engagement with the Bible, arguing that the more pernicious cultural effects of biblical texts and their interpretation, for disabled people, should not be ignored.

Chapter 2 continued by exploring a key historical discourse of disability that have been advanced in theology and biblical studies, namely the pastoral model. I explored this model as a common framework for discussions of disability in theology. Such theology arises from the church's historical focus on charitable care for disabled people, and may have unintended disempowering consequences for disabled people. Disabled people's own theologies have been overlooked or dismissed by some theologians working within a pastoral model framework. A recurring theme of this pastoral theology of disability is the need for welcome for disabled people into churches, a theme to which I returned in Chapters 5 and 6.

In Part B, I answered research questions 1 a) and b), which asked about disabled people's experiences of access to and exclusion from churches and church cultures, and what practices and attitudes are evident in churches' treatment of disabled people. I concluded that exclusion from churches was common for these participants, arising from inaccessible buildings, practices and cultures, in which disabled Christians misfit. In these chapters, there is evidence of church buildings that are inaccessible or unsuitable for disabled people's needs; institutional choices around uses of buildings which marginalise disabled worshippers by prioritising normative bodies; audio- and visio-centric cultures that exclude people with certain impairments; worship cultures which require disabled Christians to be able to follow ritual conventions; church social cultures focused on groups and friendship which exclude those who find many aspects of these social cultures difficult; and other environmental and cultural barriers which marginalise disabled Christians. Attitudes in churches to resistance to such poor access and exclusion are often framed by the pastoral model, with churches commonly not encouraging participants to assert their own access needs. These chapters also explored ways in which disabled people can be marginalised by the pastoral model in their own ministry and service, where they are positioned by church buildings, cultures and theologies as objects rather than agents of ministry. Where some participants are better included than others in their churches, this is often as a result of these churches' conscious attempts to transform building access and/or church cultures, in a process of conscientisation which makes physical and cultural space for disabled Christians' divergent bodyminds, both as church members who may sometimes require support from churches, and as church leaders with their own service and ministry to offer to churches.

In Chapter 3, I argued that access is not neutral, but that institutional power is expressed through choices around uses of buildings. Those whose bodyminds deviate from a normative range can be challenging for church institutions, which attempt to contain misfitting bodies by discipl(in)ing them. Participants often misfit in the physical and social environments of churches. Church buildings functioned as landscapes of power, designed to sustain only bodyminds that fell within a normative range. Misfitting disabled members were often a source of disruption, contained through institutional strategies including segregation. For many, the result was a poorer experience of church compared with other Christians. Conversely, participants were enthusiastic about inclusion when they were enabled to exist in church as they were; they experienced good access to buildings as a material, embodied form of welcome.

Chapter 3 then explored church worship and cultural norms. Beginning with a focus on access to communion, we saw that normalcy was also reinforced through ritual order in churches. Many felt that they had to allow their bodyminds to be discipl(in)ed by acquiescing to ritual order which was painful or had other negative impacts on their embodiment. However, participants appreciated churches which made an effort to include those who could not follow ritual order in the same ways as others. The cultural and worship features of certain styles of churches could have a similar marginalising effect.

The second half of Chapter 3 discussed church social cultures, particularly in their emphasis on friendship. The timing, structure and cultures of social groups in churches presented challenges to many participants; while many wished to be included, it was difficult for some to see how they could take part in groups without the transformation of these to accommodate them. Some found the social culture of churches exclusionary. However, for many, the social aspects of church were important and they wished to be included in social church, but it was challenging for them to overcome social, physical and cultural barriers. In this chapter I also discussed social encounters with power, as participants were discipl(in)ed as they misfit against social norms. Nonetheless, some churches' informal support and willingness to accommodate disabled members helped them to feel a sense of belonging in their church.

Chapter 4 examined ways in which the pastoral model positioned participants as objects, rather than agents, of care and service in churches. I considered the individualised focus of the pastoral model, with its "analgesic function," and whether it allowed participants opportunities to offer their own ministries in churches. Segregation and care models often created vulnerability, arising as a result of participants' misfitting. Subtly segregationist attitudes were common, particularly the perception of disabled people as receivers of pastoral care, rather than experts in their own needs. Within this framework, some experienced pastoral care as inappropriate and damaging, particularly those who experienced mental distress. Others encountered failures of informal support, when churches relied on this to remedy access difficulties inherent to environments or cultures. Informal support and frequency of contact with disabled people in churches was cited by some participants as positive for disability inclusion, but it is unclear whether this created long-term structural change in churches. In contrast, successful pastoral care more often took place in partnership with disabled people, and was contingent on disabled people being allowed to be the arbiters of their own needs.

The second part of this chapter considered disabled people's own ministries, both volunteer and professional, in churches. Many participants had their own service that they wished to offer, often arising from their socially located positions as disabled people. However, this was limited in many churches by an underestimation of disabled members, discounting them as leaders or theologians. Despite this, some participants felt a responsibility to challenge pastoral structures that constrained disabled people's opportunities to be involved in church leadership, and were determined to offer their own ministry and service.

In the final section of this chapter, I discussed how those participants who were ordained, or seeking ordination, frequently encountered church cultures and buildings which positioned disabled people as laypeople rather than ministers. A ministerial ideal of compulsory non-disability was communicated through church environments and practices. I argued, here and in Chapter 5, that while the disabled body is a dys-appearing body, the ministerial body in churches is required to be a disappearing body. This ministerial ideal also created barriers to ordination and leadership. These included cultural and structural barriers in churches and denominations, and external social barriers. However, the presence of disabled ministers could be a challenge to compulsory non-disability for ministers, acting as agents of change. Accordingly, disabled ministers' success was sometimes contingent on the informal support of congregations and other church leaders.

The pastoral model, I concluded, is often disempowering for disabled people. It positions them as objects of service, ministry and theology, rather than enabling them to participate fully in transformed churches which make room for them in their difference. However, this does not mean that it is never positive, as a number of participants' experiences of positive informal and mutual support in churches showed. I closed this chapter by outlining some alternative models of interdependency which, rather than individualising disability, take more seriously the social issues underlying pastoral problems. In such alternative models of interdependency, the needs of all are prioritised, in churches which enable disabled people to find their own voices and which value their expertise.

In Chapter 5, I brought together the issues discussed in Chapters 3 and 4, theorising them in more detail. Exploring misfitting in the context of landscapes of power, I examined the ways in which not participants were marginalised not only by pre-existing church architecture, but also by institutional choices around its use. Misfitting is social as well as environmental, occurring as disabled people move within the material world, and this could be seen in choices and negotiations around access to churches. I then analysed church cultural and worship norms from a Foucauldian perspective, looking at churches as pastoral institutions which enact power; I argued that, while institutional discrimination is often not malicious or intentional, it arises from pre-existing cultures which were not designed to accommodate disabled people. Not all church power was purely Christian, with churches taking on board many wider social norms and assumptions about disability. Creating better inclusion for disabled people in churches will have implications for church culture, including careful consideration of how to "do church" differently. In this chapter I also considered the ways in which participants used adaptive strategies and creative acts of misfitting to resist exclusionary elements of church culture, while also noting that it was often very difficult for participants to create change in their churches without institutional and leadership support. Some participants' churches were transforming their cultures in ways that better accommodated the divergent bodyminds of their disabled members, but this involved conscious and active work, rather than simply being an issue of passive, rhetorical welcome. Many participants were already working towards such change with imagined and physical communities of disabled Christians, using models of working *with* disabled Christians, as alternatives to purely pastoral models which provide services *for* them.

In the final section of Chapter 5, I analysed the conditional welcome often faced by disabled people in churches. Drawing on theories of hospitality, I argued that, while rhetorical and affective concepts of welcome for disabled people in theology are not disingenuous, they may both invoke and overlook politics of participation in churches, where non-disabled hosts control the access and welcome of disabled (permanent) guests. Participants' narratives often raised the issue of their conditional inclusion, dependent on the goodwill and willingness of their church hosts, who take a pastoral and paternalistic approach to disabled people. To end the chapter, I returned to Metzger's analysis of the Parable of the Banquet, arguing that in maintaining normalcy and creating docile bodies of their disabled members, churches only allow disabled people limited access to the status quo. Instead, I argued that full membership and participation for all requires conscientisation: the conscious transformation of cultures and environments. To allow for a better fit for a wider range of bodyminds, church social and spiritual norms would be questioned and redesigned for the benefit of all, including disabled Christians. Thus, rather than simply asserting that the gospel is for all, churches would make it accessible to all.

In Part C, I explored research question 3, which asked how the disabled Christians in this study understand their own social locations as disabled Christians, and what theologies they have encountered and themselves profess. In a return to issues first explored in the Introduction and Chapter 2, I considered the barriers that prevent disabled people from entering the theological conversation about disability, churches and faith. As I have emphasised throughout the thesis, disabled Christians' theologies are heterogeneous. Nonetheless, a number of theological themes emerged from these chapters, in socially located theologies which emerged from disabled people's marginal perspectives. These included the theology of the "upside-down Kingdom of God," which placed churches' responses to disability in a wider social theology context. Most notably, there is evidence in these chapters that disabled people are capable of acting as theological agents, particularly when enabled to do so; for example, when given access to the theological resources and imagined community of disabled Christians that many participants were seeking.

In Chapter 6, I began by discussing the reasons why disabled people might have lower spiritual capital than others, exploring how entrance to the theological conversation is predicated on spiritual capital. I also discussed the elite/lived theology binary and why this may further marginalise disabled people's ideas about God and churches, when they are already more talked about than listened to in theologies of disability. I illustrated with reference to participants, who variously had difficulties finding theology of disability which resonated with their experiences or, more commonly, finding and accessing theology about disability at all. Those who had encountered such theology had concerns about its quality of engagement with the subject of disability, and often did not see their needs and interests reflected there. However, despite their lack of spiritual capital, many were finding ways to engage with and create disabled theologies themselves. Imagined and physical communities of disabled people were often significant in this undertaking. For many, this study's focus groups and interviews were their first opportunity to discuss and create theology; nonetheless, many were still capable of forming creative theologies which resisted normative hermeneutics. The disability theologies which participants shared were not always *about* disability, but they were always rooted in participants' social locations as disabled people.

A number of themes emerged from the theologies that participants shared. First, participants used strategies to engage with the Bible and its representations of disability, which I analysed using concepts of resymbolisation. There was a wide variety of confidence levels among participants, regarding their ability and right to interpret the Bible. However, they nonetheless engaged in imaginative identification to shift the subject of interpretation towards those they interpreted as disabled people in the text, resisting normative ideological inscription of these figures. Second, a number of participants placed disability oppression in a wider, Christian theological context. A tapestry of different kinds of theologies emerged here. One theme was that of theologies of privilege and marginality, again centring participants' social location as disabled people, with some discussing the invisibility of privilege in churches and the role of disabled people in highlighting non-disabled privilege.

Where participants explored a social gospel of the "upside-down Kingdom of God," their theologies were very practical, examining the implications of this social theology for the access and inclusion of disabled people in churches. Many were capable of theological agency from this socially-located perspective.

In the second part of this chapter, I further discussed the ecclesiastical and academic monopoly over theologies of disability, contrasting this with participants' subaltern disability theologies. In theological systems which privilege intellectual thought, there is little space for the embodied and experiential theologies of disabled Christians, who are likely to encounter barriers to entering these systems. Drawing on liberatory theological traditions, which acknowledge that theology has social contexts, I argued that ways must be found to compensate for disabled people's lower spiritual and religious capital, enabling them to enter the theological conversation about disability.

I ended this chapter by examining the silencing of disabled people's theological voices by hegemonic theologies. Yet disabled people's subjugated theologies are sources of what Hull calls "frontier" (2014:91) and prophetic theologies, with broad relevance beyond disabled people themselves. This concept speaks back to Swinton's contention that disability theologies such as Eiesland's are only relevant to disabled people, and are thus exclusive. Instead, such theologies have the potential to transform the entire Church.

2. Recommendations for Churches and Theology

A number of themes emerged from this research which have relevance for churches. Most important is the concept of conscientisation and transformation, rather than a conditional, rhetorical welcome of disabled people into unchanged church spaces in which they misfit and where their peripheral embodiment is marginalised. Centring disabled people's perspectives, asking them what they would like churches to do for—and with—them, will be necessary if churches wish to understand how disabled people are marginalised in church environments and cultures. Disabled people themselves are resources for change and transformation in churches, including through informal networks in which they are already beginning this work of transformation.

In this research, many of the ways in which participants misfit in church culture, related to the ways in which institutions "do church." Building access is important, but the way churches use their spaces, and the politics of access and welcome, is just as important. Cultural elements of services that marginalise certain bodyminds will need to be considered in the light of access for all, as will church social cultures. The ways in which the pastoral model creates only precarious inclusion for some, where informal support is expected to compensate for poor access to churches, will also need to be considered. Furthermore, a top-down denominational policy approach to change is likely to be insufficient. Whole churches will need be involved in conscientisation and transformation of church cultures. Such conscientisation in churches must be led and owned by disabled people. As in my research, emancipatory principles of change led by disabled people are one model by which this may be achieved, as established in user-led disability movements and disability studies.

Theologians are unlikely to find disability theologies in traditional centres of theology. As Katie, who set up a disabled people's theology group, put it, "books go on shelves" (focus group 1), but alternative locations such as the internet have the potential to reach people who cannot enter elite theological venues, and sometimes cannot even enter churches. To reach disabled people and enable them to speak about their theologies is likely to require creating enabling spaces. In Chapter 6, I argued that academic and church theologians, who already have access to theological venues and conversations, have a responsibility to create such spaces. This will also necessitate theologians moving into the marginal spaces where informal and new disabled people's networks are beginning to create more theology. It will require a culture of change, both in churches and in the field of theology, where Christian leaders and theologians actively seek out the theologies of disabled people.

3. Recommendations for Future Research

As I noted in the Introduction and Chapter 1, there were groups of disabled people who could not be encompassed by this research. Further research is recommended to remediate the gap in research with Christians with learning difficulties and Deaf Christians, including members of Deaf churches. Such research will ideally be conducted from a critical disability standpoint, centring the voices of disabled Christians. Furthermore, while it was not appropriate for this research to consider specific impairment groups, the experiences of certain groups were highlighted as slightly different from those of others, including Christians with autistic spectrum conditions and those experiencing mental distress. Discrete research with these impairment groups, into their experiences of churches and their theologies, would allow further explorations of the issues raised for these groups in this research.

Further critical research into pastoral segregated ministries run by non-disabled people would also be a useful contribution to the discussion of these groups' role in disabled people's church life. My visits to WAVE Church found that this segregated but user-involved group was a useful additional support to some members with learning difficulties who also attended mainstream churches. However, research is needed to place these groups into the context of the barriers in mainstream churches that they aim to remediate, and to examine whether their pastoral approach is empowering or disempowering for disabled people in this context. Furthermore, as I discussed in Chapter 1, Black majority churches are among the fastest-growing churches in the United Kingdom, and the research was not able to engage with their views on disability. Further research with disabled members of Black majority churches would allow the views of these communities to be explored, such that their particular cultural framings of disability are accounted for. Finally, the RAG stressed the need for research into the experiences of older disabled people in churches, including those who would not necessarily define as disabled. Although a number of older disabled people were participants in this research, discrete research on this group's experiences would be revealing, in conversation with existing research into disabled people's experiences of churches more generally.

Additionally, a fuller understanding of trends of participation among disabled people in churches is needed. The findings of this research suggest issues of accessibility and relevance of churches and theologies, for disabled people. However, we do not know whether these issues are leading disabled people to leave churches, on a larger scale than this research could examine. Further research is needed to establish whether, in common with research findings on Deaf young people, there are wider trends of decreasing participation of disabled people in churches and Christianity. Research with disabled people outside churches, into the impact of pastoral, healing and other theological discourses and practices in their lives, would also give a more complete picture of the influence of Christian discourses and churches for disabled people in society. Similarly, research into new and loosely-affiliated networks would be able to consider the patterns of imagined, virtual and physical communities that disabled Christians are forming, from user-led communities such the disability and church conferences discussed above, to informal online networks.

I would like to end on a note of hope and gratitude. The recent growth in theologies of disability and networks of disabled people suggests that disability in churches is a topic whose time has come. This thesis has demonstrated that disabled people are capable of theological agency, resistance to normalcy, and contribution to change, especially where they are enabled by their churches. This can also be seen in the broader research context, including the emergence of user-led networks of disabled Christians, such as the *Disability and Jesus* virtual network and the St Martin-in-the-Fields/Inclusive Church conference on disability and Christianity. I am grateful to my participants, both interview participants and the groups that I observed, for allowing and encouraging me to explore some of the ways in which threshold spaces are emerging, in which disabled people together are developing disability theology and working towards transformation of churches. I offer thanks to the Disability Advisory Group at St Martin-in-the-Fields Church, to WAVE Church, and to my individual participants, for giving me insight into their transformational work of theological and ecclesial agency for disabled people.

Bibliography

1997. *The Holy Bible: New International Version.* London: Hodder & Stoughton.

1998. Data Protection Act. *c.29.* United Kingdom.

2006. Safeguarding Vulnerable Groups Act. *c.47.* United Kingdom.

2010. Equality Act. *c.15.* United Kingdom.

2018. General Data Protection Regulation (EU) 2016/679. European Union.

AHMED, S. 2013. *Strange Encounters: Embodied Others in Post-Coloniality.* London: Routledge.

AHMED, S. 2014. *Willful Subjects.* Durham, NC: Duke University Press.

ALBRECHT, G. L. 1992. *The Disability Business: Rehabilitation in America.* Newbury Park: Sage Publications.

ALTHAUS-REID, M. 2007. *The Queer God.* London: Routledge.

ALTHAUS-REID, M. 2010. *Indecent Theology: Theological Perversions in Sex, Gender and Politics.* London: Routledge.

AMMERMAN, N. T. 2007. *Everyday Religion: Observing Modern Religious Lives.* Oxford: Oxford University Press.

ANDERBERG, P. & JÖNSSON, B. 2005. Being There. *Disability & Society,* 20 (7)**,** 719-733.

ANDERSON, B. R. 1991. *Imagined Communities: Reflections on the Origin and Spread of Nationalism.* London: Verso.

ANDREWS, J. 2005. Wheeling Uphill? Reflections of Practical and Methodological Difficulties Encountered in Researching the Experiences of Disabled Volunteers. *Disability & Society,* 20 (2)**,** 201-212.

ANGROSINO, M. V. 2003. L'Arche: The Phenomenology of Christian Counterculturalism. *Qualitative Inquiry,* 9 (6)**,** 934-954.

AQUINO, J. A. 2010. Liberation Theology. *In:* JACKSON, R. L. (ed.) *Sage Encyclopedia of Identity.* Thousand Oaks, CA: Sage Publications, 429-433.

ASCH, A. & FINE, M. 1992. Beyond Pedestals: Revisiting the Lives of Women with Disabilities. *In:* FINE, M. (ed.) *Disruptive Voices: The Possibilities of Feminist Research.* Ann Arbor, MI: University of Michigan Press, 139-174.

ATKINS, L. 2013. Researching 'With', Not 'On': Engaging Marginalised Learners in the Research Process. *Research in Post-Compulsory Education,* 18 (1-2)**,** 143-158.

AUNE, K. 2016. Singleness and Secularization: British Evangelical Women and Church (Dis)affiliation. *In:* SHARMA, S. (ed.) *Women and Religion in the West: Challenging Secularization.* Aldershot: Ashgate, 57-70.

AVALOS, H. 1998. Disability and Liturgy in Ancient and Modern Religious Traditions. *In:* EIELSAND, N. L. & SALIERS, D. E. (eds.) *Human Disability and the Service of God.* Nashville, TN: Abingdon Press, 35-54.

AVALOS, H. 2007a. Introducing Sensory Criticism in Biblical Studies: Audiocentricity and Visiocentricity. *In:* AVALOS, H., MELCHER, S. J. & SCHIPPER, J. (eds.) *This Abled Body: Rethinking Disabilities in Biblical Studies.* Atlanta, GA: Society of Biblical Literature, 47-59.

AVALOS, H. 2007b. Redemptionism, Rejectionism and Historicism as Emerging Approaches in Disability Studies. *Perspectives in Religious Studies,* 34 (1)**,** 91-100.

AVALOS, H., MELCHER, S. J. & SCHIPPER, J. (eds.) 2007. *This Abled Body: Rethinking Disabilities in Biblical Studies.* Atlanta, GA: Society of Biblical Literature.

BAER, J. R. 2001. Redeemed Bodies: The Functions of Divine Healing in Incipient Pentecostalism. *Church History: Studies in Christianity and Culture,* 70 (4), 735-771.

BALMER, R. H. 1993. *Mine Eyes Have Seen the Glory: A Journey into the Evangelical Subculture in America.* New York, NY: Oxford University Press.

BARBOUR, R. S. & BARBOUR, M. 2003. Evaluating and Synthesizing Qualitative Research: The Need to Develop a Distinctive Approach. *Journal of Evaluation in Clinical Practice,* 9 (2), 179-186.

BARNES, C. 1992. Qualitative Research: Valuable or Irrelevant? *Disability, Handicap & Society,* 7 (2), 115-124.

BARNES, C. 1997. A Legacy of Oppression: A History of Disability in Western Culture. *In:* BARTON, L. & OLIVER, M. (eds.) *Disability Studies: Past, Present and Future.* Leeds: The Disability Press, 3-24.

BARNES, C. 2002. 'Emancipatory Disability Research': Project or Process? *Journal of Research in Special Educational Needs* [Online], 2. Available: http://citeseerx.ist.psu.edu.

BARNES, C. 2007a. Disability Studies: What's the Point? *Intersticios* [Online], 1. Available: http://www.intersticios.es/.

BARNES, C. 2007b. Disability, Higher Education and the Inclusive Society. *British Journal of Sociology of Education,* 28 (1), 135-145.

BARNES, C. & MERCER, G. 1997a. Breaking the Mould? An Introduction to Doing Disability Research. *In:* BARNES, C. & MERCER, G. (eds.) *Doing Disability Research.* Leeds: The Disability Press, 1-14.

BARNES, C. & MERCER, G. (eds.) 1997b. *Doing Disability Research.* Leeds: The Disability Press.

BARNES, C., MERCER, G. & SHAKESPEARE, T. 1999. *Exploring Disability: A Sociological Introduction.* Oxford: Polity.

BARTON, L. & OLIVER, M. (eds.) 1997. *Disability Studies: Past, Present and Future*. Leeds: The Disability Press.

BEAZLEY, H. & ENNEW, J. 2006. Participatory Methods and Approaches: Tackling the Two Tyrannies. *In:* DESAI, V. & POTTER, R. B. (eds.) *Doing Development Research.* London: Sage Publications, 189-199.

BECKER, H. S. 1963. *Outsiders: Studies in the Sociology of Deviance.* New York, NY: Free Press.

BECKETT, A. E. 2006. Understanding Social Movements: Theorising the Disability Movement in Conditions of Late Modernity. *The Sociological Review,* 54 (4), 734-752.

BECKFORD, J. A. 2003. *Social Theory and Religion.* Cambridge: Cambridge University Press.

BEGUM, N. 1992. Disabled Women and the Feminist Agenda. *Feminist Review,* 40, 70–84.

BEGUM, N. 1996. Doctor, Doctor... Disabled Women's Experience of General Practitioners. *In:* MORRIS, J. (ed.) *Encounters with Strangers: Feminism and Disability.* London: The Women's Press, 168-193.

BENNETT, J. E. 1994. Prayer for Healing in a State Mental Hospital. *Journal of Religion in Disability & Rehabilitation,* 2 (1), 21-25.

BENNETT MOORE, Z. 2002. *Introducing Feminist Perspectives on Pastoral Theology.* London: Sheffield Academic.

BERGER, P. L. 1967. *The Sacred Canopy: Elements of a Sociological Theory of Religion.* Garden City, NY: Doubleday.

BERGIN, A. E. 1983. Religiosity and Mental Health: A Critical Reevaluation and Meta-analysis. *Professional Psychology: Research and Practice,* 14 (2)**,** 170–84.

BERINYUU, A. 2005. Healing and Disability. *International Journal of Practical Theology,* 8 (2)**,** 202-211.

BETCHER, S. V. 2007. *Spirit and the Politics of Disablement.* Minneapolis, MN: Fortress Press.

BHABHA, H. K. 1996. Unsatisfied: Notes on Vernacular Cosmopolitanism. *In:* GARCIA-MORENO, L. & PFEIFFER, P. C. (eds.) *Text and Nation: Cross-Disciplinary Essays on Cultural and National Identities.* London: Camden House, 191–207.

BJARNASON, D. S. 2005. Dignity of Risk: My Son's Adult Life. *In:* JOHNSON, K. & TRAUSTADÓTTIR, R. (eds.) *Deinstitutionalisation and People with Intellectual Disabilities: In and Out of Institutions.* London: Jessica Kingsley, 206-214.

BLACK, K. 1996. *A Healing Homiletic: Preaching and Disability.* Nashville, TN: Abingdon Press.

BLAIKIE, N. 2000. *Designing Social Research.* Cambridge: Polity.

BLAIR, W. A. & BLAIR, D. D. 1996. Who Will Move the Next Mountain? *Journal of Religion in Disability & Rehabilitation,* 2 (4)**,** 81-90.

BOFF, C. 1996. Methodology of the Theology of Liberation. *In:* SOBRINO, J. & ELLACURIA, I. (eds.) *Systematic Theology: Perspectives from Liberation Theology.* London: SCM Press, 1-21.

BORSAY, A. 2005. *Disability and Social Policy in Britain Since 1750.* Basingstoke: Palgrave Macmillan.

BOURDIEU, P. 1984. *Distinction: A Social Critique of the Judgement of Taste.* London: Routledge.

BOURDIEU, P. 1986. The Forms of Capital. *In:* RICHARDSON, J. G. (ed.) *Handbook of Theory and Research for the Sociology of Education.* New York, NY: Greenwood, 241-58.

BOURDIEU, P. & BOLTANKSI, L. 1978. Changes in Social Structure and Changes in the Demand for Education. *In:* GINER, S. & ARCHER, M. S. (eds.) *Contemporary Europe: Social Structures and Cultural Patterns.* London: Routledge & Kegan Paul, 197-227.

BOWLER, C. 2011. Blessed Bodies: Healing within the African American Faith Movement. *In:* BROWN, C. G. (ed.) *Global Pentecostal and Charismatic Healing.* Oxford: Oxford University Press.

BOXALL, K., CARSON, I. & DOCHERTY, D. 2004. Room at the Academy? People with Learning Difficulties and Higher Education. *Disability & Society,* 19 (2)**,** 99-112.

BREDBERG, E. 1999. Writing Disability History: Problems, Perspectives and Sources. *Disability & Society,* 14 (2)**,** 189-201.

BREEN, R. & HAYES, B. C. 1996. Religious Mobility in the U.K. *Journal of the Royal Statistical Society,* 159 (3)**,** 493-504.

BRITISH SOCIOLOGICAL ASSOCIATION. 2017a. *Ethics Guidelines and Collated Resources for Digital Research: Statement of Ethical Practice Annexe* [Online]. Durham: BSA Publications. Available: https://www.britsoc.co.uk/ [Accessed 8th March 2018].

BRITISH SOCIOLOGICAL ASSOCIATION. 2017b. *Statement of Ethical Practice* [Online]. Durham: BSA Publications. Available: http://www.britsoc.co.uk/ [Accessed 8th March 2018].

BROCK, B. 2011. Theologizing Inclusion: 1 Corinthians 12 and the Politics of the Body of Christ. *Journal of Religion, Disability & Health,* 15 (4)**,** 351-376.

BROESTERHUIZEN, M. 2005. FAITH IN DEAF CULTURE. *Theological Studies,* 66 (2)**,** 304-26.

BRONHEIM, H. 1994. The Role of Faith in Mental Healing. *Journal of Religion in Disability & Rehabilitation,* 1 (2)**,** 3-18.

BROWN, L. & BOARDMAN, F. 2010. Accessing the Field: Disability and the Research Process.

BRUCE, D. A., STERLAND, S. J. R., BROOKES, N. E. & ESCOTT, P. 2006. An International Survey of Congregations and Worshipers: Methodology and Basic Comparisons. *Journal of Beliefs & Values,* 27 (1)**,** 3-12.

BRUNE, J. A. & WILSON, D. J. 2013. *Disability and Passing: Blurring the Lines of Identity.* Philadelphia, PA: Temple University Press.

BRYMAN, A. 2012. *Social Research Methods (4th ed.).* Oxford: Oxford University Press.

BUNDON, A. & HURD CLARKE, L. 2015. Unless You Go Online You Are on Your Own: Blogging as a Bridge in Para-Sport. *Disability & Society,* 30 (2)**,** 185-198.

BURY, M. 1982. Chronic Illness as Biographical Disruption. *Sociology of Health & Illness,* 4 (2)**,** 167-182.

CALDER, A. 2004. ‘God Has Chosen This for You.’ ‘Really?’ A Pastoral and Theological Appraisal of This and Some Other Well-known Clichés Used in Australia to Support People with Disabilities. *Journal of Religion, Disability & Health,* 8 (1-2)**,** 5-19.

CAMERON, C. 2007. Whose Problem? Disability Narratives and Available Identities. *Community Development Journal,* 42 (4)**,** 501-511.

CAMERON, C. 2011. Not Our Problem: Impairment as Difference, Disability as Role. *Journal of Inclusive Practice in Further and Higher Education,* 3 (2)**,** 10-25.

CAMERON, C. 2014. Discrimination. *In:* CAMERON, C. (ed.) *Disability Studies: A Student's Guide.* London: Sage Publications, 43-46.

CAMPBELL, J. & OLIVER, M. 1996. *Disability Politics: Understanding Our Past, Changing Our Future.* London: Routledge.

CAPLAN, P. 2016. Big Society or Broken Society? Food Banks in the U.K. *Anthropology Today,* 32**,** 5-9.

CARTER, W. 2011. 'The Blind, Lame and Paralyzed' (John 5:3): John's Gospel, Disability Studies and Postcolonial Perspectives. *In:* MOSS, C. R. & SCHIPPER, J. (eds.) *Disability Studies and Biblical Literature.* New York, NY: Palgrave Macmillan, 129-150.

CHAPPELL, A. L., GOODLEY, D. & LAWTHOM, R. 2001. Making Connections: The Relevance of the Social Model of Disability for People with Learning Difficulties. *British Journal of Learning Disabilities,* 29 (2)**,** 45-50.

CHARLTON, J. I. 1998. *Nothing About Us Without Us: Disability Oppression and Empowerment.* Berkeley, CA: University of California Press.

CHOPP, R. S. 1987. Practical Theology and Liberation. *In:* MUDGE, L. S. & POLING, J. N. (eds.) *Formation and Reflection: the Promise of Practical Theology.* Philadelphia, PA: Fortress Press, 120-138.

CHOPP, R. S. 1989. *The Power to Speak.* New York, NY: Crossroads.

CHRIST, C. P. 1997. *Rebirth of the Goddess: Finding Meaning in Feminist Spirituality.* Reading, MA: Addison-Wesley.

CHRYSSIDES, G. D. & GRAVES, R. 2007. *The Study of Religion: An Introduction to Key Ideas and Methods.* London: Continuum.

CHURCH OF ENGLAND. 2014. National Church and Social Action Survey Results 2014. Shrewsbury: Jubilee Plus

CLAPTON, J. 1997. Disability, Inclusion and the Christian Church: Practice, Paradox or Promise? *Disability and Rehabilitation,* 19 (10)**,** 420-426.

CONE, J. 1975. *God of the Oppressed.* New York, NY: Harper Collins.

CORKER, M. 1999. Differences, Conflations and Foundations: The Limits to 'Accurate' Theoretical Representation of Disabled People's Experience? *Disability & Society,* 14 (5)**,** 627-642.

CORNWALL, A. & JEWKES, R. 1995. What is Participatory Research? *Social Science & Medicine,* 41 (12)**,** 1667-1676.

COVEY, H. 2005. Western Christianity's Two Historical Treatments of People with Disabilities or Mental Illness. *The Social Science Journal,* 42 (1)**,** 107-114.

CREAMER, D. 1995. Finding God in our Bodies: Theology from the Perspective of People with Disabilities, Part I. *Journal of Religion, Disability & Health,* 2 (1)**,** 27-42.

CREAMER, D. 2003. Toward a Theology That Includes the Human Experience of Disability. *Journal of Religion, Disability & Health,* 7 (3)**,** 57-67.

CREAMER, D. 2006. Theological Accessibility: The Contribution of Disability. *Disability Studies Quarterly* [Online], 26. Available: http://dsq-sds.org/ [Accessed 12th April 2017].

CREAMER, D. 2009. *Disability and Christian Theology: Embodied Limits & Constructive Possibilities.* Oxford: Oxford University Press.

CROW, L. 1996. Including All Of Our Lives: Renewing the Social Model of Disability. *In:* BARNES, C. & MERCER, G. (eds.) *Exploring the Divide: Illness and Disability.* Leeds: The Disability Press, 55-72.

CSORDAS, T. J. 1994. *The Sacred Self: A Cultural Phenomenology of Charismatic Healing.* Berkeley, CA: University of California Press.

CSORDAS, T. J. 2002. *Body/Meaning/Healing.* Basingstoke: Palgrave Macmillan.

CUNNINGHAM, J. L., MULVIHILL, B. A. & SPECK, P. M. 2009. Disability and the Church: How Wide is Your Door? *Journal of Christian Nursing,* 26 (3)**,** 140-147.

CUSACK, C. M. 1997. *Graciosi:* Medieval Christian Attitudes to Disability. *Disability and Rehabilitation,* 19 (10)**,** 414-419.

DARE, H. & WOODMAN, S. P. (eds.) 2011. *The 'Plainly Revealed' Word of God? Baptist Hermeneutics in Theory and Practice.* Macon, GA: Mercer University Press.

DAUGHTON-FEAR, A. 2009. *Healing in the Early Church: The Church's Ministry of Healing & Exorcism from the First to the Fifth Century.* Milton Keynes: Paternoster.

DAVIES, P. R. 1995. *Whose Bible is it Anyway?* Sheffield: Sheffield Academic Press.

DAVIS, L. J. 1995. *Enforcing Normalcy: Disability, Deafness, and the Body.* London: Verso.

DAVIS, L. J. 1997. Constructing Normalcy: The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century. *In:* DAVIS, L. J. (ed.) *The Disability Studies Reader.* London: Routledge, 9-28.

DAVIS, L. J. 2002. *Bending Over Backwards: Disability, Dismodernism, and Other Difficult Positions.* New York: New York University Press.

DAVIS, L. J. 2013. Disability, Normality, and Power. *In:* DAVIS, L. J. (ed.) *The Disability Studies Reader (4th ed.).* New York: Routledge, 1-16.

DEAL, M. 2003. Disabled People's Attitudes Toward Other Impairment Groups: A Hierarchy of Impairments. *Disability & Society,* 18 (7)**,** 897-910.

DELAND, J. S. 1994. Breaking Down Barriers So All May Worship. *Journal of Religion in Disability & Rehabilitation,* 2 (1)**,** 5-20.

DERRIDA, J. & DUFOURMANTELLE, A. 2000. *Of Hospitality.* Stanford, CA: Stanford University Press.

DISABILITY AND JESUS. 2018. *Disability and Jesus* [Online]. Available: http://disabilityandjesus.org.uk/ [Accessed 20th September 2018].

DOCHERTY, D., HUGHES, R. & PHILLIPS, P. 2005. This is What we Think. *In:* GOODLEY, D. & VAN HOVE, G. (eds.) *Another Disability Studies Reader? People with Learning Difficulties and a Disabling World.* Antwerpen: Garant, 27-50.

DOUGLAS, M. 1966. *Purity and Danger: An Analysis of the Concept of Pollution and Taboo.* Abingdon: Taylor & Francis.

DUNSTAN, P. 2000. The Twentieth-Century Anglican Franciscans. *In:* EVANS, G. R. (ed.) *A History of Pastoral Care.* London: Cassell, 335-343.

DYRNESS, W. A. 1992. *Invitation to Cross-Cultural Theology: Case Studies in Vernacular Theologies.* Grand Rapids, MI: Zondervan Publishing House.

EARECKSON TADA, J. 2010. *A Place of Healing: Wrestling with the Mysteries of Suffering, Pain, and God's Sovereignty.* Colorado Springs, CO: David C. Cook.

EDMONDS, M. 2011. *A Theological Diagnosis: A New Direction on Genetic Therapy, 'Disability' and the Ethics of Healing.* London: Jessica Kingsley.

EIESLAND, N. L. 1994. *The Disabled God: Toward a Liberatory Theology of Disability.* Nashville, TN: Abingdon Press.

EIESLAND, N. L. 1999. Changing the Subject: Toward an Interfaith Theology of Disability. *Journal of Religion, Disability & Health,* 3 (1)**,** 55-62.

EIESLAND, N. L. & SALIERS, D. E. (eds.) 1998. *Human Disability and the Service of God: Reassessing Religious Practice.* Nashville, TN: Abingdon Press.

ELFORD, R. J. 1981. The Care of All for the Souls of All. *The Expository Times,* 92 (11)**,** 333-336.

ELLISON, C. G. & LEVIN, J. S. 1998. The Religion-Health Connection: Evidence, Theory, and Future Directions. *Health Education and Behavior,* 25**,** 700-720.

EPPERLY, B. G. 2003. Healing and Hospitality in Jesus' Ministry. *Journal of Religion, Disability & Health,* 7 (3)**,** 81-93.

EREVELLES, N. 2005. Educating Unruly Bodies: Critical Pedagogy, Disability Studies, and the Politics of Schooling. *Educational Theory,* 50 (1)**,** 25-47.

ERGUN, A. & ERDEMIR, A. 2009. Negotiating Insider and Outsider Identities in the Field: 'Insider' in a Foreign Land; 'Outsider' in One's Own Land. *Field Methods,* 22 (1)**,** 16-38.

ESLER, P. F. 1994. *The First Christians in their Social Worlds.* London: Routledge.

EVANS, G. R. 2000. Introduction. *In:* EVANS, G. R. (ed.) *A History of Pastoral Care.* London: Cassell, 1-14.
EXUM, J. C. 1993. *Fragemented Women: Feminist (Sub)versions of Biblical Narratives.* Valley Forge, PA: Trinity Press.
EXUM, J. C. & MOORE, S. D. (eds.) 1998. *Biblical Studies/Cultural Studies: The Third Sheffield Colloquium.* Sheffield: Sheffield Academic Press.
FAIRCHILD, S. R. 2002. Women with Disabilities: The Long Road to Equality. *Journal of Human Behavior in the Social Environment,* 6 (2)**,** 13-28.
FAIRCLOUGH, N. 1995. *Critical Discourse Analysis: The Critical Study of Language.* London: Longman.
FARRELL, D. & PETERSEN, J. C. 2010. The Growth of Internet Research Methods and the Reluctant Sociologist. *Sociological Inquiry,* 80 (1)**,** 114-125.
FERNGREN, G. B. 2009. *Medicine and Health Care in Early Christianity.* Baltimore, MA: John Hopkins University Press.
FINKE, R. & DOUGHERTY, K. D. 2002. The Effects of Professional Training: The Social and Religious Capital Acquired in Seminaries. *Journal for the Scientific Study of Religion,* 41 (1)**,** 103-120.
FINKE, R. & STARK, R. 1988. Religious Economies and Sacred Canopies: Religious Mobilisation in American Cities, 1906. *American Sociological Review,* 53 (2)**,** 41–49.
FINKELSTEIN, V. 1980. *Attitudes and Disabled People: Issues for Discussion.* New York, NY: World Rehabilitation Fund, Inc.
FINKELSTEIN, V. 2007. The 'Social Model of Disability' and the Disability Movement. *Coalition* [Online]. Available: https://disability-studies.leeds.ac.uk [Accessed 25th May 2015].
FISH, S. 1980. *Is There a Text in this Class? The Authority of Interpretive Communities.* Cambridge, MA: Harvard University Press.
FLEISCHER, D. & ZAMES, F. 2011. *The Disability Rights Movement: From Charity to Confrontation.* Philadelphia, PA: Temple University Press.
FOSTER, D. & WILLIAMS, J. 2014. Gender, Disability and Professional Work: The Need to Question Established Norms. The Gender, Work and Organization 8th Biennial International Interdisciplinary Conference, Keele University.
FOSTER, E. 1992. Women and the Inverted Pyramid of the Black Churches in Britain. *In:* SAHGAL, G. & YUVAL-DAVIS, N. (eds.) *Refusing Holy Orders: Women and Fundamentalism in Britain.* London: Virago Press, 45-68.
FOUCAULT, M. 1979. *Discipline and Punish: The Birth of the Prison.* London: Penguin.
FOUCAULT, M. 1982. The Subject and Power. *Critical Inquiry,* 8 (4)**,** 777-795.
FREEDMAN, D. M. 2006. Reflections on the Research Process: Emancipatory Research or Emancipatory Zeal? *Reflective Practice,* 7 (1)**,** 87-99.
FREEMAN, D. 2002. A Feminist Theology of Disability. *Feminist Theology,* 10 (29)**,** 71-85.
FREIRE, P. 1972. *Pedagogy of the Oppressed.* Harmondsworth: Penguin.
FRENCH, S. & SWAIN, J. 1997. Changing Disability Research: Participating and Emancipatory Research with Disabled People. *Physiotherapy,* 83 (1)**,** 26-32.
FRENCH, S. & SWAIN, J. 2001. The Relationship between Disabled People and Health and Welfare Professionals. *In:* ALBRECHT, G. L., SEELMAN, K. D.

& BURY, M. (eds.) *The Handbook of Disability Studies.* Thousand Oaks: Sage Publications, 734-753.

GARLAND-THOMSON, R. 1997. *Extraordinary Bodies: Figuring Disability in American Culture and Literature.* New York, NY: Columbia University Press.

GARLAND-THOMSON, R. 2011. Misfits: A Feminist Materialist Disability Concept. *Hypatia,* 26 (3)**,** 591-609.

GARTNER, J. D., LARSON, D. B. & ALLEN, G. D. 1991. Religious Commitment and Mental Health: A Review of the Empirical Literature. *Journal of Psychology and Theology,* 19**,** 6–25.

GHAI, A. 2003. *(Dis)embodied Form: Issues of Disabled Women.* New Delhi: Har-Anand Publications.

GILBURT, H., ROSE, D. & SLADE, M. 2008. The Importance of Relationships in Mental Health Care: A Qualitative Study of Service Users' Experiences of Psychiatric Hospital Admission in the U.K. *BMC Health Services Research,* 8 (1)**,** 92.

GILL, R. 1998. Theology. *In:* SWATOS, W. H. J. (ed.) *Encyclopedia of Religion and Society.* Walnut Creek, CA: AltaMira, 519-520.

GILLIBRAND, J. 2014. *Disabled Church - Disabled Society: The Implications of Autism for Philosophy, Theology and Politics.* London: Jessica Kingsley.

GILSON, S. F., TUSLER, A. & GILL, C. J. 1997. Ethnographic Research in Disability Identity: Self-Determination and Community. *Journal of Vocational Rehabilitation,* 9 (1)**,** 7-17.

GLEESON, B. J. 1997. Disability Studies: A Historical Materialist View. *Disability & Society,* 12 (2)**,** 179-202.

GOODEY, C. F. 2011. *A History of Intelligence and 'Intellectual Disability': The Shaping of Psychology in Early Modern Europe.* Farnham: Ashgate.

GOODHEW, D. (ed.) 2016. *Church Growth in Britain: 1980 to the Present.* Oxford: Routledge.

GOODLEY, D. 1996. Tales of Hidden Lives: A Critical Examination of Life History Research with People who have Learning Difficulties. *Disability & Society,* 11 (3)**,** 333-348.

GOODLEY, D. 2001. 'Learning Difficulties', the Social Model of Disability and Impairment: Challenging Epistemologies. *Disability & Society,* 16 (2)**,** 207-231.

GOODLEY, D. 2011. *Disability Studies: An Interdisciplinary Introduction.* Los Angeles, CA: Sage Publications.

GOODLEY, D. 2014. *Dis/ability Studies: Theorising Disablism and Ableism.* Abingdon: Routledge.

GOODLEY, D. & MOORE, M. 2000. Doing Disability Research: Activist Lives and the Academy. *Disability & Society,* 15 (6)**,** 861-882.

GORRINGE, T. 1998. Political Readings of Scripture. *In:* BARTON, J. (ed.) *The Cambridge Companion to Biblical Interpretation.* Cambridge: Cambridge University Press, 67-80.

GOSS, R. E. 2002. *Queering Christ.* Cleveland, OH: Pilgrim Press.

GOURGEY, C. 1995. Making Our Hearts Accessible, Too. *Journal of Religion in Disability & Rehabilitation,* 2 (3)**,** 1-11.

GRAHAM, D. 2000. The New Testament. *In:* EVANS, G. R. (ed.) *A History of Pastoral Care.* London: Cassell, 31-40.

GRAMSCI, A. & HOARE, Q. 2008. *Selections from the Prison Notebooks of Antonio Gramsci.* New York: International Publishers.

GRANT, C. C. 1998. Reinterpreting the Healing Narratives. *In:* EIESLAND, N. L. & SALIERS, D. E. (eds.) *Human Disability and the Service of God: Reassessing Religious Practice.* Nashville, TN: Abingdon Press, 72-87.

GRECH, S. 2012. Disability and the Majority World: A Neocolonial Approach *In:* GOODLEY, D., HUGHES, B. & DAVIS, L. J. (eds.) *Disability and Social Theory.* London: Palgrave Macmillan, 52-69.

GUTIÉRREZ, G. 2001 [1971]. *A Theology of Liberation: History, Politics, and Salvation.* London: SCM.

HALL, D. D. (ed.) 1997. *Lived Religion in America: Toward a History of Practice.* Princeton, NJ: Princeton University Press.

HALLAHAN, L. 2008. On Relationships Not Things: Exploring Disability and Spirituality. *In:* MACKINLAY, E. (ed.) *Ageing, Disability and Spirituality: Addressing the Challenge of Disability in Later Life.* London: Jessica Kingsley, 94-105.

HAMMERSLEY, M. 2003. Analytic Induction. *In:* LEWIS-BECK, M., BRYMAN, A. E. & LIAO, T. F. (eds.) *The Sage Encyclopedia of Social Science Research Methods.* Thousand Oaks, CA: Sage Publications, 16-18.

HAMMERSLEY, M. & ATKINSON, P. 1983. *Ethnography: Principles in Practice.* London; New York: Tavistock.

HARDIE, J. B. 1966. Medicine and the Biblical World. *Canadian Medical Association Journal,* 94 (1)**,** 32-6.

HARRIS, J. H. 1991. *Pastoral Theology: A Black-church Perspective.* Minneapolis, MN: Fortress Press.

HARVEY, D. 2003. Cell Church: Its Situation in British Evangelical Culture. *Journal of Contemporary Religion,* 18 (1)**,** 95-109.

HAUERWAS, S. 1982. *Responsibility for Devalued Persons: Ethical Interactions Between Society, the Family, and the Retarded.* Springfield, IL: C.C. Thomas.

HAYFIELD, N. & HUXLEY, C. 2015. Insider and Outsider Perspectives: Reflections on Researcher Identities in Research with Lesbian and Bisexual Women. *Qualitative Research in Psychology,* 12 (2)**,** 91-106.

HELY, J. 2002. Hospitality as a Sign and Sacrament. *Journal of Religion, Disability and Health,* 6 (4)**,** 67-80.

HENDERSON, J. 2003. What is Wrong with Pastoral Theology? *British Journal of Theological Education,* 13 (2)**,** 107-117.

HERZOG, A. A. 2004. Spires, Wheelchairs and Committees: Organizing for Disability Advocacy at the Judicatory Level. *Review of Religious Research,* 45 (4)**,** 349-367.

HOGAN, P. C. 1999. Christian Pharisees and the Scandalous Ethics of Jesus: Teaching Luke's Gospel at the End of a Millennium. *College Literature,* 26 (6)**,** 95-114.

HOLLOMOTZ, A. 2011. *Learning Difficulties and Sexual Vulnerability: A Social Approach.* London: Jessica Kingsley.

HUGHES, B. 1999. The Constitution of Impairment: Modernity and the Aesthetic of Oppression. *Disability & Society,* 14 (2)**,** 155-172.

HUGHES, B. 2007. Being Disabled: Towards a Critical Social Ontology for Disability Studies. *Disability & Society,* 22 (7)**,** 673-684.

HULL, J. M. 2001a. Blindness and the Face of God. *In:* ZIEBERTZ, H. G. (ed.) *The Human Image of God.* Leiden: Brill, 215-229.

HULL, J. M. 2001b. *In the Beginning There was Darkness: A Blind Person's Conversations with the Bible.* London: SCM Press.

HULL, J. M. 2002. 'Sight to the Inly Blind'? Attitudes to Blindness in the Hymnbooks. *Theology,* 105 (827), 333-341.

HULL, J. M. 2003a. The Broken Body in a Broken World: A Contribution to a Christian Doctrine of the Person from a Disabled Point of View. *Journal of Religion, Disability & Health,* 7 (4), 5-23.

HULL, J. M. 2003b. A Spirituality of Disability: The Christian Heritage as Both Problem and Potential. *Studies in Christian Ethics,* 16 (2), 21-35.

HULL, J. M. 2013. *The Tactile Heart: Blindness and Faith.* London: SCM Press.

HULL, J. M. 2014. *Disability: The Inclusive Church Resource.* London: Darton, Longman and Todd Ltd.

HUNT, P. 1981. Settling Accounts with the Parasite People. *Disability Challenge,* 1, 37-50.

HUNT, S. 1998. Managing the Demonic: Some Aspects of the Neo-Pentecostal Deliverance Ministry. *Journal of Contemporary Religion,* 13 (2), 215–230.

HUNT, S. 2005. The Alpha Course and Its Critics: An Overview of the Debates. *PentecoStudies,* 4, 1-22.

HUTCHINSON, N. 2006. Disabling Beliefs? Impaired Embodiment in the Religious Tradition of the West. *Body & Society,* 12 (4), 1-23.

IANNACCONE, L. R. 2001. Religious Practice: A Human Capital Approach. *Journal for the Scientific Study of Religion,* 29 (3), 297-314.

ILLINGWORTH, N. 2001. The Internet Matters: Exploring the Use of the Internet as a Research Tool. *Sociological Research Online,* 6 (2), 1-12.

IMRIE, R. 1998. Oppression, Disability and Access in the Built Environment. *In:* SHAKESPEARE, T. (ed.) *The Disability Reader: Social Science Perspectives.* London: Continuum, 129-146.

IMRIE, R. & EDWARDS, C. 2007. The Geographies of Disability: Reflections on the Development of a Sub-discipline. *Geography Compass,* 1 (3), 623-640.

INAHARA, M. 2009. This Body Which is Not One: The Body, Femininity and Disability. *Body & Society,* 15 (1), 47-62.

INBODY, T. 2005. *The Faith of the Christian Church: An Introduction to Theology.* Grand Rapids, MI: Eerdmans.

INCLUSIVE CHURCH 2018. *Calling from the Edge.* London: Inclusive Church.

IOZZIO, M. J. 2011. Solidarity: Restoring Communion with Those Who are Disabled. *Journal of Religion, Disability & Health,* 15 (2), 139-152.

JAFRI, O. 2012. Cost of Ignorance: Girl Dies During 'Exorcism'. *Express Tribune.*

JERSAK, B. 2006. *Kissing the Leper.* Abbotswood: Fresh Wind Press.

JOHNS, G. 2010. Presenteeism in the Workplace: A Review and Research Agenda. *Journal of Organizational Behavior,* 31 (4), 519-542.

JONES, D. L. 2009. A Pastoral Model for Caring for Persons with Diminished Hope. *Pastoral Psychology,* 58 (5-6), 641-654.

KELLEY, N. 2007. Deformity and Disability in Greece and Rome. *In:* AVALOS, H., MELCHER, S. J. & SCHIPPER, J. (eds.) *This Abled Body: Rethinking Disabilities in Biblical Studies.* Atlanta, GA: Society of Biblical Literature, 31-45.

KELLEY, N. 2011. 'The Punishment of the Devil was Apparent in the Torment of the Human Body': Epilepsy in Ancient Christianity. *In:* MOSS, C. R. &

SCHIPPER, J. (eds.) *Disability Studies and Biblical Literature.* New York, NY: Palgrave Macmillan, 205-221.

KELSEY, D. H. 1980. The Bible and Christian Theology. *Journal of the American Academy of Religion,* 48 (3)**,** 385-402.

KENNEDY, P. 1998. Satisfied Customers: Miracles at the Vineyard Christian Fellowship. *Mental Health, Religion & Culture,* 1 (2)**,** 135-152.

KENT, M. & ELLIS, K. 2015. People with Disability and New Disaster Communications: Access and the Social Media Mash-Up. *Disability & Society,* 30 (3)**,** 419-431.

KENT, M. & ELLIS, K. 2018. *Disability and Social Media: Global Perspectives.* London: Routledge.

KIERNAN, C. 1999. Participation in Research by People with Learning Disability: Origins and Issues. *British Journal of Learning Disabilities,* 27 (2)**,** 43-47.

KINNAMAN, D. 2011. *You Lost Me: Why Young Christians are Leaving Church and Rethinking Faith.* Grand Rapids, MI: BakerBooks.

KITCHIN, R. 1998. 'Out of Place', 'Knowing One's Place': Space, Power and the Exclusion of Disabled People. *Disability & Society,* 13 (3)**,** 343-356.

KITCHIN, R. 2000. The Researched Opinions on Research: Disabled People and Disability Research. *Disability & Society,* 15 (1)**,** 25-47.

KLASSEN, P. 2005. Ritual Appropriation and Appropriate Ritual: Christian Healing and Adaptations of Asian Religions. *History and Anthropology,* 16 (3)**,** 377-391.

KLAWANS, J. 2006. Moral and Ritual Purity. *In:* LEVINE, A. J., ALLISON, D. C. & CROSSAN, J. D. (eds.) *The Historical Jesus in Context.* Princeton, NJ: Princeton University Press, 266-284.

KNIGHT, G. & KNIGHT, J. 2009. *Disturbed by Mind & Spirit: Mental Health & Healing in Parish Ministry.* London: Mowbray.

KNOTT, K. 2009. Insider/Outsider Perspectives. *In:* HINNELLS, J. R. (ed.) *The Routledge Companion to the Study of Religion.* London: Routledge, 273-287.

KOOSED, J. L. & SCHUMM, D. 2005. Out of the Darkness: Examining the Rhetoric of Blindness in the Gospel of John. *Disability Studies Quarterly* [Online], 25. Available: http://dsq-sds.org/.

KRAUT, R., OLSON, J., BANAJI, M., BRUCKMAN, A., COHEN, J. & COUPER, M. 2004. Psychological Research Online: Report of Board of Scientific Affairs' Advisory Group on the Conduct of Research on the Internet. *American Psychologist,* 59 (2)**,** 105-117.

KUMARI CAMPBELL, F. 2005. Legislating Disability: Negative Ontologies and the Government of Legal Identities. *In:* TREMAIN, S. (ed.) *Foucault and the Government of Disability.* Ann Arbor: University of Michigan Press, 108-130.

KUMARI CAMPBELL, F. 2012. *Contours of Ableism: The Production of Disability and Abledness.* New York, NY: Palgrave Macmillan.

KUNZ, R. 2011. You Have Not Forgotten Us: Towards a Disability-accessible Church and Society. *Journal of Religion, Disability & Health,* 15 (1)**,** 20-33.

KUSTERS, A., DE MEULDER, M. & O'BRIEN, D. (eds.) 2017. *Innovations in Deaf Studies: The Role of Deaf Scholars.* Oxford: Oxford University Press.

LANCIONI, G. E. 2014. *Assistive Technologies for People with Diverse Abilities.* New York: Springer.

LAWRENCE, L. J. 2009. Sign Sources: Reading Matthew with Deaf Cultures. SBL Annual Meeting, Chicago. University of Chicago.

LAWRENCE, L. J. 2011. Exploring the Sense-scape of the Gospel of Mark. *Journal for the Study of the New Testament,* 33 (4)**,** 387–397.

LAWSON JACOBS, N. 2012. Book Review: A Theological Diagnosis: A New Direction on Genetic Therapy, 'Disability' and the Ethics of Healing. *Disability & Society,* 27 (1)**,** 151-152.

LAWSON JACOBS, N. 2016. The Cult of Health and Wholeness: Normalcy and the Charismatic Christian Healing Movement. *In:* MALLETT, R., OGDEN, C. A. & SLATER, J. (eds.) *Theorising Normalcy: Precarious Positions.* Chester: Chester University Press, 202-227.

LEAVEY, G. 2008. U.K. Clergy and People in Mental Distress: Community and Patterns of Pastoral Care. *Transcultural Psychiatry,* 45 (1)**,** 79-104.

LEFEBVRE, H. 2014. The Production of Space. *In:* GIESEKING, J. J., MANGOLD, W., KATZ, C., LOW, S. & SAEGERT, S. (eds.) *The People, Place, and Space Reader.* Florence: Routledge, 289-293.

LEFRANCOIS, B. A., MENZIES, R. & REAUME, G. (eds.) 2013. *Mad Matters: A Critical Reader in Canadian Mad Studies.* Toronto: Canadian Scholars' Press Inc.

LEGASPI, M. 2011. *The Death of Scripture and the Rise of Biblical Studies.* Oxford: Oxford University Press.

LEVINAS, E. 2011 [1985]. *Ethics and Infinity.* Pittsburgh, PA: Duquesne University Press.

LEVINE, D. H. 1988. Assessing the Impacts of Liberation Theology in Latin America. *The Review of Politics,* 50 (2)**,** 241-263.

LEWIS, H. 2007. *Deaf Liberation Theology.* Aldershot and Burlington, VT: Ashgate Publishing.

LEWIS, H. & VANGILDER, K. 2017. A Dialogue on Deaf Theology: Deaf Ontologies Seeking Theology. *In:* KUSTERS, A., DE MEULDER, M. & O'BRIEN, D. (eds.) *Innovations in Deaf Studies: the Role of Deaf Scholars.* Oxford: Oxford University Press, 169-190.

LIVABILITY. 2017. *Prospects Groups* [Online]. Livability. Available: https://www.livability.org.uk/ [Accessed 14th January 2018].

LIVEABILITY. 2017. *It all Adds up to Liveability* [Online]. Liveability. Available: https://livability.org.uk/ [Accessed 25th March 2018].

LONG, S. A. 2015. Seeking the Intrinsic Quality of Life. *Journal of Disability & Religion,* 19 (3)**,** 209-227.

LONGMORE, P. K. 2015. *Telethons: Spectacle, Disability, and the Business of Charity.* New York, NY: Oxford University Press.

LOVE, J. W. 2008. The Concept of Medicine in the Early Church. *The Linacre Quarterly,* 75 (3)**,** 225-238.

LOW, J. 2013. Unstructured and Semi-structured Interviews in Health Research. *In:* SAKS, M. & ALLSOP, J. (eds.) *Researching Health: Qualitative, Quantitative and Mixed Methods.* London: Sage Publications, 87-105.

LOWE, W. 1993. *Theology and Difference: The Wound of Reason.* Bloomington: Indiana University Press.

MACDONALD, S. J. & CLAYTON, J. 2013. Back to the Future: Disability and the Digital Divide. *Disability & Society,* 28 (5)**,** 702-718.

MACKENNEY-JEFFS, F. 2013. *Widening Participation in the Church: An Ethnographic Case Study of Two Evangelical Churches in Relation to Inclusion of Believers with Intellectual Impairments.* Ph.D., King's College London.

MACLEOD, A. 2010. ‘Welcome to my First Rant!’ Report on a Participatory Pilot Project to Develop the AS Portal, an Online Peer Support Network for Higher Education Students on the Autism Spectrum. *Journal of Assistive Technologies,* 4 (1)**,** 14-24.

MACNUTT, F. 1995. *Deliverance from Evil Spirits: A Practical Manual.* Grand Rapids, MI: Chosen Books.

MACQUARRIE, J. 1967. *God-Talk: An Examination of the Language and Logic of Theology.* London: SCM Press.

MADDOCKS, M. 1981. *The Christian Healing Ministry.* London: SPCK.

MADDOCKS, M., CHURCH OF ENGLAND & DIOCESE OF YORK 1976. *The Christian Ministry of Deliverance & Healing: A Report from the York Group.* York: Diocese of York.

MADDOX, M. 2012. 'In the Goofy Parking Lot': Growth Churches as a Novel Religious Form for Late Capitalism. *Social Compass,* 59 (2)**,** 146-158.

MALLETT, R., OGDEN, C. A. & SLATER, J. (eds.) 2016. *Theorising Normalcy and the Mundane: Precarious Positions.* Chester: University of Chester Press.

MARKS, D. 1999. *Disability: Controversial Debates and Psychosocial Perspectives.* London: Routledge.

MASON, J. 1996. *Qualitative Researching.* London: Sage Publications.

MASON, M. & RIESER, R. 1990. *Disability Equality in the Classroom: A Human Rights Issue.* London: Inner London Education Authority.

MBAKWE, T. 2018. Justin Welby Says he Doesn't Pray for Healing for Daughter's Disability. *Premier News* [Online]. Available: http://www.premier.org.uk/ [Accessed 25th October 2018].

MCCLINTOCK FULKERSON, M. 1998. Is There a (Non-sexist) Bible in This Church?' A Feminist Case for the Priority of Interpretive Communities. *Modern Theology,* 14 (2)**,** 225-242.

MCCLINTOCK FULKERSON, M. 2007. Places of Redemption: Theology for a Worldly Church. Oxford: Oxford University Press.

MCCLOUGHRY, R. & MORRIS, W. 2002. *Making a World of Difference: Christian Reflections on Disability.* London: SPCK.

MCCOLL, M. A. & ASCOUGH, R. S. 2009. Jesus and People with Disabilities: Old Stories, New Approaches. *Journal of Pastoral Care and Counselling,* 63 (3-4)**,** 1-11.

MCCUTCHEON, R. (ed.) 1998. *The Insider/Outsider Problem in the Study of Religion: A Reader.* London: Cassell.

MCCUTCHEON, R. 2001. *Critics not Caretakers: Redescribing the Public Study of Religion.* Albany, NY: State University of New York Press.

MCGOWAN, A. B. 1999. ‘Is There a Liturgical Text in This Gospel?': The Institution Narratives and Their Early Interpretive Communities. *Journal of Biblical Literature,* 118 (1)**,** 73-87.

MCGUIRE, M. B. 1988. *Ritual Healing in Suburban America.* New Brunswick, NJ: Rutgers University Press.

MCGUIRE, M. B. 1997. *Religion: The Social Context.* Belmont, CA: Wadsworth.

MCGUIRE, M. B. 2008. *Lived Religion: Faith and Practice in Everyday Life.* Oxford: Oxford University Press.

MCKINNON, A. M., TRZEBIATOWSKA, M. & BRITTAIN, C. C. 2011. Bourdieu, Capital, and Conflict in a Religious Field: The Case of the

‘Homosexuality' Conflict in the Anglican Communion. *Journal of Contemporary Religion,* 26 (3)**,** 355-370.

MCRUER, R. 2006. *Crip Theory: Cultural Signs of Queerness and Disability.* New York, NY: New York University Press.

MEEKOSHA, H. & SHUTTLEWORTH, R. 2009. What's So ‘Critical’ About Critical Disability Studies? *Australian Journal of Human Rights,* 15 (1)**,** 47-75.

MELCHER, S. J. 1998. Visualizing the Perfect Cult: The Priestly Rationale for Exclusion. *In:* EIESLAND, N. & SALIERS, D. E. (eds.) *Human Disability and the Service of God.* Nashville, TN: Abingdon Press, 55-71.

MELCHER, S. J. 2004. 'I Will Lead the Blind by a Road they Do Not Know': Disability in Prophetic Eschatology. Society of Biblical Literature 2004, Chicago, IL.

MELVILLE, P. 2003. *Romantic Hospitality: Theorizing the Welcome in Rousseau, Kant, Coleridge, and Mary Shelley.* Ph.D., McMaster University.

MEMMOTT, A. 2018. *Ann’s Autism Blog* [Online]. Available: http://annsautism.blogspot.com/ [Accessed 20th November 2018].

MERCER, G. 2002. Emancipatory Disability Research. *In:* BARNES, C., OLIVER, M. & BARTON, L. (eds.) *Disability Studies Today.* Cambridge: Polity Press/Blackwell Publishers, 228-249.

MERCER, G. 2004. From Critique to Practice: Emancipatory Disability Research. *In:* BARNES, C. & MERCER, G. (eds.) *Implementing the Social Model of Disability: Theory and Research.* Leeds: The Disability Press, 118-137.

MERRIAM, S. B., JOHNSON-BAILEY, J., LEE, M. Y., KEE, Y., NTSEANE, G. & MUHAMAD, M. 2001. Power and Positionality: Negotiating Insider/Outsider Status Within and Across Cultures. *International Journal of Lifelong Education,* 20 (5)**,** 405-416.

METHODIST CHURCH 2004. The Christ We Share: A World Church Resource for Local Mission. London: CMS, USPG, Methodist Publishing.

METZGER, J. A. 2009. Where Has Yahweh Gone? Reclaiming Unsavory Images of God in New Testament Studies. *Horizons in Biblical Theology***,** 51-76.

METZGER, J. A. 2010. Disability and the Marginalisation of God in the Parable of the Snubbed Host (Luke 14.15-24). *The Bible and Critical Theory,* 6 (2).

METZGER, J. A. 2011. Reclaiming ‘a Dark and Malefic Sacred’ for a Theology of Disability. *Journal of Religion, Disability & Health,* 15 (3)**,** 296-316.

MICHALKO, R. 2002. *The Difference that Disability Makes.* Philadelphia, PA: Temple University Press.

MINGUS, M. 2010. *Wherever You Are is Where I Want to Be: Crip Solidarity* [Online]. Available: http://leavingevidence.wordpress.com/ [Accessed 1st March 2014].

MITCHELL, D. T. 2015. *The Biopolitics of Disability: Neoliberalism, Ablenationalism and Peripheral Embodiment.* Ann Arbor, MI: University of Michigan Press.

MITCHELL, D. T. & SNYDER, S. H. 2000. *Narrative Prosthesis: Disability and the Dependencies of Discourse.* Ann Arbor, MI: University of Michigan Press.

MOLTMANN-WENDEL, E. 1994. *I Am My Body: A Theology of Embodiment.* London: SCM.

MORRIS, J. 1991. *Pride Against Prejudice.* London: The Women's Press.

MORRIS, J. 1996 (ed.) *Encounters with Strangers: Feminism and Disability.* London: The Women's Press.

MORRIS, J. 2001. Social Exclusion and Young Disabled People with High Levels of Support Needs. *Critical Social Policy,* 21 (2)**,** 161-183.

MORRIS, W. 2008. *Theology Without Words: Theology in the Deaf Community.* Aldershot: Ashgate.

MORRIS, W. 2010. Church as Sign and Alternative: Disabled People in the Churches. *Journal of Religion, Disability & Health,* 14 (1)**,** 47-59.

MOSS, C. R. & SCHIPPER, J. 2011. Introduction. *In:* MOSS, C. R. & SCHIPPER, J. (eds.) *Disability Studies and Biblical Literature.* New York: Palgrave Macmillan, 1-11.

MUERS, R. 2004. *Keeping God's Silence: Towards a Theological Ethics of Communication.* Oxford: Blackwell.

MUERS, R. & GRANT, R. 2017. Theology at Thresholds: Learning from a Practice 'In Transition'. *Ecclesial Practices,* 4 (1)**,** 45–62.

MULVANY, J. 2000. Disability, Impairment or Illness? The Relevance of the Social Model of Disability to the Study of Mental Disorder. *Sociology of Health & Illness,* 22 (5)**,** 582-601.

MURPHY, R. 1987. *The Body Silent.* London: Phoenix House.

NESBITT, P. 1998. Ministry. *In:* SWATOS, W. H. J. (ed.) *Encyclopedia of Religion and Society.* Walnut Creek, CA: AltaMira, 301-303.

NIND, M. & SEALE, J. 2009. Concepts of Access for People with Learning Difficulties: Towards a Shared Understanding. *Disability & Society,* 24 (3)**,** 273-287.

NOUWEN, H. J. M. 1986. *Reaching Out: The Three Movements of the Spiritual Life.* New York, NY: Doubleday.

NOUWEN, H. J. M. 2012. *Adam: God's Beloved.* Maryknoll, NY: Orbis Books.

NOVICK, G. 2008. Is There a Bias Against Telephone Interviews in Qualitative Research? *Research in Nursing & Health,* 31 (4)**,** 391-398.

O'MALLEY, J. 2000. The Ministry to Outsiders: The Jesuits. *In:* EVANS, G. R. (ed.) *A History of Pastoral Care.* London: Cassell, 252-264.

OLIVER, M. 1990. *The Politics of Disablement.* Basingstoke & London: Macmillan Press.

OLIVER, M. 1992. Changing the Social Relations of Research Production? *Disability, Handicap and Society,* 7 (2)**,** 101-114.

OLIVER, M. 1996a. Defining Impairment and Disability: Issues at Stake. *In:* BARNES, C. & MERCER, G. (eds.) *Exploring the Divide: Illness and Disability.* Leeds: The Disability Press, 39-54.

OLIVER, M. 1996b. *Understanding Disability: From Theory to Practice.* Basingstoke & London: Macmillan.

OLIVER, M. 1997. Emancipatory Research: Realistic Goal or Impossible Dream? *In:* BARNES, C. & MERCER, G. (eds.) *Doing Disability Research.* Leeds: The Disability Press, 15-31.

OLYAN, S. M. 2008. *Disability in the Hebrew Bible: Interpreting Mental and Physical Differences.* Cambridge: Cambridge University Press.

PARGAMENT, K. I., TARAKESHWAR, N., ELLISON, C. G. & WULFF, K. M. 2001. Religious Coping Among the Religious: The Relationships Between Religious Coping and Well-being in a National Sample of Presbyterian Clergy, Elders, and Members. *Journal for the Scientific Study of Religion,* 43 (3)**,** 497–513.

PATERSON, G. W. 2015. Ministering to the Family of the Handicapped Child. *Journal of Religion and Health,* 14 (3)**,** 165-176.

PATERSON, K. & HUGHES, B. 1999. Disability Studies and Phenomenology: The Carnal Politics of Everyday Life. *Disability & Society,* 14 (5)**,** 597-610.

PATSAVAS, A. 2014. Recovering a Cripistemology of Pain: Leaky Bodies, Connective Tissue, and Feeling Discourse. *Journal of Literary and Cultural Disability Studies,* 8 (2)**,** 203-18.

PATTISON, S. 1988. *A Critique of Pastoral Care.* London: SCM Press.

PATTISON, S. 1989. *Alive and Kicking: Towards a Practical Theology of Illness and Healing.* London: SCM Press.

PATTISON, S. 1994. *Pastoral Care and Liberation Theology.* London: SPCK.

PEARSON, C. & TREVISAN, F. 2015. Disability Activism in the New Media Ecology: Campaigning Strategies in the Digital Era. *Disability & Society,* 30 (6)**,** 924-940.

PETERS, J. M. & ARMSTRONG, J. L. 1998. Collaborative Learning: People Laboring Together to Construct Knowledge. *New Directions for Adult and Continuing Education,* 79**,** 75-85.

PETERS, S. 2006. Is There a Disability Culture? A Syncretisation of Three Possible World Views. *In:* BARTON, L. (ed.) *Overcoming Disabling Barriers.* London: Routledge, 135-154.

PETERS, S. & CHIMEDZA, R. 2000. Conscientization and the Cultural Politics of Education: A Radical Minority Perspective. *Comparative Education Review,* 44 (3)**,** 245-271.

PLASKOW, J. 2005. *The Coming of Lilith: Essays on Feminism, Judaism and Sexual Ethics, 1972-2003.* Boston: Beacon Press.

POLLACK, D. 2008. Religious Change in Europe: Theoretical Considerations and Empirical Findings. *Social Compass,* 55 (2)**,** 168-186.

PORTERFIELD, A. 2005. *Healing in the History of Christianity.* Oxford and New York, NY: Oxford University Press.

POTTER, D. 2002. Spirituality and People with Learning Disabilities. *Tizard Learning Disability Review,* 7 (4)**,** 36-38.

PRICE, M. 2015. The Bodymind Problem and the Possibilities of Pain. *Hypatia,* 30 (1)**,** 268-284.

PRICE, M. 2017. Education. *IN:* ADAMS, R., REISS, B & SERLIN, D. (eds.) *Keywords for Disability Studies.* New York, NY: New York University Press, 64-66.

PRIESTLEY, M. 1998. Constructions and Creations: Idealism, Materialism and Disability Theory. *Disability & Society,* 13 (1)**,** 75-94.

RALPH, S. & BOXALL, K. 2005. Visible Images of Disabled Students: An Analysis of U.K. University Publicity Materials. *Teaching in Higher Education,* 10 (3)**,** 371-385.

RAPHAEL, R. 2008. *Biblical Corpora: Representations of Disability in Hebrew Biblical Literature.* London: T&T Clark International.

REEVE, D. 2012. Psycho-Emotional Disablism: The Missing Link? *In:* WATSON, N., ROULSTONE, A. & THOMAS, C. (eds.) *Routledge Handbook of Disability Studies.* New York: Routledge, 78-92.

REINDERS, H. 2008. *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics.* Grand Rapids, MI: Eerdmans.

REINDERS, H. (ed.) 2010. *The Paradox of Disability: Responses to Jean Vanier and L'Arche Communities from Theology and the Sciences.* Grand Rapids, MI: Eerdmans.

REINDERS, H. 2012. 'Doing Theology and Disability' in Europe. *Journal of Religion, Disability & Health,* 16 (4)**,** 439-442.

REINDERS, H. S. 2011. The Power of Inclusion and Friendship. *Journal of Religion, Disability & Health,* 15 (4)**,** 431-436.

RENNEBOHM, C. & PAUL, D. 2008. *Souls in the Hands of a Tender God: Stories of the Search for Home and Healing on the Streets.* Boston, MA: Beacon Press.

RESEARCH AND STATISTICS. 2018. *Ministry Statistics 2017* [Online]. London: Church of England. Available: https://www.churchofengland.org [Accessed 12th October 2018].

REYNOLDS, T. E. 2008. *Vulnerable Communion: A Theology of Disability and Hospitality.* Grand Rapids, MI: Brazos Press.

REYNOLDS, T. E. 2012. Theology and Disability: Changing the Conversation. *Journal of Religion, Disability & Health,* 16 (1)**,** 33-48.

RHOADES, D. 2008. Crossing Boundaries. *In:* CAPEL ANDERSON, J. & MOORE, S. D. (eds.) *Mark and Method: New Approaches in Biblical Studies.* Minneapolis: Fortress Press, 145-180.

RIDDELL, S. & WATSON, N. (eds.) 2014. *Disability, Culture and Identity.* London: Routledge.

ROBINSON, J. 2011. *Divine Healing, The Formative Years, 1830-1890: Theological Roots in the Transatlantic World.* Eugene, OR: Pickwick Publications.

ROBINSON, J. 2014. *Divine Healing, The Years of Expansion, 1906-1930: Theological Variation in the Transatlantic World.* Eugene, OR: Pickwick Publications.

ROBITSCHER, J. B. 1998. Through Glasses Darkly: Discovering a Liturgical Place. *In:* EIESLAND, N. L. & SALIERS, D. E. (eds.) *Human Disability and the Service of God: Reassessing Religious Practice.* Nashville: Abingdon Press, 144-164.

ROOF, W. C. 1999. *Spiritual Marketplace: Baby Boomers and the Remaking of American Religion.* Princeton, NJ: Princeton University Press.

ROOZEN, D. A. 1980. Church Dropouts: Changing Patterns of Disengagement and Re-Entry. *Review of Religious Research,* 21 (4)**,** 427-450.

ROSE, A. 1997. ‘Who Causes the Blind to See’: Disability and Quality of Religious Life. *Disability & Society,* 12 (3)**,** 395-405.

ROULSTONE, A. & SADIQUE, K. 2013. Vulnerable to Misinformation: Disabled People, ‘Vulnerability’, Hate Crime and the Fight for Legal Recognition. *In:* ROULSTONE, A. & MASON-BISH, H. (eds.) *Disability, Hate Crime and Violence.* London: Routledge, 25-39.

RUKUNDWA, L. S. & VAN AARDE, A. G. 2009. Revisiting Justice in the first four Beatitudes in Matthew (5:3-6) and the story of the Canaanite woman (Mt 15:21-28): A Postcolonial Reading. *Theological Studies,* 61 (3)**,** 927-951.

SAYE, S. C. 1996. The Wild and Crooked Tree: Barth, Fish, and Interpretive Communities. *Modern Theology,* 12 (4)**,** 483-500.

SCHEFF, T. J. 1979. *Catharsis in Healing, Ritual and Drama.* Berkeley & Los Angeles, CA: University of California Press.

SCHIPPER, J. 2006. *Disability Studies and the Hebrew Bible: Figuring Mephibosheth in the David Story.* London: T&T Clark International.

SCHUMM, D. & STOLTZFUS, M. (eds.) 2011. *Disability in Judaism, Christianity, and Islam: Sacred Texts, Historical Traditions, and Social Analysis.* New York, NY: Palgrave Macmillan.

SCHUMM, D. & STOLTZFUS, M. (eds.) 2016. *Disability and World Religions: An Introduction.* Waco, TX: Baylor University Press.

SCHURTER, D. D. 1994. Jesus' Ministry with People with Disabilities. *Journal of Religion in Disability & Rehabilitation,* 1 (4)**,** 33-54.

SCHÜSSLER FIORENZA, E. 1983. *In Memory of Her: A Feminist Theological Reconstruction of Christian Origins.* New York, NY: Crossroad.

SCHÜSSLER FIORENZA, E. 1988. The Ethics of Biblical Interpretation: Decentering Biblical Scholarship. *Journal of Biblical Literature,* 107 (1)**,** 3-17.

SCHÜSSLER FIORENZA, E. 1992. *But She Said: Feminist Practices of Biblical Interpretation.* Boston, MA: Beacon Press.

SCHÜSSLER FIORENZA, E. 1998. *Sharing Her Word: Feminist Biblical Interpretation in Context.* Boston, MA: Beacon Press.

SEGOVIA, F. F. 2000. *Decolonizing Biblical Studies: A View from the Margins.* Maryknoll, NY: Orbis Books.

SEYMOUR, W. & LUPTON, D. 2004. Holding the Line Online: Exploring Wired Relationships for People with Disabilities. *Disability & Society,* 19 (4)**,** 291-305.

SHAKESPEARE, T. 1993. Disabled People's Self-organisation: A New Social Movement? *Disability, Handicap & Society,* 8 (3)**,** 249-264.

SHAKESPEARE, T. 1996. Disability, Identity and Difference. *Exploring the Divide: Illness and Disability.* Leeds: Disability Press, 94-113.

SHEILS, W. J. (ed.) 1982. *The Church and Healing: Papers Read at the Twentieth Summer Meeting and the Twenty-First Winter Meeting of the Ecclesiastical History Society.* Oxford: Basil Blackwell.

SHERIF, B. 2001. The Ambiguity of Boundaries in the Fieldwork Experience: Establishing Rapport and Negotiating Insider/Outsider Status. *Qualitative Inquiry,* 7 (4)**,** 436-447.

SHILDRICK, M. 1997. *Leaky Bodies and Boundaries: Feminism, Postmodernism and (Bio)Ethics.* London: Routledge.

SHILDRICK, M. 2009. *Dangerous Discourses of Disability, Subjectivity and Sexuality.* Basingstoke: Palgrave Macmillan.

SLATER, J. 2013. *Constructions, Perceptions and Expectations of being 'Young' and 'Disabled': A Critical Disability Perspective.* Ph.D., Manchester Metropolitan University.

SNYDER, S. H. & MITCHELL, D. T. 2006. *Cultural Locations of Disability.* Chicago: University of Chicago Press.

SÖDERSTRÖM, S. & YTTERHUS, B. 2010. The Use and Non-Use of Assistive Technologies from the World of Information and Communication Technology by Visually Impaired Young People: A Walk on the Tightrope of Peer Inclusion. *Disability & Society,* 25 (3)**,** 303-315.

SPIVAK, G. 1988. *Can the Subaltern Speak?* Basingstoke: Macmillan.

STEELE, R. B. 1994. Accessibility or Hospitality? *Journal of Religion in Disability & Rehabilitation,* 1 (1)**,** 11-26.

STIKER, H. J. 1999. *A History of Disability.* Ann Arbor, MI: University of Michigan Press.

STILL, J. 2010. *Derrida and Hospitality: Theory and Practice.* Edinburgh: Edinburgh University Press.

STOLZ, J. 2011. 'All Things are Possible.' Towards a Sociological Explanation of Pentecostal Miracles and Healings. *Sociology of Religion,* 72 (4)**,** 456-482.

STONE, E. & PRIESTLEY, M. 1996. Parasites, Pawns and Partners: Disability Research and the Role of Non-disabled Researchers. *British Journal of Sociology,* 47 (4)**,** 699-716.

STONE, H. W. 1983. *The Caring Church: A Guide for Lay Pastoral Care.* San Francisco, CA: Harper & Row.

STOOKEY, L. H. 2003. Inclusiveness as Hospitality in Worship Settings. *Journal of Religion, Disability & Health,* 7 (3)**,** 95-102.

STRECKER, C. 2002. Jesus and the Demoniacs. *In:* STEGEMANN, W., MALINA, B. J. & THEISSEN, G. (eds.) *The Social Setting of Jesus and the Gospels.* Minneapolis, MN: Fortress Press, 117-133.

SUGIRTHARAJAH, R. S. 2002. *Postcolonial Criticism and Biblical Interpretation.* Oxford: Oxford University Press.

SUTHERLAND, A. T. 1981. *Disabled We Stand.* London: Souvenir Press.

SWAIN, J. & FRENCH, S. 2008. *Disability On Equal Terms.* London: Sage Publications.

SWAIN, J., FRENCH, S. & CAMERON, C. 2003. *Controversial Issues in a Disabling Society.* Maidenhead: Open University Press.

SWINTON, J. 1997. Restoring the Image: Spirituality, Faith, and Cognitive Disability. *Journal of Religion and Health,* 36 (1)**,** 21-28.

SWINTON, J. 2000. *Resurrecting the Person: Friendship and the Care of People with Mental Health Problems.* Nashville, TN: Abingdon Press.

SWINTON, J. 2002. Spirituality and the Lives of People with Learning Disabilities and Review. *Learning Disability Review,* 7 (4)**,** 29-35.

SWINTON, J. 2011. Who is the God We Worship? Theologies of Disability; Challenges and New Possibilities. *International Journal of Practical Theology,* 14**,** 273-307.

SWINTON, J. 2012a. *Critical Reflections on Stanley Hauerwas' Theology of Disability: Disabling Society, Enabling Theology.* Hoboken, NJ: Taylor and Francis.

SWINTON, J. 2012b. From Inclusion to Belonging: A Practical Theology of Community, Disability and Humanness. *Journal of Religion, Disability & Health,* 16 (2)**,** 172-190.

SWINTON, J., MOWAT, H. & BAINES, S. 2011. Whose Story Am I? Redescribing Profound Intellectual Disability in the Kingdom of God. *Journal of Religion, Disability & Health,* 15 (1)**,** 5-19.

TAIRA, T. 2013. Making Space for Discursive Study in Religious Studies. *Religion,* 43 (1)**,** 26-45.

TANNER, K. 1996. Theology and Popular Culture. *In:* HOPKINS, D. N. & DAVANEY, S. G. (eds.) *Changing Conversations: Religious Reflection and Cultural Analysis.* London: Routledge, 101-122.

TEAHAN, M. 2012. Down's Syndrome Boy Denied Communion, Says Mother. *Catholic Herald* [Online]. Available: https://catholicherald.co.uk/ [Accessed 18th April 2018].

THE ARCHBISHOPS' COUNCIL. 2015. Everyone Counts 2014: Diversity Audit Key Findings. London: Church of England

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

THOMAS, C. 2004. How is Disability Understood? An Examination of Sociological Approaches. *Disability & Society,* 19 (6)**,** 569-583.

THOMAS, C. 2007. *Sociologies of Disability and Illness: Contested Ideas in Disability Studies and Medical Sociology.* London: Palgrave Macmillan.

THOMPSON, J. L. 2007. *Reading the Bible with the Dead.* Grand Rapids, MI: Eerdmans.

THOMPSON, N. 2010. *Promoting Equality, Valuing Diversity: A Learning and Training Manual.* Lyme Regis: Russell House.

THORNICROFT, G. 2006. *Shunned: Discriminating Against People with Mental Illness.* Oxford: Oxford University Press.

TINKLIN, T., RIDDELL, S. & WILSON, A. 2004. Policy and Provision for Disabled Students in Higher Education in Scotland and England: The Current State of Play. *Studies in Higher Education,* 29 (5)**,** 637-657.

TOENSING, H. J. 2007. Living Among The Tombs: Society, Mental Illness, and Self-Destruction in Mark 5: 1-20. *This Abled Body: Rethinking Disabilities in Biblical Studies.* Atlanta, GA: Society of Biblical Literature, 131-144.

TORBERT, W. R. 1981. Why Educational Research Has Been So Uneducational: The Case for a New Model of Social Science Based on Collaborative Inquiry. *In:* REASON, P. (ed.) *Human Inquiry in Action: Developments in New Paradigm Research.* London: Sage Publications, 141-151.

TORCH TRUST. 2018. *Torch Trust: Vision for People with Sight Loss* [Online]. Torch Trust. Available: http://www.torchtrust.org/ [Accessed 28th August 2018].

TOURAINE, A. 1981. *The Voice and The Eye: An Analysis of Social Movements.* Cambridge: Cambridge University Press.

TRELOAR, L. L. 2000a. Spiritual Beliefs, Response to Disability, and the Church - Part 1. *Journal of Religion, Disability & Health,* 3 (4)**,** 5-32.

TRELOAR, L. L. 2000b. Spiritual Beliefs, Response to Disability, and the Church - Part 2. *Journal of Religion, Disability & Health,* 4 (1)**,** 5-31.

TRELOAR, L. L. 2002. Disability, Spiritual Beliefs and the Church: The Experiences of Adults with Disabilities and Family Members. *Journal of Advanced Nursing,* 40 (5)**,** 594-603.

TREMAIN, S. 2002. On The Subject Of Impairment. *In:* CORKER, M. & SHAKESPEARE, T. (eds.) *Disability/Postmodernity.* London: Continuum, 32-47.

TREMAIN, S. 2010. *Foucault and the Government of Disability.* Ann Arbor, MI: University of Michigan Press.

TREVISAN, F. & REILLY, P. 2014. Ethical Dilemmas in Researching Sensitive Issues Online: Lessons from the Study of British Disability Dissent Networks. *Information, Communication & Society,* 17 (9)**,** 1131-1146.

TWELFTREE, G. H. 1985. *Christ Triumphant: Exorcism Then and Now.* London: Hodder & Stoughton.

UPIAS 1976. Fundamental Principles of Disability. London: Union of the Physically Impaired Against Segregation.

UPSON-SAIA, K. 2011. Resurrecting Deformity: Augustine on Wounded & Scarred Bodies in the Heavenly Realm. *In:* SCHUMM, D. & STOLTZFUS, M. (eds.)

Disability in Judaism, Christianity, and Islam: Sacred Texts, Historical Traditions, and Social Analysis. New York, NY: Palgrave Macmillan, 93-122.

VANIER, J. 1999. *Becoming Human.* London: Darton, Longman & Todd.

VELLENGA, S. J. 2008. Hope for Healing: The Mobilization of Interest in Three Types of Religious Healing in the Netherlands since 1850. *Social Compass,* 55 (3), 330-350.

VERTER, B. 2003. Spiritual Capital: Theorizing Religion with Bourdieu against Bourdieu. *Sociological Theory,* 21 (2), 150-174.

VILLAGE, A. 2005. Dimensions of Belief about Miraculous Healing. *Mental Health, Religion & Culture,* 8 (2), 97-107.

WALLMAN, J. 2001. *Disability as Hermeneutic: Towards a Theology of Community.* Ph.D., University of Birmingham.

WALLS, N. H. 2007. The Origins of the Disabled Body. *In:* AVALOS, H., MELCHER, S. J. & SCHIPPER, J. (eds.) *This Abled Body: Rethinking Disabilities in Biblical Studies.* Atlanta, GA: Society of Biblical Literature, 13-30.

WALMSLEY, J. 2004. Inclusive Learning Disability Research: The (Nondisabled) Researcher's Role. *British Journal of Learning Disabilities,* 32 (2), 65-71.

WALTER, T. & DAVIE, G. 1998. The Religiosity of Women in the Modern West. *British Journal of Sociology,* 49 (4), 640-660.

WALTZ, M. 2005. Reading Case Studies of People with Autistic Spectrum Disorders: A Cultural Studies Approach to Issues of Disability Representation. *Disability & Society,* 20 (4), 421-435.

WARE, L. 2016. Writing, Identity, and the Other: Dare We Do Disability Studies? *Journal of Teacher Education,* 52 (2), 107-123.

WARNER, J. 2008. Community Care, Risk and the Shifting Locus of Danger and Vulnerability in Mental Health. *In:* PETERSON, A. & WILKINSON, I. (eds.) *Health, Risk and Vulnerability.* London: Routledge.

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 & Society,* 17 (5), 509-527.

WATSON, N. 2012. Researching Disablement *In:* WATSON, N., ROULSTONE, A. & THOMAS, C. (eds.) *Routledge Handbook of Disability Studies.* New York, NY: Routledge, 93-106.

WATTS BELSER, J. 2011. Reading Talmudic Bodies: Disability, Narrative, and the Gaze in Rabbinic Judaism. *In:* SCHUMM, D. & STOLTZFUS, M. (eds.). New York, NY: Palgrave Macmillan, 5-27.

WATTS, F. N. 2011. *Spiritual Healing: Scientific and Religious Perspectives.* Cambridge: Cambridge University Press.

WEBB-MITCHELL, B. 1988. *L'Arche: An Ethnographic Study of Persons with Disabilities Living in a Community with Non-disabled People.* Ph.D., University of North Carolina.

WEBB-MITCHELL, B. 1994. *Unexpected Guests at God's Banquet: Welcoming People with Disabilities Into the Church.* New York: Crossroad.

WEBSTER, C. M. 2007. Paradox in the Development of the Non-Disabled Church: Reflection on John 9: 1-41. *Journal of Religion, Disability & Health,* 11 (3), 23-49.

WEEMS, R. J. 1995. *Battered Love: Marriage, Sex, and Violence in the Hebrew Prophets.* Minneapolis, MN: Fortress Press.

WEISS BLOCK, J. 2002. *Copious Hosting: A Theology of Access for People with Disabilities.* New York, NY: Continuum.

WELLS, S. & QUASH, B. 2010. *Introducing Christian Ethics.* Hoboken, NJ: Wiley Blackwell.

WENDELL, S. 1996. *The Rejected Body.* London: Routledge.

WENDELL, S. 2010. Toward a Feminist Theory of Disability. *In:* DAVIS, L. J. (ed.) *The Disability Studies Reader (3rd ed.).* New York, NY: Routledge, 336-352.

WHITE, J. F. 2003. *Protestant Worship and Church Architecture: Theological and Historical Considerations.* Eugene, OR: Wipf and Stock Publishers.

WILLETT, J. & DEEGAN, M. J. 2001. Liminality and Disability: Rites of Passage and Community in Hypermodern Society. *Disability Studies Quarterly,* 21 (3)**,** 137-152.

WILLIAMS, D. S. 1993. *Sisters in the Wilderness: The Challenge of Womanist God-talk.* Maryknoll, NY: Orbis Books.

WOLBRING, G. 2007. New and Emerging Sciences and Technologies, Ableism, Transhumanism and Religion, Faith, Theology and Churches. *Madang* [Online], 7. Available: http://www.dbpia.co.kr/ [Accessed 17th October 2018].

WOLBRING, G. 2008. The Politics of Ableism. *Development,* 51 (2)**,** 252-258.

WUTHNOW, R. 1994. *'I Come Away Stronger': How Small Groups are Shaping American Religion.* Grand Rapids, MI: Eerdmans.

WUTHNOW, R. 1998. *After Heaven: Spirituality in America Since the 1950s.* Berkeley, CA: University of Califomia Press.

WUTHNOW, R. 2002. Religious Involvement and Status-Bridging Social Capital. *Journal for the Scientific Study of Religion,* 41 (4)**,** 669-684.

WYNN, K. H. 2007. The Normate Hermeneutic and Interpretations of Disabiliy within the Yahwistic Narratives. *In:* AVALOS, H., MELCHER, S. J. & SCHIPPER, J. (eds.) *This Abled Body: Rethinking Disabilities in Biblical Literature.* Atlanta, GA: Society of Biblical Literature, 91-102.

YONG, A. 2007. *Theology and Down Syndrome: Reimagining Disability in Late Modernity.* Waco, TX: Baylor University Press.

YONG, A. 2011a. *The Bible, Disability, and the Church: A New Vision of the People of God.* Grand Rapids, MI: Eerdmans.

YONG, A. 2011b. Disability from the Margins to the Center: Hospitality and Inclusion in the Church. *Journal of Religion, Disability & Health,* 15 (4)**,** 339-350.

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

ZARB, G. 1997. Researching Disabling Barriers. *In:* BARNES, C. & MERCER, G. (eds.) *Doing Disability Research.* Leeds: The Disability Press, 49-66.

ZIMMER, M. 2010. 'But The Data is Already Public': On The Ethics of Research in Facebook. *Ethics and Information Technology,* 12 (4)**,** 313-325.

ZUCKERMAN, P. 2011. *Faith No More: Why People Reject Religion.* New York, NY: Oxford University Press.

ZUKIN, S. 1993. *Landscapes of Power: From Detroit to Disney World.* Berkeley, CA: University of California Press.

Appendix 1: Glossary

Asperger Syndrome: An autistic spectrum disorder. Some participants referred to their condition as Asperger*'s* Syndrome, and I have kept this usage in transcription.

Anglo-Catholic: A description of a church which grew out of the 19th-century Oxford Movement, which sought to renew Catholic aspects of faith and practice in Anglican churches. Anglo-Catholic churches are sometimes called "high," because they give a "high" place to liturgical ritual.

Autistic spectrum disorder: One of a range of conditions, including autism and Asperger Syndrome, characterised by difficulties in social interaction and communication, sometimes accompanied by learning difficulties. Some of the participants in this study referred to themselves as autistic people, while others referred to themselves as people with Asperger Syndrome. I use the umbrella term "autistic," following the conventions of the autistic people's movement, when referring to autistic participants as a group, but I have otherwise reflected their self-definition with regard to language about their impairments.

Charismatic churches: Churches which, in common with Pentecostal churches, emphasise the gifts of the Holy Spirit such as speaking in tongues, and informal worship.

Christology: Christian theology relating to the person, nature and role of Christ.

Circuit: In a Methodist denominational context, a circuit is a grouping of churches. The circuit has pastoral and administrative oversight of several local churches.

Communicant: A person who receives Holy Communion.

Deaf/deaf: As defined in the Introduction, "Deaf" (with a capital D) is generally used to indicate someone who is culturally Deaf, uses British Sign Language and sees themselves as part of the Deaf community, a linguistic and cultural minority. In contrast, those who identify as "deaf" (with a lower-case d) tend to be those people with hearing impairments who do not use BSL, nor consider themselves part of the Deaf community. Although the field of deaf studies has recently challenged this division, my D/deaf participants used these distinctions.

Deanery: In an Anglican denominational context, a deanery is an administrative grouping of parishes, presided over by a rural dean.

Deliverance ministry: A growing ministry in neo-Pentecostal and charismatic churches, Hunt defines it as "a 'low level' means of expelling evil spirits" (1998:215). The concept of *exorcism* is comparable.

Disability vs impairment: As discussed in the Introduction, the social model separates disability from impairment, considering impairment as the effects of an individual's illness, injury or health condition, and disability as the loss or limitation of opportunities to participate in society as a result of social and environmental barriers.

Disabled People's Organisation (DPO): Participatory, user-led organisations of disabled people, with activist aims of societal change for disabled people, especially in service provision. They are central to the history of the disabled people's activist movement, as it has been defined in disability studies. [See also entry for *user-led organisation* and *service user*.]

Ecclesiastical: Of or relating to churches as established institutions.

Ecclesial: Of or relating to churches or their nature, without the institutional focus contained in "ecclesiastical."

Eschatology: Christian theology relating to death, the end times and the afterlife.

Eucharist: The Christian service, rite or sacrament commemorating the Last Supper, also referred to as *Holy Communion.*

Evangelical churches: Protestant churches that focus on personal salvation (including conversion or being "born again"), have a high, often literalist regard for the Bible, and have a missionary commitment to sharing the gospel.

Fall, the: A theological term, this concept refers to the fall of Adam from God's grace through his first sin of disobedience, and through him the Fall of humanity from grace. Referred to by some participants.

Franciscan Tertiary: A member of the Third Order of Saint Francis, a lay order which originated in the Franciscan movement of the Catholic Church. There is now also an Anglican Third Order. Members are part of ecclesiastical communities called fraternities. Several participants were either Third Order members or interested in membership.

Gospel vs. gospel: The different capitalisation distinguishes the *Gospels*, the four books of the Bible that narrativise Jesus' life, from the *gospel* or Christian message of Christ and salvation. See also entry for *social gospel.*

Hermeneutic[s]: The field of study dealing with interpretation of the Bible and other religious texts, or a method or theory of interpretation.

"High" church: See entry for *Anglo-Catholic church*.

Independent living movement: A movement which argues that disabled people are the experts on their own needs, and that they should control the services which are designed to meet those needs. In Chapter 4 and 5 I refer to the independent living model, which is similar to the social model of disability, but with a particular focus on enabling the independence of disabled people through the principles established by the independent living movement.

Lay minister: A minister who carries out some or all of the functions of ordained clergy, but are not ordained and are usually volunteers.

Liturgical church: A church with prescribed, formal structures or orders of service, in such denominations as Anglican, Lutheran and Roman Catholic.

Makaton: A simple sign language, primarily used by and with those with learning difficulties. Discussed in relation to WAVE Church in Chapter 1.

Mental distress: The field of mad studies increasingly uses the terms *mental distress* or *madness* to describe mental health problems, as these are user-defined and social model terms that allow a focus on societal oppression.

Neurodivergent: Neurological and neurocognitively atypical patterns of thought and behaviour, in comparison with social norms. Used occasionally in this thesis as an umbrella term to refer to participants with autistic spectrum disorders, who had different diagnoses, following the conventions of the autistic people's movement. [See also entries for *neurotypical* and *autistic spectrum disorder*.]

Neurotypical: Not displaying autistic or other neurologically atypical patterns of thought or behaviour; or a person without a neurodivergent condition such as autism. [See also entry for *neurodivergent.*]

New Churches: The British New Church movement developed out of the earlier house church movement; churches in this movement tend to be charismatic, Restorationist (aiming to restore New Testament church structure), and have a focus on the discipleship of Christians by church leaders. The movement includes the New Frontiers church network, of which one participant had been a member.

Ordained ministers: Ecclesiastically appointed ministers, authorised to perform church rites and sacraments.

Parachurch: Christian organisations that work outside and/or across denominations.

Passing: The ability of a person to be overlooked as a member of a marked category, passing as a member of the unmarked category; in the case of the subject of this thesis, passing as non-disabled or less disabled than is true in one's subjective experience.

Preside (at communion): To lead in administering communion to a congregation; in many denominations, a function only undertaken by ordained priests.

Religious capital: As defined by Iannaccone, "The skills and experience specific to one's religion includ[ing] religious knowledge, familiarity with church ritual and doctrine, and friendships with fellow worshippers" (2001:299). [See also entry for *spiritual capital*.]

Service user: A person who uses health and/or social care services. Much research in disability studies considers service users' involvement in and ownership of services. [See also entry for *user-led organisation*.]

Social gospel: The Christian message of the gospel understood not just as about personal salvation, but as a call to social reform.

Spiritual capital: As defined by Verter (2003), this encompasses the skills, experiences and resources needed for an active engagement in church and spirituality, including religious knowledge and theological thought. [See also entry for *religious capital.*]

Transhumanism: Defined as "the intellectual and cultural movement that affirms the possibility and desirability of fundamentally improving the human condition through applied reason, especially by developing and making widely available technologies to eliminate aging and to greatly enhance human intellectual, physical, and psychological capacities" (World Transhumanist Association, 2003).

User-led organisation/group (ULO): A body that is organised and controlled by people who use support services: by disabled people, or by members of a specific impairment group. Such a group has a minimum of 75% of its board made up of disabled people, and demonstrates a commitment to the social model (Social Care Institute for Excellence, 2014).

Appendix 2: Participant Summaries

Participants are listed in first-name alphabetical order using terms they chose for themselves, except where clarification was required.

Andrew (focus group 2)

Andrew was 46 years old at time of interview. He identifies as deaf and disabled, and used a British Sign Language interpreter to access the focus group discussion. He is an evangelical Christian. Andrew was not attending church at time of interview, but he had previously attended a New Frontiers charismatic church and a Church of England church. He left when it became too difficult for him to access hearing-centred church culture. He was continuing to visit Church of England churches occasionally. After the interview, Andrew provided an update by e-mail that he now identifies as Deaf, culturally and linguistically. He is white British and is a carer for his two disabled children.

Anthony (individual interview)

Anthony has Asperger Syndrome and identifies as disabled. He used to attend a liturgical, "high" Anglican church, but he was no longer attending any church at time of interview. When he was younger, he had considered ordination in the Church of England. One of his key reasons for leaving churches was his difficulty with their social cultures. He continues to define as a Christian, even though he is no longer a churchgoer. Anthony is white British, was 34 years old at time of interview, and lives in London.

Brianna (individual interview)

Brianna has multiple sclerosis, is a wheelchair user and identifies as disabled. At the time of interview, Brianna had been worshipping at a cathedral church for the past 15 years. For 10 of those years she had attended as a wheelchair user. She had significant difficulties accessing her cathedral church. She was actively involved in the cathedral community, organising Sunday school and events. She said of the research that "disability and Christianity…is definitely an area we need to develop." In post-interview email communication she said that "nothing has changed" at her cathedral church since the research. Brianna's interview took place over Skype video call; she is white European and was 55 years old at time of interview.

Charlotte (focus group 2)

Charlotte has a fatigue condition, and she identifies as disabled and chronically ill. Charlotte attended a liberal, liturgical Church of England church at time of interview, but had previously attended Baptist and independent evangelical churches. Charlotte described her faith as "Franciscan, Contemplative, Eucharistic, Inclusive." Charlotte was working as a spiritual director, at time of interview; she now works in a hospital chaplaincy, although she is not ordained—barriers to exploring ordination have been an ongoing frustration for her. Charlotte is a Franciscan Tertiary, was 31 years old at time of interview, is white British and lives in the South East of England.

Clare (pair interview 1)

Clare has ME/chronic fatigue syndrome and identifies as disabled. She described her church background as evangelical. At time of interview, Clare was attending an evangelical free church. She had moved churches after some negative experiences since becoming unwell. She described her current church as a more welcoming environment, although she said that she had mixed experiences of inclusion in churches. Clare's interview took place over Skype video call; she was 28 years old at time of interview and is white British.

Deirdre (individual Skype text-based interview and follow-up emails)

Deirdre is a member of an evangelical Baptist church. She identifies as chronically ill. She had been housebound with severe ME/chronic fatigue syndrome for 18 years, at time of interview, which meant that she could not attend church. She had been attending her church for 19 years. Despite being unable to leave her house, she stayed involved in church remotely, with the support of fellow church members. She said that her church has been very supportive during her illness, although it was sometimes difficult to stay connected to her church, given barriers relating to her inability to attend physically. Deirdre is white British and was 57 years old at time of interview.

Emily (focus group 3 and research message board contributions)

Emily has ME/chronic fatigue syndrome and cerebral palsy. She identifies as a disabled person. She has attended multiple churches through her life, primarily Church of England. At time of interview, she attended a liturgical Anglican church for midweek services, and on Sunday evenings she was involved with a New Monastic community—these alternative ways of attending church were more accessible to her than standard Sunday morning services. Her churches were generally supportive, although she had sometimes encountered difficulties like being offered prayer for healing when this did not interest her. Emily has a theology degree and is active in online and other networks of disabled Christians. She is white British, lives in London, and was 35 years old at time of interview.

Faith (focus group 2, message board contributions and follow-up emails)
Faith lives in the East Midlands. She is invisibly impaired with a condition that causes fatigue and identifies as a disabled and chronically ill person. She described herself as a born-again Christian. In the past she has attended various churches, including Church of England and independent evangelical. At time of interview she was unable to find a home church, due to difficulties leaving the house. However, she had formed her own Bible study groups via the internet and in person with other disabled Christians. Faith was 45 at time of interview.

George (individual Skype text-based interview)
George has an autistic spectrum disorder and identifies as disabled. She has attended many different types of church. At time of interview, she was attending a liturgical Anglican church, and seeking widely outside of church for answers to theological questions. George was 33 years old at time of interview, is white British and lives in the South East of England.

Hazel (pair interview 2)
Hazel is blind and identifies as disabled. She had attended her evangelical church (nominally Baptist) for 25 years. She said of her church that she was “not very well included,” although she enjoyed the worship and evangelical teaching. She is married to Victor, with whom she was interviewed. Hazel was 65 years old at time of interview, is white British and lives in London.

Helen (individual interview)
Helen is blind, but prefers not to think of herself as a disabled person, instead aiming to be “as normal as I can be.” She had been a Church of England minister since 1981, and said she was the first blind woman minister in the Anglican church. Her ministry has mainly been in evangelical Anglican churches. She had faced something of a struggle to become ordained, but felt she had had a successful ministerial career after that, despite some barriers of church buildings and facilities.

She felt a calling from God and that he had helped her to manage as a blind minister. Helen was 71 years old at time of interview, is white British, and lives in the South East of England.

Isabelle (individual interview)

Isabelle is a full-time wheelchair user and identifies as disabled. She was attending a Church of England church at time of interview, and described her church background as evangelical and charismatic. She had recently been accepted to train as an ordained local minister in her church, where she felt very included, although she continued to face some barriers which she said sometimes led her to feel excluded. Isabelle's interview took place over Skype video call. She was 50 years old at time of interview and is white British.

James (focus group 3)

James has Asperger Syndrome and identifies as disabled. He describes his faith as conservative, evangelical and Bible-believing. He attends a small independent evangelical church, where he has been a congregant all his life. He said that he felt very included there, and thought this was partly because of how well he was known in the congregation. He was also involved in the Christian Union at his university. James describes his ethnicity as British Asian and Welsh; at time of interview he was 23 and lived in London.

Jean (individual interview)

Jean describes herself as "recently disabled," after having a stroke 5 years prior to interview, which caused mobility impairments. She uses a wheeled walker for mobility. She is a carer for her son, who has learning difficulties. Jean has attended her liturgical Church of England church since 1989, and felt very included there, partly because they know her very well. She said that they also try to include her son, and that she explains aspects of church and faith to him at home. Jean's interview took place over the telephone; she was 82 years old at time of interview, is white British, and lives in the north of England.

Katie (focus group 1)

Katie has cerebral palsy and identifies as disabled. She is an ordained Church of England minister, and has been a vicar in more than one church. Katie had been seeking theologies of disability for a long time; not finding any that resonated with her, she established a user-led theology group which has become host to a virtual network of disabled Christians. The group has run forums and provides resources. Katie had had a mixed range of experiences as a disabled person in churches, but felt that more were positive than negative. Katie was 40 years old at time of interview, is white British and lives in the Midlands.

Liz (individual interview)

Liz is blind, but prefers not to think of herself as disabled. She has been attending her Church of England church since 1984. Liz was interested in theology, and had taken courses at a spiritual centre in London. She is actively involved in her church where she runs a Torch Trust group for other blind people. She had at one point considered becoming a Franciscan Tertiary, but decided this would be too difficult, given her blindness. At time of interview, Liz was 74. She is white British and lives in London.

Lucy (individual interview)

Lucy has Asperger Syndrome, dyspraxia and insulin-dependent diabetes, and identifies as disabled. At time of interview, she was attending an independent evangelical church where she sometimes found it difficult to participate for reasons relating to her disability needs, including the large size of the church. She had taken some time to find a church where she felt comfortable. Lucy's interview took place on Skype video call. She is white British, was 27 years old at time of interview and lives on the south coast of England.

Maria (pair interview 3)

Maria has fibromyalgia, which causes impairments of chronic pain and fatigue, and identifies as disabled. At time of interview, she attended an independent evangelical church, where she had not always felt included and had struggled with attendance and other requirements. In post-interview emails she said that she had left her church and was seeking another, prioritising her disability access needs in her search. Maria was 40 years old at time of interview, lives on the south coast of England and is white British.

Mary (individual interview)

Mary identifies as having long-term mental health problems, but not specifically as disabled. She has several mental health diagnoses. She has attended a number of different churches and denominations, including Assemblies of God (Pentecostal) and Church of England. At time of interview, Mary had more recently been attending a church in an evangelical charismatic church network. Although she had not felt included in previous churches, she felt very included in her current church, where people were thoughtful about her needs. Mary's interview took place over Skype video call. At time of interview, Mary was 24 years old. She lives in Norfolk and is white British.

Mims (individual interview)

Mims identifies both as a disabled person, and as a person who experienced long-term mental distress. She is an active member of a large liturgical Anglican church, where she has been involved with the church's disability work and disability activism. She found ways to stay involved in the church, including attending smaller evening services, although she sometimes struggled with the larger services and social focus of the church. At time of interview, Mims was 48 years old. She is white British and lives in London.

Miranda (individual interview)

Miranda has incomplete tetraplegia (paralysis), uses a wheelchair and identifies as disabled. Miranda has attended Church of England churches all her life and is a Franciscan Tertiary. She has attended three different churches since she became disabled twenty years ago. Although she enjoyed attending her church and was involved in disability activism there, she encountered barriers relating to the building and the way that communion was offered. In post-interview communication, she told me that she had moved churches, and that the issues of building accessibility were her main reason for doing so. Miranda was 67 years old at time of interview, is white British and lives in the Midlands.

Pauline (pair interview 4)

Pauline has cerebral palsy, is a wheelchair user and identifies as a disabled person. She uses a text-to-speech device for communication. Pauline had attended her independent evangelical church for 30 years, at time of interview. She was also involved with the Disabled Christian Fellowship, a group for disabled Christians. Pauline is white British, lives in the South of England, and was 56 years old at time of interview.

Rhona (focus group 1)

Rhona is visually impaired and identifies as disabled. She is a local minister (lay minister) in the Methodist Church. She is active in her church, which she described as evangelical and charismatic, and in her wider circuit. She said that her experiences of church had been mixed: “negative in catering for my disability, positive in sense of growing my faith and gifts.” She lives in the Midlands, was 61 at time of interview and is white British.

Sheila (pair interview 1)

Sheila defines as disabled, has multiple sclerosis, and at time of interview she had been a wheelchair user for 10 years. She attended a Church of England evangelical charismatic church, where she said she had mostly positive experiences, with a few more negative. Sheila was 57 years old at time of interview, is white British and lives in the South of England.

Shona (focus group 1)

Shona identifies as disabled. She is profoundly deaf and has a cochlear implant; she also has other impairments, but in her interview she preferred mainly to discuss her experiences as a deaf person. Her background is in Anglo-Catholic churches. At time of interview, she was attending a Church of England liberal and liturgical church. She has a theology degree and was considering ordination. She had mixed experiences as a disabled person in churches, although more generally positive over the past 4-5 years. Her biggest frustration was with stereotypes and poor understanding of deafness in churches, which she felt was particularly because it is a hidden impairment. Shona was 33 years old at time of interview, is white British and lives in the North of England.

Stephen (pair interview 3)

Stephen has had ME (also known as chronic fatigue syndrome) since 1994 and uses a mobility scooter. Stephen’s background is in Church of England churches; at time of interview, he had recently moved to a local church where the building was not fully accessible for his needs, but where he felt very included as a result of positive attitudes. However, he felt forgotten when he could not attend church for a while, as a result of illness. As well as being disabled himself, Stephen is a carer for his disabled wife. Stephen was 32 at time of interview, is white British and lives in the East of England.

Susanna (individual interview)

Susanna has ME/chronic fatigue syndrome and identifies as disabled. She is white British and lives in the north west of England. Susanna grew up in Anglican churches and has since then attended a number of types of churches including Methodist, which was the denomination of her church at time of interview. However, she prefers not to identify with denominations, saying "I tend just identify as 'Christian' as I attend the church I feel is the best fit rather than refer to denomination or type." She has more often felt included than excluded, as a disabled person in churches, in part because of the positive attitudes of those she has encountered in churches. Susanna's interview took place over Skype video call. Susanna was 33 years old at time of interview, lives in the North of England and is white British.

Talitha (pair interview 4)

Talitha has cerebral palsy, is a wheelchair user, and identifies as a disabled person. She had attended an independent evangelical church for 9 years at time of interview. Talitha described herself as an evangelical, Bible-believing Christian. She was actively involved in her church, and found the church generally very welcoming, but said that sometimes she felt "a bit on the outside." Talitha is white British, was 31 years old at time of interview and lives in the South of England.

Victor (pair interview 2)

Victor is blind and had attended his evangelical church (nominally Baptist) for 11 years. He identifies as disabled and, outside of churches, has been active in Disabled People's Organisations and the disability movement for many years. He had faced significant barriers in as a blind person in his church. Victor is married to Hazel, with whom he was interviewed. He was 50 years old at time of interview, is white British and lives in London.

Zoe (focus group 1)

Zoe is a wheelchair user with a chronic pain condition; she became disabled seven years before time of interview. She is an ordained Church of England minister; at time of interview, she was a curate in a liberal 'high' Anglican church. Zoe was 39 years old at time of interview, is white British and lives in the West Midlands.

Appendix 3: Research Consent and Confidentiality Materials

a) Informed Consent Form

Informed Consent Form

Thank you for responding to the request for research participants. The research is being conducted by Naomi Jacobs, PhD student in the Dept. of the Study of Religions, SOAS, University of London. There is a separate information sheet which explains what the research is about.

I will do everything I can to ensure that the group meetings are accessible to everyone. However, if you meet with any access problems, at any time, please inform me and I will do everything I can to help.

If you are happy to continue, please read the following agreement carefully. If you are comfortable with what you have read and are willing to take part, please sign the form (by typing your name below) and e-mail it back to me, **by the end of March** (if possible), along with the sampling questions. I will then email you a copy with my signature.

Confidentiality

I will be taking measures to ensure that everything you say during the research is kept confidential or anonymous. Everything said at meetings will be made anonymous for my research reports. I will ask other group members to keep information confidential.

No identifying information will be published or presented about you, in order to protect your identity. Any identifying details (name, church membership etc.) will be changed or made anonymous before the information is released or presented.

All paper-based information about this study will be kept in a locked cabinet in a locked office. All files held on computer will be password-protected. Your identifying information will only ever be seen by me. You will be given a unique number, so that you are completely anonymous to anyone who helps me to type up interviews or analyse them. Other people who may see this data (once it has been made anonymous) include my supervisor, my support workers, and the research advisory group. My support workers will also sign confidentiality agreements.

If at any time you have any concerns about any aspect of the study, please raise these with me. If you then decide that you no longer want to take part, you are free to withdraw from the group, at any time. You can then decide what you want to happen to your contributions to the study. If you decide to withdraw, please try to let me know by 30th January 2017, which is ten months before I hand in my final project.

You can request a copy of the results of this research, as a summary. You may have to wait a little longer if you request the results in an accessible format, such as Braille.

This study aims to follow the principles of **emancipatory disability research**, which was created by disability studies researchers, including Mike Oliver and Geof Mercer. This approach starts by asking disabled people about what needs researching. I will be starting with you, by asking for your ideas of the issues that are facing disabled people in Christian churches. Separately, I will also be working with an advisory group of disabled people, who will be helping me with the process of analysing the information that I gather as part of the research.

This is a new area of research, and I hope that it will have some impact on the way in which issues of disability are approached in Christian churches. I very much appreciate your participation and engagement in the project.

Agreement

The researcher, Naomi Jacobs:

- Agrees to attend every group meeting.
- Will ensure that group meetings are accessible to all, as far as possible.
- Will keep all group members' information confidential. Any comments to be used in presentations, articles or the thesis will be made anonymous.

I, __________________ *(participant's full name)*:

- Agree to participate in one group or individual interview (depending on access needs and preferences, as discussed with Naomi).
- Agree to keep all group members' information and details confidential.
- Understand that my comments in the interview will be recorded, but that any identifying details will be changed before my information is released or presented.
- Will discuss any problems with Naomi before asking to withdraw from the research, although I have the right to leave without giving a reason.

Informed Consent:

I sign here to state that I have read the above information and the information sheet about the research project. I have understood how I will participate in this research project. I understand that any questions I have about the study will be answered by the researcher as soon as possible, and that I may withdraw from the study at any time. I also understand that I am participating in a voluntary capacity.

Signed: ____ (participant)

Date: ____

Signed: ____ (Naomi Jacobs)

Date: ____

Please tick below to show whether you want your real first name or a different name used for you in research reports and the PhD thesis:

I would like a pseudonym (different name) used for me in research reports: ☐

I would like my first name used for me in research reports: ☐

Thanking you in advance for your help,

Naomi Jacobs

b) "Simple Words and Pictures Format" Information and Consent Form

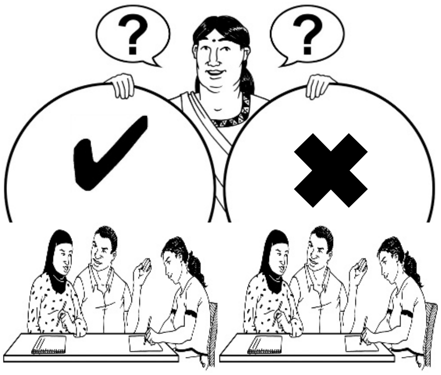
Information

Naomi Jacobs is studying at SOAS, University of London.

Naomi wants to find out what it is like for disabled people to go to church. This includes people with learning difficulties or long-term illnesses.

Naomi is looking for disabled people to tell her about this.

Naomi will meet people to talk about how they feel about church and Christianity.

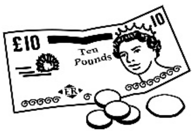


Do you want to be part of this research? You can choose to join in. You can also choose not to join in. It is up to you.

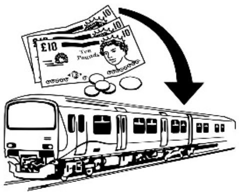
We can meet in a group. Or you can meet Naomi on your own.

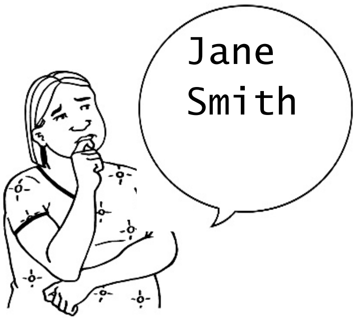
You can bring a support worker. We can arrange someone to help with sign language. The place where we meet will be accessible – as long as you tell us what you need.

It might be easier for us to talk on the internet. We can use Skype. Or we could talk on the phone.



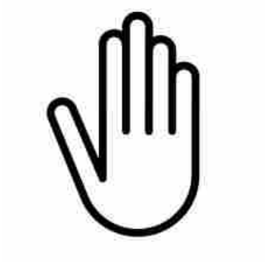
If you take part in the research, you will get some money for your time. You will also get your travel costs back.





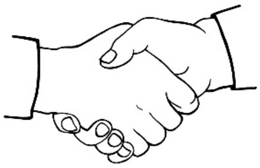
What you say to Naomi will be used when she writes about this project. Naomi can use a different name for you. That means no one will know what you said.

Naomi will record what you say. She will keep the recordings safe. No one else will listen to them except other people helping with the project.



If you want to stop taking part in the research, you can. Then you can decide if you still want Naomi to use your words in the project. But when the project is finished, you won't be able to change your mind about that.

You can ask **questions** at any time. Naomi can ask her support worker to phone you. You can e-mail with your question. Or Naomi can visit you to answer your questions. Naomi's details are at the end of this sheet.



Agreement

Naomi agrees that…

1. Naomi will be careful with the recordings and typed up words of what you say. She will only show them to people who are helping with the typing.

2. Naomi will not use your real name in the project. You can choose a different name so that people do not know what you have said.

I agree that…

1. I want to help with finding out about disabled Christians and churches. I am happy to take part in the research.

2. I have seen the leaflet about the project. Naomi has explained what the project is about. I have had a chance to ask questions.

3. I understand that I can stop taking part at any time. I don't need to explain why.

4. It is my own choice to take part.

Please sign here if you want to take part in the research:

Your name:

……………………………………………………………………

Signature:

………………………………………………………………………

Naomi will sign the agreement too:

Name: **Naomi Jacobs**

Signature:

……………………………………………..……………………………

You can e-mail Naomi at [*email address*]. If you prefer to talk on the telephone, you can email with your phone number and Naomi's support worker will ring you back. Or we can talk on Skype (internet chat). You can write to Naomi at: Naomi Jacobs, [*address*].

Thank you for reading this information sheet.

c) Participant Information Sheet

‘Uncovering the Roof’ – Research into Christianity and Disability: Information Sheet

You are being invited to take part in a research project. Before you decide if you want to take part, it is important for you to understand why the research is being carried out and what it will involve. Please read the following information carefully. You can discuss it with others. Take time to decide whether or not you wish to take part. Thank you for reading.

The research project

This research study is about **the experiences of disabled people who attend Christian churches** (or who used to). I will be investigating this through focus (discussion) groups. It is being partly funded by the St Luke’s College Foundation.

The researcher

I’m **Naomi Jacobs**[1]. I am studying for a PhD at SOAS, University of London. I am disabled myself. I also have past experience of attending various churches, although I do not currently attend a church. There will be an opportunity for you to ask me questions about my research and background before you take part in an interview.

Taking part in the research

Individually…

If you would like to meet me individually, I may be able to come to you (depending on distance), or we can talk on the internet e.g. over Skype. We can either meet over coffee and cakes, or in a quiet setting such as a room in a church. **The interview will take about an hour** (but a shorter interview can be arranged if this is too long for you). You can request a break at any time.

Or in a group, if you prefer…

About 3-5 people will meet for 1-2 hours each time. There will be breaks, and food and drink will be provided. We will mainly be talking, but there will also be some activities, such as discussing scenarios. You don’t have to take part in any activity that you are not completely comfortable with. I will talk to you in advance about what we will be doing.

If 1-2 hours is too long for you, we can discuss a different, shorter interview format.

What we’ll talk about…

We will talk about anything you think is important to Christians who are disabled (or who have learning difficulties, mental health problems, or long-term health conditions). This might include the way that stories from the Bible showing disabled people are used, or how well disabled people are included in church services and activities.

Accessibility

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[1] I publish under the name of Naomi Lawson Jacobs.

I will do everything I can to make discussions as accessible as possible. They will be held in a wheelchair-accessible venue. British Sign Language translation can be organised on request. Different diets can be catered for. You are welcome to bring a support worker. I will try to meet other access needs, as long as you tell me in advance.

I'm aware that not everyone will be able to meet in person, for disability-related reasons. There is a space on the attached questionnaire to tell me about your access needs. We can arrange interviews over Skype (either video chat or text chat) or by telephone.

After the group meeting…

There will be the opportunity take part in follow-up interviews. However, there is no obligation to take part in this. You can choose to come to just one group discussion, and end your involvement there.

You will be shown everything I write about you, before I publish my thesis.

Time

You will be asked to attend one individual or group interview between January and March 2015. There will be several groups – I will try to make sure that one is convenient for you.

Expenses

You will receive a contribution of £10 per hour for your time**. You will also get travel expenses and access costs refunded.** If you cannot accept payment because of your benefits situation, we can give the money to a charity/Disabled People's Organisation.

Risks and benefits of taking part

Although you will be paid for your time and expenses, you will be giving up your time. We will be discussing sensitive topics, such as your beliefs and experiences of disability at church. In group interviews, there will be a range of views represented. I will do everything I can to make sure you feel safe in the group. We will only use your first name in the group, or a pseudonym if you prefer.

I hope that the research will benefit disabled people and their churches. We will talk before the interview about some of the ways that the research might be used.

Recording and using information about you

Everything you say will be anonymous. I will be changing your name, or just using your first name (depending on which you prefer), when I write research reports. No one will be able to identify you.

I will be making audio (tape) recordings so that I have a record of what has been said in the group. Some short clips from the recordings may be used in presentations about the research, but only with your permission. In this case, names will be changed.

I will be assisted by transcribers and support workers. They will have access to the recordings and transcripts of what you have said. However, names will be changed first, if you have requested this.

Choosing not to take part

You can choose not to take part in the study. **You can also withdraw from the research at any time.** If you choose to withdraw from the research, we will talk about whether you want your information to be part of the study, or whether you would prefer us not to use it. (But if you do decide you want to withdraw, please discuss this with me, in case I can help.)

If you decide to take part in the study, you will need to sign a consent form (attached).

Contact details

You can contact me (Naomi Jacobs) by e-mail at [*email address*]. I find it difficult to talk on the phone for disability reasons, but we can arrange for my support worker to telephone you. You can also write to me: Naomi Jacobs, [*address*]. Or we can arrange to talk over Skype (internet-based video chat).

My supervisor is Sîan Hawthorne, who is also based at SOAS. She can be contacted at [*email address*]. There is a research blog for the project at http://naomijacobs.wordpress.com/ where I talk very generally about the project. (There will be no references on the blog to people who take part in the project, or what they say, except with permission and after publication of the thesis, in which case names will be changed.)

This research project has been ethically reviewed and agreed by SOAS, University of London.

Thank you in advance for considering taking part in the project.