# The perceptions of persons with disabilities, primary caregivers and church leaders regarding barriers and facilitators to participation in a Methodist congregation

**by**

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Since this research was conceived, I have been acutely aware that I would learn through experience what it really means to trust God. To what extent, I am still discovering as I write this… One thing is certain though; He can be trusted!

It is intriguing how the growing strength of my spiritual inquiry into the mystery of belonging to the *body of Christ* would also increasingly manifest the feebleness of my physical body. Facing trials and adversities I could never imagine, I was tested beyond my ability to endure, even to the point of despair. But this happened that I might not rely on myself but on God, who raises the dead. You have delivered me, and You will continue to deliver me as you firm up my frame in Christ. Jesus, my *'Yes'* and *'Amen'*, to the glory of God, You are faithful to all Your promises (2 Corinthians 1:8-21). Your Word will accomplish the purposes for which You sent it.

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# DECLARATION

With this, I Gail McMahon-Panther, declare that the dissertation with the title *"The perceptions of persons with disabilities, primary caregivers and church leaders regarding barriers and facilitators to participation in a Methodist congregation"*, is an original piece of work written by me, under the supervision of Prof. Juan Bornman.

Gail McMahon-Panther

September 2019

# ETHICS STATEMENT

The author, whose name appears on the title page of this dissertation, has obtained, for the research described in this work, the applicable research ethics approval.

The author declares that she has observed the ethical standards required in terms of the University of Pretoria's Code of ethics for researchers and the Policy guidelines for responsible research.

## ABSTRACT

Stereotypical definitions associating disability with incapacity or abnormality, marginalise persons with disabilities and subject them to discrimination, neglect and abuse. Although societal inclusion of persons with disabilities is progressively recognised as a human right, many obstacles still prevent them from participating in all aspects of community life, including church activities. The paucity of literature on disability within religious environments include few studies applicable to the diverse Southern African socio-cultural context.

The purpose of this study was to determine and describe the perceptions of persons with disabilities, primary caregivers of persons with disabilities, and church leaders within a specific Christian congregation, to determine what they deem barriers and facilitators to participation within their unique context. The study was framed within a qualitative, descriptive case study design. Using focus groups with three different participant groups as the data collection method, a comprehensive and in-depth account of the participants' (n=17) perceptions was documented. Data analysis occurred inductively and deductively. Emergent themes were linked to the relevant theoretical framework, the ICF. Themes included perceptions concerning the social status of persons with disabilities, and how this relates to addressing and accommodating their needs, based on the levels of awareness and understanding of disability. Additionally, perceptions surfaced around access to the physical environment and necessary resources. Numerous connections between the themes and the ICF environmental codes verified the participants' perceptions that factors in their congregation's environment hinder, rather than enable, the participation of persons with disabilities in church-related activities. The findings were presented by a social deconstruction of disability, describing disability from a systems thinking perspective.

The results implied the need for practical measures to ensure the participation of persons with disabilities in church ministries, and for open communication among all the stakeholders. It is essential to recognise and change the mental conceptualisations that sustain exclusion. The findings also provide recommendations where future research can make additional contributions to the relatively small body of knowledge addressing participation in local churches.



**Keywords:** barriers, belonging, church, disability, exclusion, facilitators, faith, ICF, inclusion, Methodist, participation, religion, systems

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# CHAPTER 1
# PROBLEM STATEMENT

## 1.1 Introduction

In this chapter, an outline of the research is presented with reference to the background, motivation and purpose for the study, presented as a problem statement. In addition to the provision of clarifying definitions of frequently used terminology, a list of abbreviations is included, after which an overview of each chapter in the dissertation is given.

## 1.2 Problem statement

Entrenched in bias and stereotypes, the pervasive definitions that associate disability with incapacity or abnormality continually hurl persons with disabilities to the fringes of society where they are often patronised, dehumanised and subjected to discrimination, neglect and abuse (Ochs, 2014). They are familiar with exclusion, not only from society at large but also from their own faith communities (Gurbai, 2014; Leshota, 2015). In these settings, the negation of their value is unveiled both practically and abstractly, ranging respectively from the physical inaccessibility of church buildings (Möller, 2012), to the fixed intangible traditions that prohibit sharing certain sacraments with those who cannot verbally express their understanding of the rituals (Peters, 2009).

Societal inclusion of persons with disabilities is progressively recognised as a human right, yet many obstacles remain that prevent those with disabilities from participating and making meaningful contributions to society in all areas of community life (Donohue & Bornman, 2014). This includes participation in church activities (Gurbai, 2014; Lid, 2017). As an instrument for the implementation of human rights mandates and legislation globally, the International Classification of Functioning, Disability and Health (ICF) endorses the engagement and participation in religious or spiritual activities as an important life area that promotes improved levels of functioning (WHO, 2001).

Against a South African backdrop, despite the country's constitutional commitment to adhere to various treaties to create enabling environments that will ensure the full participation of persons with disabilities (McEwan & Butler, 2007), tacit exclusion is perhaps also mirrored in

the shortage of literature on disability, in particular, within religious environments (Leshota, 2015). The research available on disability mostly defines the concept from a Western viewpoint and suggests inclusion strategies that are not necessarily practical or applicable to the Southern African socio-cultural context (McEwan & Butler, 2007). With specific reference to Christian faith communities, hardly any local research on disability experiences exists, with the exception of that undertaken by Leshota (2015) and Möller (2012). These researchers situate their studies within the unique milieu that characterise the diverse cultural contexts of their participants and echo the voices that narrate the lived experiences of persons with disabilities.

Since disability studies is an emergent field in theology (Lid, 2017), the topic could be aptly discussed from that viewpoint; however, this study will instead focus on disability inclusion in the church, with particular emphasis on the construct of participation, as outlined by the ICF. Captured in Article 3 as one of its core principles, the United Nations' Convention on the Rights of Persons with Disabilities (CRPD), regards the inclusion and full participation of persons with disabilities in society as a human right (United Nations, 2006). Yet, apart from an incidental mention in its preamble, religion is not granted a stand-alone article in the CRPD, nor does religious participation feature anywhere else in the document (Degener, 2017). It is not certain if this was a deliberate omission, or an inadvertent oversight. Nonetheless, no recognition of the importance of religion, or of the right to protect the freedom and exercise of religion, is found in this seemingly comprehensive document (Silecchia, 2013). Regardless of efforts by landmark treaties to uphold and protect the dignity and rights of persons with disabilities, failures such as these perpetuate the exclusion of persons with disabilities from participation in important life areas like religion (Imhoff, 2017).

Despite the provision of a new definition for disability (Beaudry, 2016), tenets from oppressive belief systems are still wholly embedded in society and church doctrine alike (Lid, 2017). This study sets off with a discussion of the literature about the longstanding disability models identified by scholars within the fields of disability studies and theology. In doing so, the literature review focuses on how definitions of disability have shaped experiences and reinforced perceptions held in society by those with, and those without, disability. Furthermore, it looks at how these definitions have wrought the operational worldview of the church and how these social constructions have aided or impeded the inclusion and participation of persons with disabilities in the church.

In order to appreciate the persistent nature of the enduring discriminatory views on disability, a theoretical explication of this phenomenon is offered to grasp why change in society and in the church has been so resistantly slow over the years. Underpinnings of general systems theory are explored as a basis for understanding social change. This theory offers a suitable rationale, as it birthed the biopsychosocial model of disability upon which the ICF is founded. It also sheds light on the selection of the ICF as a theoretical framework for understanding and gauging participation, with its particular focus on contextual factors.

The purpose of the study is to determine and describe the perceptions of persons with disabilities, primary caregivers of persons with disabilities, and church leaders within a specific faith-based congregation, in order to determine what they consider to be barriers and facilitators to participation in their unique context. Based on the aforementioned, the subsequent question for this study is formulated as follows:

> *What are the perceptions of persons with disabilities, primary caregivers of persons with disabilities, and church leaders regarding barriers and facilitators to participation in ceremonies, activities and events in the church?*

## 1.3 Definition of terms

The following terms are frequently used and are therefore defined here for clarity regarding its meaning within this dissertation.

### *1.3.1 Disability*

*"Disability is the umbrella term for impairments (loss or abnormality of body function or structure), activity limitations (difficulties individuals may have in executing activities), and participation restrictions (problems individuals may experience in involvement in life situations)"* (Welch Saleeby, 2016b, p. 2). Building on the above description aligned with the ICF, (WHO, 2001), the professional training guide of the CRPD explains that *"the the notion of 'disability' cannot be rigid but rather depends on the prevailing environment and varies from one society to the next. While the Convention recognizes disability as an evolving concept, it clearly endorses the understanding of it as a social construct, when it states that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with*

*others"* (United Nations, 2014, p. 17). In the current study, disability is used to describe the **negative** outcome flowing from the interaction among persons with disabilities' impairments, activity limitations, and participation restrictions. The term *disability* is thus associated with hindering factors (barriers) to participation (WHO, 2001).

### ***1.3.2 Faith*** (see also Religion and Spirituality)

Judging by the varied definitions in the literature, Hellwig (1990) states that *"Faith is nearly impossible to define. It means something different to each individual. Faith is understood to be intensely personal and often seen as extremely private. The term 'faith' ranges in meaning from a general religious attitude on the one hand to personal acceptance of a specific set of beliefs on the other hand"* (Hellwig, 1990, p. 3). The distinction between faith, religion and spirituality is also not clearly delineated and the terms are often used interchangeably. Even so, the concept of *faith* is easily understood by the following description: *"spirituality and religion are a function of faith. Both religion and spirituality require faith as a foundation. In other words, faith is the guiding principle by which individuals are either religious or spiritual. Faith serves as both the source and the target of their religion or spirituality. Devotion to religion or perception of growth in spirituality may be seen as a measure of greater valence of understanding one's faith"* (Newman, 2004, p. 106). While several references to faith are made in the dissertation, the term *religion* bears more resemblance to the purpose of the study. Accordingly, the frequent mentions of the terms 'faith-based' and 'faith communities' pertain to the organised religious gathering of people from a specific Christian community (Koenig, 2012).

### ***1.3.3 Functioning***

*"Functioning is the umbrella term for all body functions and structures, activities and participation (execution of a task or activity by an individual) and participation (involvement in a life situation)"* (Welch Saleeby, 2016b, p. 2). In the current study, functioning is used to describe the **positive** outcome arising from the interaction among persons with disabilities' body functions and structures (physiological and psychological functions, and anatomical integrity), activities (execution of tasks or actions), and participation (involvement in a life situation). The term *functioning* is thus associated with factors that enable participation (facilitators) (WHO, 2001).

### *1.3.4 Participation*

Participation, as defined in the ICF, *"is involvement in a life situation"*, which incorporates *"taking part, being included or engaged in an area of life, being accepted, or having access to needed resources"* (WHO, 2001, p. 15). Since societal exclusion and the lack of participation of persons with disabilities in their faith communities is part of the wider focus of this study, the term *participation* in this dissertation pertains to the definitive **positive** outcome that is to be achieved from being included in a life area, such as religious or spiritual activities.

### *1.3.5 Perception*

Perception is defined as the *"conscious awareness of elements in the environment by the mental processing of sensory stimuli; sometimes used in a broader sense to refer to the mental process by which all kinds of data, intellectual, emotional, and sensory, are meaningfully organized"* (Sadock & Sadock, 2007, p. 281). Perception includes the aspect **apperception**, which is described by the same authors as the *"awareness of the meaning and significance of a particular sensory stimulus as modified by one's own experiences, knowledge, thoughts, and emotions"* (p. 274). Moving closer to the usage of *perception* in the current study, von Bertalanffy (1968) asserts that *"Man is not a passive receiver of stimuli coming from an external world, but in a very concrete sense creates his universe… The world as we experience it is the product of perception, not the cause of it"* (von Bertalanffy, 1968, p. 194). Going along with this social construction of reality, *"People spontaneously organize their perceptions, thoughts and beliefs about a social situation into simple, meaningful form… [T]his perception and interpretation of the world, affects how [they] behave in social situations"* (Sears, Peplau, Freedman, & Taylor, 1988, p. 11). For the purpose of this study, the 'social situation' refers specifically to the participation and inclusion (or exclusion) of persons with disabilities in a specific congregation. The term *perception* thus pertains to the way in which the participants give their own meaning to their observations and experiences, which do not necessarily reflect the reality of the 'social situation' as others may experience and interpret it.

***1.3.6 Religion*** (see also Faith and Spirituality)

*"Religion is a multidimensional construct that includes beliefs, behaviors, rituals, and ceremonies that may be held or practiced in private or public settings, but are in some way derived from established traditions that developed over time within a community. Religion is also an organized system of beliefs, practices, and symbols designed (a) to facilitate closeness to the transcendent [God], and (b) to foster an understanding of one's relationship and responsibility to others in living together in a community"* (Koenig, 2012, p. 3). This definition presents the closest fit to the purpose of the study, where specific inquiry was made around persons with disabilities' involvement and participation in their Christian congregation's ceremonies, activities and events, according to the Methodist traditions of Wesleyan theology (Methodist Publishing House, 2016).

***1.3.7 Spirituality*** (see also Faith and Religion)

Pertaining to the Christian perspective of the current study, spirituality is defined as *"an existence before God and amid the created world. It is a praying and living in Jesus Christ. It is the human spirit being grasped, sustained, and transformed by the Holy Spirit. It is the search of believers for a communion that arrives as a gift*" (Wainwright, 1987, p. 452). Given that the concept spirituality was not the focus of the research, the term *religion* (which encompasses the terms 'faith-based' and 'faith communities'), is more relevant in its application to the study.

## 1.4 List of abbreviations

| | |
|---|---|
| AAC: | Augmentative and Alternative Communication |
| ADA: | Americans with Disabilities Act |
| ADAAA: | ADA Amendments Act |
| ASD: | Autism Spectrum Disorder |
| CRPD: | Convention on the Rights of Persons with Disabilities (United Nations, 2006) |
| HI: | High-sensitivity Microphone Sensitivity Mode |
| HQ: | High Quality Recording Mode |
| ICF: | International Classification of Functioning, Disability and Health (WHO, 2001) |

| | |
|---|---|
| PwD: | Person(s) with Disability |
| SP: | Standard Playback Recording Mode |
| WPRPD: | White Paper on the Rights of Persons with Disabilities |

**1.5 Overview of chapters**

Chapter 1 offers an introduction to the study and presents the problem statement. Clarifying definitions of terms that are frequently used, as well as a list of abbreviations are added. It concludes with an outline of the content of each of the subsequent chapters in this dissertation.

Chapter 2 provides an in-depth review of the literature concerning disability inclusion, with an emphasis on the construct of participation in social and religious environments. This chapter further unpacks the conceptual models of thought that underpin the traditional definitions of disability underneath the social structures that persons with disabilities face on multi-system levels, including their faith communities. It also describes the impact of disability models on persons with disabilities and their family units, and how these models have wrought the operational worldview of the church, paying specific attention to Wesleyan theology in a Methodist context. Integrating the above discussions, this chapter concludes with a theoretical framework by which to consider the interactive nature between the individual and their wider contexts.

Chapter 3 discusses the research methodology of the study, including a description of the aims, design, participants, materials and equipment. Specific attention is given to the description of the procedures followed, including a thorough report on the pilot study and the ensuing recommendations for the main study. A detailed account of the participant selection and recruitment process, and a rich description of the sample is offered. In addition, the data collection and analysis processes are fully explained.

Chapter 4 presents a comprehensive portrayal of the research results. Encapsulating the main aim of the study, the findings are reported according to the study's four sub-aims, where emergent themes from the integrated participant perceptions are arranged. Subsequent links between the data and the relevant ICF environmental codes are made to connect the results of the study to its theoretical framework.

Chapter 5 discusses the results of the study in relation to the relevant literature. The ICF's multi-dimensional framework for describing the process of functioning of persons with disabilities is applied to the congregation used as a case study in the research. This is followed by a social deconstruction of disability and a description of disability from a systems thinking perspective.

Chapter 6 marks the conclusion of the research and provides a brief overview of the study's findings. A critical evaluation of the study reveals its strengths and limitations, which is followed by practical implications and recommendations for future research.

## 1.6 Conclusion

This chapter presented an introduction to the research, providing an overview of the problem statement, rationale and purpose of the study. In order to explain the meaning of frequently used terminology, clarifying definitions were provided, along with a list of abbreviations used. A brief outline of each chapter of the dissertation was also outlined.

# CHAPTER 2
# LITERATURE REVIEW

## 2.1 Introduction

The focus of this chapter is on disability inclusion in the church, with an emphasis on the construct of participation. Included is a discussion on the most salient disability models documented in the literature, which considers how definitions of disability and certain social structures have impacted persons with disabilities and their family units. Furthermore, this chapter looks at how traditional definitions of disability have wrought the operational worldview of the church and how these social constructions have aided or impeded the inclusion of persons with disabilities in the church, paying specific attention to Wesleyan theology in a Methodist context. Assimilating the above discussions, this chapter also provides a theoretical framework by which to consider the interactive nature between the individual and their wider contexts. In doing so, explanations are given to specific responses to stress or change, to understand why certain social structures that prevent the welfare of persons with disabilities remain unyielding despite the numerous attempts at effecting social change to address discrimination against persons with disabilities.

## 2.2 Models of disability

Given that disability is a multi-faceted socio-cultural construct, its meaning is bound to change over time and continually vary for different contexts and cultures, rendering it conceptually problematic to define (McEwan & Butler, 2007). The challenge with delineating disability is thus not a modern-day dilemma but has existed since ancient times, when disability and its aetiology was philosophically and theologically contemplated and debated by influential philosophers and early church fathers alike, and ultimately appreciated at the time as a cultural construct that was to be understood in terms of persons' with disabilities integration in their community's activities, and not in terms of their medical condition (Stander, 2013). In the same vein, Leshota (2015) argues that disability *"finds its most tangible and concrete expression in the context within which people with disability live"* (p.2), therefore making it less important to find

a collective definition for *what* disability is, than explaining *how* disability has been experienced and described by individuals within particular situations.

For the purpose of this study, the main long-standing models of disability, as identified by scholars of disability studies and theology, are outlined – primarily in relation to disability in its broadest sense, but with specific application to the context of theology.

### 2.2.1 The medical model

With the advancement of medical science in the mid-1800's, and the concurrent decline in the authority of religion, the medical model began to establish its own influence over that of its pre-modern precursor, the moral/religious model. While the medical model does not espouse the moral/religious model's conception of disability as an act of God, it retained the basic underlying philosophy of its forerunner, in that disability is viewed as innate to the individual with the disability (Retief & Letšosa, 2018). With its particular focus on intrinsic features, thoughts purported by the medical model, also known as the *individual* model (Lawson & Priestly, 2017), construe disability on the basis of pathology – as an inherent quality, or defect – *within* the individual, that needs to be fixed or prevented at best, or at worst, hidden or exterminated, if attempts to cure, avert or normalise it have failed. Viewing disability as a personal tragedy, the medical model's negative conception of disability has resulted in many dubious practices, such as involuntary sterilisation and even euthanasia (Retief & Letšosa, 2018). For the affected person, this model deems impairment as the result of some 'deviation' from 'normal' body functioning, which also leads to other undesirable consequences, not least the labels they receive (Berghs, Atkin, Graham, Hatton, & Thomas, 2016; Creamer, 2012).

For Nancy Eiesland (1994), a religious scholar who herself lived with a lifelong disability, discriminatory behaviour toward persons with disabilities speaks of a power dynamic, whereby the one who assigns the label to the person with a disability gains power over the one named (Anderson, 2015). In her own words, she expresses how she, and others with disabilities, have *"been named by medical and scientific professionals or by people who have denied our full personhood"* (Eiesland, 1994, p. 25). By treating these individuals as problems to be solved and emphasising their differences, instead of focusing on the similarities they share with others, the labels assigned to persons with disabilities within the medical model, deny not only their worth as unique human beings but also the gifts they have to share with their friends, families and

communities (Anderson, 2015; Retief & Letšosa, 2018; Terzi, 2005). Such labelling and differential treatment of persons with disabilities at societal level also permeated the church, where disability has long been synonymous with dependency, characterised by Christian charity works. This perpetuated the medical model's notion that those with disabilities should be seen as objects of pity and at the mercy of others, depicting them as mere recipients of aid with nothing of worth to contribute to society, or to their own faith communities (Gurbai, 2014; Leshota, 2015). As a result, their participation in society is reduced to playing the 'sick role' (Retief & Letšosa, 2018). Retief and Letšosa (2018) also refer to this approach as the *charity* model, viewing disability as victimhood. Creamer (2012) describes how similar notions imposed by individual models, such as the medical model, revert back to its progenitorial roots in the moral/religious model, attributing values of good or bad, and blessing or curse to the incidence of disability in an individual, relating it directly to their personal character. This dichotomy of virtue and vice was also observed in the early church, where the occurrence of disability evoked the perception of sin, punishment and separation from God on the one hand, and stirred up compassion and the duty to care for those with disabilities, on the other (Stander, 2013). These socially constructed perceptions are still deep-seated in the church and have persisted throughout history, where equal opposite beliefs, viewing persons with disabilities as demon-possessed, or saintly representatives from God – demonstrating childlike faith – linger in churches today (Meininger, 2008; Möller, 2012). Occurring insidiously, Anderson (2015) alerts how negative biases about disability imperceptibly infiltrate the receptive minds of young children. Though not overtly taught, and probably inadvertent, the preconception that a person's character is reflected in physical ability or appearance, is subtly introduced in innocuous cartoons and fairytales with characters such as the mentally slow Goofy, Daffy Duck with his lisping speech, Porky Pig with his stutter, the rogue Captain Hook with his amputated hand, and Hansel and Gretel's arthritic witch, whose names have become derogatory labels for children and adults who display these features. Consistent with the above imprinted worldview of humanity, physical ability and attractiveness eventually become the criteria by which an individual's worth or character is determined, and their inherent value and dignity as human beings subsequently overlooked (Anderson, 2015), which echoes Eiesland's (1994) sentiments quoted earlier.

It is evident from these accounts that such labels, redolent of the medical model's problem-saturated narrative of disability, fail to recognise persons with disabilities as whole,

unified human beings aside from their impairments, and so truncate them, reducing their entire existence to a single aspect of their lives – ultimately disregarding the numerous indelible attributes that collectively make up who they are. Moreover, as though humans exist in isolation, all interrelated societal and cultural impacts are ignored. Any attempt to sweepingly define a person based on an isolated feature they possess, reveals a myopic worldview, reflecting a glaring misunderstanding of both disability and the individual to whom the label is assigned, as these are given without knowing the individual, or understanding their experiences (Anderson, 2015). '*What's in a name?'* may yet be the retort from some obstinate thinkers. But words contain tremendous power and Davis (2004) responds emphatically to this way of thinking by ardently advocating for altered views along with edited discourse, to ensure that the person is placed before the disability. She maintains that, when recognised that persons with disabilities are people first, it will become clear to everyone how they generally share more qualities than not with peers without disabilities. Topically, Swinton (2012) elaborates on Jean Vanier's (1998, p. 36) notion of all people belonging to a *"common humanity"*, by promoting viewing dissimilarities among people in the different manner proposed above, and additionally, dealing lovingly with these differences. Moreover, rather than looking to one another to find the sameness that unite them, Swinton counsels that people look beyond themselves and others, to Jesus, who is *"the image of the invisible God"* (Colossians 1:15, NIV), so that everyone, including persons with disabilities, are understood to be created in the likeness of God. Looking to Jesus describes who God is and looking at one another through Jesus, will inform how to welcome those who are drastically different from oneself (Swinton, 2012).

### 2.2.2 The social model

By the end of the 20th century, yielded mainly from the distressing experiences and activism of persons with disabilities, the social model of disability emerged in response to the discriminatory ideology undergirding the medical model (Beaudry, 2016). Fundamentally, the social model challenged the long-established definition of disability as an empirical biological fact, by reframing and redefining disability as a label and a situation created by human culture and the built environment (Imhoff, 2017). In stark contrast to traditionally held ideas, the social model effectively averted the attention that was once on the individual – seemingly incapable of navigating his or her environment – and instead shed the limelight on the physical and social

environments – which were previously deflected – as the culprits that oppress and exclude certain people based on their perceived differences. The social model thus acknowledges the ongoing influence of social and cultural environments on human functioning, and views disability as a challenge originating *within society*, rather than finding its aetiology within the individual, as contended by the medical model (Creamer, 2012; Imhoff, 2017; Simeonsson, 2009).

These modified views, with their strong human rights focus, have taken considerably longer to penetrate religious settings, where some faith communities have been very slow to embrace any inclusive practices, for example, making architectural alterations and employing persons with disabilities (Creamer, 2012). To illustrate, in the 1990's, some Christian denominations in the United States attempted to make a case for their own congregations' exemption from the implementation of the Americans with Disabilities Act (ADA), the newly-appointed anti-discrimination laws at the time, and many have been successful in their appeals (Eiesland & Saliers, 1998). During the ADA petitioning process, the relational tension that developed between religious groups and disability activists grew stronger and has not improved much since (Creamer, 2009). These examples support Creamer's (2012) notion that religious environments tend to be resistant to disability advocacy.

Though the above instances occurred abroad, this phenomenon was also observed locally. Despite South Africa's coveted reputation for its constitution's progressive recognition and protection of human rights, the religious values upheld in the conservative belief systems of the population at large have often been in conflict with the liberal, secular values of the constitution, which have not always been welcomed or supported by members of the public (Kotzé & Loubser, 2017). It is no surprise then, that, despite its prominence in Southern Africa, disability has not featured much in African theological research either, both historically and at present (Leshota, 2015). In an indictment against the church, Leshota (2015) charges Christian faith communities with neglect in their responsibility to serve everyone through love and promote unity through *koinonia* – the love-bound communion, fellowship, sharing, belonging and joint participation among all believers. He continues to argue that the absence of disability discourse in theology – both theoretically and practically – is a blatant act of exclusion, the very opposite of koinonia.

## Chapter 2: Literature Review

Given that the Christian faith is an embodied faith, yielded from beliefs of creation and incarnation (Eiesland, 1994), Christianity has concerned itself with embodiment and healing since its inception. Likewise, the topic of disability, either as bodily impairment, or as societal exclusion, has been addressed by the earliest Christian theologies, and persons with disabilities have been part of faith communities from the very beginning (Creamer, 2012; Stander, 2013). One would thus have expected that campaigns against discrimination and advocacy for disability inclusion would have been initiated and championed by religious, rather than human rights, groups. It may seem as though the rest of the world cares more, and therefore speaks up more, about the aspects with which Christianity should chiefly be concerned. Could it be that the neglect on the part of Christian churches to preserve the core values of kindness and compassion through caring for the marginalised and liberating the oppressed (Luke 4:18-19 New International Version), is tantamount to Christianity's failure to defend the very people it was mandated to protect? Certainly, within the Christian religion, attitudes toward impairment and disability have mostly been negative, and while some antiquated perceptions have waned, some Christian interpretations of disability, such as it being punishment for sin, a test of faith, an inspiration to others, or a mysterious act of God, still remain in a number of elements in religious practice (Creamer, 2012). Is it then any wonder that theology, steeped in conventional thought patterns, would begin to skirt around the subject of disability in the face of continually shifting – and not necessarily welcome – views concerning disability and the rights of those affected by it?

It may therefore be fair to conceive that the ever-present traditional beliefs about disability from a theology perspective, and the ever-changing views on disability from a human rights perspective, are at odds, and that they are perhaps irreconcilable (Kotzé & Loubser, 2017). However, in her combined capacity and experience as a Christian theologian and disability activist, Nancy Eiesland (1994), argued that both parties have contributed to the dissonance between them, and that they should in fact both contribute to bridging the rift they created. Beneath the resistance that delayed the necessary changes, most churches were largely oblivious to disability rights movements, and, by the same token, disability rights groups were typically inattentive to spiritual and religious issues, or altogether indifferent to it (Eiesland, 2002). So, in the same way that religious studies have rebuffed disability issues, as outlined earlier, the exploration of religion by those within the field of disability studies was considered uninteresting, irrelevant and unnecessary (Creamer, 2009).

However, for human rights groups to dismiss theology as unimportant, is to blindly ignore literature that confirm the importance of religion in many of the lives of persons with disabilities (Imhoff, 2017). There are studies that attest the significance of religion in understanding the human experience of disability, as it helps those affected by it to manage the pain and suffering often associated with disability (Edwards et al., 2016). Still other studies have found that religious beliefs often empower people, reducing anxiety and distress, by providing answers to complex existential questions that cannot be answered otherwise (Koenig, 2012). For these reasons, religion forms an integral part in meaning-making for persons with disabilities. It is evident that religious studies can offer new insights to disability studies and therefore, the social discourses that construct disability, should include religious beliefs, texts, communities and practices (Imhoff, 2017).

Notwithstanding the occurrence that religious traditions have over the years failed to fully engage with the concepts of disability and impairment, this trend radically changed with the publication of Nancy Eiesland's revolutionary work, *The Disabled God*, in 1994 (Creamer, 2012), in which she uniquely employs the social model of disability, utilising feminist and liberation theologies to support the notion that the Christian faith is not centred on the image of an able-bodied God, but rather on Christ, who, through a *broken body*, became the enfleshment, or, embodiment, of God (Creamer, 2012; Eiesland, 1994) to secure salvation and eternal reunion with God for all who believe in Him. This idea is corroborated Biblically as captured in the climactic events of Jesus' earthly ministry (Matthew 26: 26-28; John 6: 27-59; Luke 24:36-43), as He introduced the sacrament of Holy Communion and foretold His crucifixion, whereby He would be marred, with His scars remaining, even after His resurrection and restoration to wholeness (Creamer, 2012).

Eiesland's image of a Disabled God thrust into imagination reinterpreted connections between religion and disability. While Jesus never sinned, He became disabled, and as such, the notion that disability is directly related to an individual, or that it is a consequence of their sin (as proposed by individual and moral views) can be summarily rejected. When viewing disability in this light, there is thus no reason why persons with disabilities should be excluded from worship and leadership roles in the church, since Jesus' scars did not disqualify Him from His continued leadership. Within this approach, God is on the side of the oppressed, and it is factors such as intolerance, injustice and exclusion – and most especially the people and social structures that

produce and sustain these prejudices – that need to be addressed and resolved, and not the biological impairments of individuals (Creamer, 2012; Eiesland, 1994).

With the shift that Eiesland's thinking effected, disability theology has evolved to expose and deconstruct the shortcomings of the medical and morally-laden approaches that dominated religious literature and practice, and have also led to the development of other images of God, which, as exemplified in the social model, have painted disability in a more positive light. This has helped to make God more accessible to persons with disabilities, so that those who were once deemed unwelcome, would feel accepted and at home in the church (Block, 2002; Creamer, 2012).

While disability theology has made considerable theoretical progress in a relatively short period of time, there is a need for even greater connectedness – both on paper and in practice – between religious studies and the field of disability in general, so that it can fully represent the real-life experiences of persons with disabilities (Creamer, 2012; Eiesland, 2002; Imhoff, 2017; Leshota, 2015; Weiss Block, 2002). Creamer (2012, p. 339) further asserts that *"theology and disability have something significant to say to each other"* on an ongoing basis, urging the necessity for religious studies to increasingly engage disability more broadly, and for disability studies to become more attentive to religious themes and practices, in order for the two groups to cease their discord and function in harmony.

At the risk of ignoring the inadequacy of the social model to fully describe disability and to address ongoing exclusion, this type of accord is also needed among disability scholars. Since the social model opposes the notion that disability is caused by impairment, it makes a clear distinction between *impairment* – which refers to a person's challenges with physical, cognitive and sensory functioning – and *disability*, as the person's experience of oppression caused by society. However, key thinkers within the domain of disability studies have differed in their views. While some hold that disability is single-handedly socially constructed, others maintain that disability is jointly caused by both biological (or medical) *and* limiting social barriers (Berghs et al., 2016). The divisive distinction between disability and impairment has led to censure, where Shakespeare (2010) argues that the social model's disclaim of the medical model may as well insinuate that impairment is no challenge at all. Apart from critique such as this, the abovementioned stance has implications for the terminology used when referring to disability, where the term *disability* from a social model perspective is strictly reserved for referring to the

collective hardship inflicted on persons with impairment through the barriers imposed by society. Consequently, the positioning of the source of disadvantage in social structures and systems calls for social change, which can only occur when the focus is veered away from individual limitations, and shifted to limitations created by societal structures (Lawson & Priestly, 2017).

Disability through the lens of the social model provided a welcome reality check to some of the fallacies of the medical model. While these shifts in focus were indeed necessary and valuable for understanding and defining disability differently, literature suggests that, despite these changes, there are still considerable gaps in addressing religious exclusion of persons with disabilities (Creamer, 2012; Imhoff, 2017; Leshota, 2015). Lest the baby is thrown out with the bathwater, it is important to resist a monochromatic 'either-or' mindset whereby a choice is ordered to adopt either a medical, or a social view of disability. Rather, as a prism refracts light at different angles, an iridescent 'both-and' approach will give a more accurate view of disability from every relevant perspective, keeping the beneficial nuances of both models, while disposing of that which is sinister. In their overview of the medical and social models of disability, McEwan and Butler (2007) and Raghavendra, Bornman, Granlund and Björck-Åkesson (2007) also highlight the inextricably linked relationship between biological and social environments, and reiterate that neither model can functionally describe disability in its own capacity.

### 2.2.3 The biopsychosocial model

The rising influence of the social model's emphasis on the impact of environmental barriers, as well as increased activism by persons with disabilities themselves, have led to the development of the World Health Organisation's International Classification of Functioning, Disability and Health (ICF) (Berghs et al., 2016), which is specifically named as such because of its focus on health and functioning, instead of on disability only (WHO, 2001). The ICF is underpinned by the biopsychosocial model – a fusion and further development of the medical and social models of disability (WHO, 2002) – which defines disablement as a result of the complex interaction between the individual and their physical and social environments (Berghs et al., 2016). The operative word being *interaction*, the biopsychosocial, or holistic, model of disability focuses on the whole experience of the condition, without making any direct causal links between impairment and disability (Kazou, 2017). Instead, this approach appreciates the interconnected influences of physical, psychological and social factors on health and recognises

the importance of understanding health and well-being from the individual's point of view (McDougall, Wright, & Rosenbaum, 2010).

Accordingly, the health and health-related domains contained in the ICF (WHO, 2001) are described on three levels of human functioning, namely body, individual and social levels, as it relates to a person's body functions and structures, and activities and participation. The term *functioning* is used as an overarching reference to an individual's body functions, personal activities, and societal participation, whereas *disability* is the umbrella term covering impairments of the individual's body, limitations they experience in performing daily activities, and restrictions to their participation in social life. Also describing the context in which individuals live, the ICF includes a list of *environmental factors*, a component of contextual factors – including features of the physical, social and attitudinal world – that interact with these components of functioning and disability with a facilitating or a hindering impact. Consistent with the holistic perspective of the biopsychosocial model, the ICF appreciates an individual's functioning, disability and participation to arise from the interaction between their health condition and environmental factors (McDougall et al., 2010; WHO, 2001), and highlights the multidirectional nature of all components of health as interconnected, and influencing each another (Berghs et al., 2016).

Participating in religious activities and building relationships with others in church settings (as captured by the *Religion and spirituality* code in the domain of *Community, social and civic life* in the Activities and Participation component of the ICF) (WHO, 2001), may be very challenging for persons with disabilities, especially for individuals with intellectual and communication impairments. These individuals frequently encounter barriers of negative attitudes, accompanied by a lack of understanding and awareness from those they wish to engage – often making their attempts at meaningful participation a very negative experience (Carroll et al., 2018). With a disproportionate focus on cerebral ability, many church denominations continue to adhere to strong intellectualistic traditions with rules and regulations that insist on the capacity to recite understanding of religious rites before being allowed to join in the sacraments. Within these practices, persons with intellectual and communication difficulties are automatically excluded from participation in certain rites because it is typically assumed that they cannot understand the doctrinal concepts fundamental to their faith, which has earned them the label *"conceptually non-expressive"* (Peters, 2009, p. 300). As if communication and

knowledge are solely contingent on words and the ability to reason abstractly, this presupposition is based purely on the ground that these individuals cannot verbally express their understanding of concepts, or confess their beliefs through conventional speech, and are therefore presumed incapable of comprehending the meaning of the sacraments (Peters, 2009). Borthwick (2012) contests that it is in reality the lack of awareness and understanding of impairment among the general population (or the church in the above instance) that create the experience of exclusion and isolation in persons with disabilities.

The former scenario demonstrates holistically how an individual with a condition such as a communication *impairment* may in fact experience communication *disability*, as an interactive result of both their impairment, and the hindering impact of environmental barriers (Carroll et al., 2018), which limit their opportunities for equal participation in their faith community. On the other hand, provided with the facilitative impact of awareness, understanding, love and support from a caring faith community, the individual may be spared the experience of disability and exclusion altogether. In the same way that different contexts can have a different impact on the same individual, environmental factors may hinder or facilitate a person's functioning (Raghavendra et al., 2007).

Since societal exclusion and the lack of participation of persons with disabilities in community life is part of the wider focus of this study, it is necessary to look particularly at *participation* as the broad and definitive outcome that is to be achieved. Researchers and practitioners within the field of AAC have laboured extensively to facilitate this goal and have developed several models for AAC assessment and intervention with the aim to optimise the participation of persons with disabilities in all areas of their daily lives. It therefore seems sensible to pay heed to existing AAC models and to consider how they aim to address participation barriers. After all, the facilitation of interaction and communication – and ultimately participation – is the main objective of AAC (Beukelman & Mirenda, 2013; Raghavendra et al., 2007).

Barring the Participation Model, which was first presented (and subsequently revised) by David Beukelman and Pat Mirenda in 1988 (Beukelman & Mirenda, 2013), the existing models for AAC, such as those proposed by Lloyd, Quist, and Windsor (1990), and Schlosser and Raghgavendra (2004), fail to view persons with disabilities within their wider systems of functioning in specific contexts (Raghavendra et al., 2007), such as the church for instance.

Comparable to the ICF's environmental factors, Beukelman and Mirenda's (2013) Participation Model address opportunity barriers (those barriers outside of the individual), such as policy, practice, skill, knowledge and attitude barriers that hinder functioning. With its name bearing resemblance to its core focus, the Participation Model may therefore seem like the obvious choice to consider for this study. However, despite this model's valuable application in AAC assessment and intervention, and its logical and useful conceptualisation of barriers, the ICF is argued as the preferable framework to understand and promote participation in persons with disabilities within the narrower focus of the church for several reasons.

Firstly, the ICF model fully recognises the importance of engaging in quality-of-life-behaviours, such as participation in religious and spiritual activities for the purpose of finding meaning, value and self-fulfillment, and has included relevant codes that can reflect positive growth and development in this important life area (McDougall et al., 2010; Raghavendra et al., 2007; WHO, 2001). Incorporating the New King James Version of Matthew 25:40 with reference to those often debarred from society, Moltmann (1977, p. 98) compellingly articulates that *"fellowship with the crucified one cannot be lived in any other way than in fellowship with the least of the brethren of the Son of Man."* With its pro-participation focus within faith communities, the ICF can be a much-needed, thought-provoking conscience to the church, increasing its sensitivity, awareness and understanding of the importance of inviting *all* into fellowship – for both the welfare of the marginalised as well as the church's own completion in spiritual union. This framework can thus assist Christian communities in their responsibility to uphold the Biblical creed petitioned above, in providing a gauge by which churches can measure their own health and functioning with respect to the extent to which they can strengthen facilitating aspects and address the factors that may hinder the full participation of persons with disabilities in their communities.

Secondly, the ICF also makes provision for describing environmental factors that facilitate functioning, and not only barriers, as the Participation Model does (Bornman, 2004; Raghavendra et al., 2007). To ensure that functioning is understood from the perspective of the individual with a disability (McDougall et al., 2010), the relevant environmental factors can be coded as either barriers or facilitators to meaningful participation in the church.

Thirdly, instead of focusing on the cause of the disability, the ICF centres on the impact the disability has on an individual's functioning in various life areas, including their religious

involvement, and is thus useful as a continuum for comparing health and disability (Raghavendra et al., 2007). It may be viewed as paradoxical that a person can experience positive life satisfaction in the face of severe disability. However, research indicates that high quality of life can, and often is, perceived among persons with severe impairment, provided that the individual can attain a balance between the interrelated body, mind and spiritual aspects of their existence. This reiterates that there is not necessarily a causal link between a health condition and the experience of disability. Since the ICF encompasses all domains of human life that affect quality of life, it can highlight the facilitative impact that participation in religious and spiritual activities may have a on an individual's health and functioning (McDougall et al., 2010).

A fourth reason for using the ICF as a theoretical framework, is based on the ICF's definition of disability, which is considered helpful in influencing advocacy cases, and that it can be used as an instrument to support the rights-based approach to disability (Hurst, 2003). Similarly, Kazou (2017) stresses that, contrary to popular belief, the United Nations' Convention on the Rights of Persons with Disabilities (CRPD) definition of disability (United Nations, 2006) bears closer resemblance to that of the ICF, than to the conceptualisation of disability within the social model. By coupling the CRPD with the ICF, instead of its typical association with the radical views of the social model that impugns society and refutes impairment as part of the experience of disability, policy makers within the church may be less skeptical toward anti-discrimination treaties, such as the CRPD, and may be more amenable to engage with issues concerning human rights (Kazou, 2017). Equally, given its recognition of both impairment, and social and environmental factors in its classification of functioning, the ICF has the potential to become a practical mediator to reconcile the remaining disparities of opinion between religious groups and human rights movements, discussed earlier.

Finally, the ICF also creates a 'universal language' of disability, which transcends beyond disciplinary boundaries (Bornman, 2004; Simeonsson, 2009; WHO, 2002). Therefore, it could be used appropriately by the church to speak to others (e.g. health care service providers), informing them how religious beliefs can play an essential role in an individual's sense of purpose, autonomy and well-being (Edwards et al., 2016; Imhoff, 2017; Koenig, 2012).

## 2.3 Theoretical underpinnings

Notwithstanding all the efforts at providing a new definition for disability and abolishing the oppressive belief systems founded upon the tenets of the medical model, these views have been maintained for many decades and have become wholly embedded in society and church doctrine (Beaudry, 2016; Lid, 2017). In order to appreciate the persistent nature of these enduring views, it is necessary to offer a theoretical explication of this phenomenon, so as to grasp why change has been resisted or so slow over the years. As a framework useful for understanding social change, *general systems theory* offers a suitable rationale, since it also birthed the biopsychosocial and family systems theories that focus on producing change at the most relevant levels, including biological, psychological, relational, as well as community and policy levels to address the disparities and discrimination against persons with disabilities (McDaniel & Pisani, 2012). A broad overview, with specific application to the present study, is supplied below.

### 2.3.1 General systems theory

Spawned by the scientific fields of mathematics, physics and biology, definitions for general systems theory have been documented by several authors as it was adapted to a variety of disciplines (Adams, Hester, Bradley, Meyers, & Keating, 2014). However, the theory is mostly attributed to the seminal works of Ludwig von Bertalanffy (1950) and Kenneth Boulding (1956), who both offer rather nebulous and somewhat cryptic descriptions of its underlying principles. Conceptualised by von Bertalanffy (1950, p. 139), general systems theory is a *"logico-mathematical field, the subject matter of which is the formulation and deduction of those principles which are valid for 'systems' in general, … whatever the nature of their component elements or the relations or 'forces' between them".* Boulding (1956, p. 208) presents a metaphor, outlining general systems theory as the *"skeleton of science"*, which *"aims to provide a framework or structure for systems on which to hang the flesh and blood of particular disciplines and particular subject matters in an orderly and coherent corpus of knowledge"*.

Failing to expound the quintessence of general systems theory, these two inexplicit definitions seem to differ vastly, not only from each other, but also from multiple others recorded in the literature. Shifting the focus away from these elaborate explanations to the more specific characteristics of general systems theory, Cabrera, Colosi and Lobdell (2008, p. 301) describe a

system as a *"complex whole of related parts"*, made up of a collection of interrelated elements that complete the whole. Thus, when looking at a system, one usually sees the whole first and then its constituent parts (Wachs, 2000). When viewed in context, each system can be seen as a subsystem of a larger hierarchy of systems (Laszlo, Levine, & Milsum, 1974), and each system has its own boundaries which separate it from its larger outside environment. From this stance, it is important not to study any of the system elements in isolation but only collectively, as a unit (Gregory, 2012). However, it is plain that the multipart structure of this theory must be broken into smaller parts for each component to be analysed and understood before being reassembled into a whole. As such, and paradoxically so, general systems theory lacks a universally agreed upon definition (Adams et al., 2014) that can consolidate all its separate parts into a single, unified explicatory whole.

Evidently, systems theory is an intricate weave of ideas that is not distinctly conveyed, nor effortlessly grasped solely by the characteristics alluded to above. It therefore seems most reasonable to unpack this complex theory by applying its tenets to the constructs of functioning, disability and health as they relate to persons with disabilities and their interrelated societal structures, in an attempt to integrate the part-whole polarities to accentuate the wholeness of these systems. Interlacing key aspects from the discussions on the main models of disability, the remainder of this section includes the fundamental characteristics of systems theory, with a particular focus on its relevance to the understanding of human functioning as espoused in the ICF.

According to the theoretical principles of a systems approach, persons with disabilities, their families, and their respective faith communities, can all be viewed as individual systems, each with their unique characteristics. However, the aforementioned systems are not regarded as systems based solely on the individual characteristics they each possess (Wachs, 2000). Contrary to the unilateral viewpoint of the medical model that defines and labels a person by a single feature of their disability without considering the interplay of their wider systems (Berghs et al., 2016), the general systems approach, as also applied in the ICF, prevents viewing the person with a disability as an isolated unit. Equally, without reducing the whole, compound concept of disability to only one of its component aspects, this framework also balances the social model's shortcomings in discounting bodily impairment and attributing disability entirely to social injustice, in a similar manner (WHO, 2002). Instead of focusing on individual or

isolated features, the key factor within a systems framework that delineates the person, the family, and the church – each as a complete system, yet interrelated – is the nature and degree of the *linkages* that exist between the elements *within* each system, as well the relationships *between* these systems. Consequently, the complex phenomenon of disability is a challenge at the level of both the individual person's body and at the social level. It is only in employing this interactionist perspective mirrored in systems theory, that disability can be understood as a social process and thus the result of the interaction between individual features within the person with a disability, and features of the larger context (e.g. family, church, and society at large) in which the individual lives (Bartlett et al., 2006; McDougall et al., 2010; WHO, 2002). This multidimensional, interactive framework of general systems theory is vividly reflected in the ICF, where the components that represent an individual's functioning at the body, individual activities, and participation levels are all potentially interlinked, implying that change in one subsystem can cause change in all the other systems and vice versa (McDougall et al., 2010).

Given that general systems theory views biological, psychological and social system elements within a holistic framework, these systems are understood as interconnected and are therefore not evaluated independently (McDougall et al., 2010). Rather, the action of one system element is seen as reliant on the existence and actions of all the other elements within the system, which implies that the whole is larger than the sum of its individual parts (Wachs, 2000). Likewise, Bartlett et al. (2006) argue that, rather than viewing disability or functioning as extreme opposite outcomes on the health spectrum, the ICF components of body, and activities and participation can be considered equivalent in their significance and are in fact meant to be two different outcomes of the single occurrence of disability.

While all system elements are interrelated, their connection is thought to be non-linear rather than sequential, meaning that the relationship between the system elements and their impact do not necessarily have a specific causal link between them (Wachs, 2000). An application of this principle is demonstrated in the ICF, where the functional components can be equally influenced by physical and psychosocial systems, with no presumed aetiological association between the presence of impairment and disability (Kazou, 2017; McDougall et al., 2010).

Because the fundamental elements of a system form a structure and arranges itself in such a way that it may change given certain conditions, the system becomes typified by the

organisational patterns that emerge as a result of the ongoing feedback and interaction among the related system elements. Even when a system experiences perturbations, or deviations, from its regular state, it usually manages to hold its existing organisational structure (Wachs, 2000). In this way, humans can be considered as self-organising systems, whose process outcomes of disability or functioning result from the perpetual co-adaptive relationship between the individual and their environment (McDougall et al., 2010). Pertinent to the ICF's conceptualisation, an individual's level of functioning results from the dynamic interaction between the health conditions and contextual factors (WHO, 2001).

Systems function over a background of time, implying that its history can influence its ongoing structure and function. Systems theory thus provides a means to explore the changes in a system's behaviour patterns over time (Wachs, 2000). Given that the individual is in constant interplay with their environment, the individual's functional abilities also change continually (McDougall et al., 2010).

Expanding on these temporal features of systems to illustrate social change, Laszlo et al. (1974) draw on the physical law of inertia to illustrate that a motionless system will remain static unless an external force is applied to it. Likewise, the only way to get a moving system to change its course of direction is to use force, which implies that the *force* is the cause of movement in both instances. Therefore, a moving system, such as the church for instance, is inclined to stay in motion in its fixed direction, and go about its traditional customs without any transformation, unless some opposing force brings it to a halt, or veers its direction (Holzner, 2006). Any forces outside of a given system that try to create change in that system are typically cancelled out by forces generated within the system that resist the change (Laszlo et al., 1974). Revisiting the earlier discussion on the social model of disability, it is evident that human rights groups and religious communities – each moving in apparent opposite directions – have both generated force, creating and sustaining movement respectively in the direction of societal change, and applying internal force to resist the imposed changes.

Even with the changes that transpired after Eiesland's (1994) influential contributions, particularly to the field of disability theology, many of the beseeched changes have not occurred in religious communities, with the result that many persons with disabilities are still excluded from their churches for various reasons (Leshota, 2015; Möller, 2012). This occurrence is consistent with systems theory, in the sense that change tends to start slowly at first, but

increases steadily until momentum is gained and inertia is overcome, where the combined effects of inertia and resistance produce another effect, called time lag. Since time lags filter, or regulate a system's response to changed conditions, not all change is perceived and received in the same manner (Laszlo et al., 1974). It is therefore possible that the changes that have occurred in faith communities with seeming ease may have been considered positive or noninvasive for the church system. Conversely, in instances where demands for change were perceived as coercive or intrusive, inertial patterns within the church system may have been reinforced and the undesirable change resisted. Ultimately, church buildings are easier to change than negative attitudes.

Generally functioning at optimal levels of inertia, systems tend to remain constant and relatively unchanged, thus maintaining a stable equilibrium, or homeostasis, which explains why change in some Christian communities has been so slow and minimal. Even so, the inertial characteristics of a social system do not necessarily lie within the control of those who manage the system (Laszlo et al., 1974), implying that other interrelated systems outside of the church system may provide the impetus behind the sorely needed movement.

In summary, a general systems approach examines principles that demonstrate connections and relationship patterns in and between the components of systems within a non-linear, holistic perspective, where change is a dynamic, multidimensional and interactive process, that occurs on the continuum of time (McDougall et al., 2010; Wachs, 2000). The previous section has provided a sound springboard from which to dive into the real-life implications of systems thinking for converting these abstract ideas to more concrete facets of everyday life, where attention will now be given to the systems that apply to human life, including that of the individual, the family and the church, as pertinent to the main components of this study.

### 2.3.2 The individual as a system

Though considered a crucial element, a relatively concise description of the individual is provided in this section, given that the central theme to the current study includes, but is not limited to – and thus goes beyond – the individual in the system.

In a sense, the individual can be viewed as a living system that exhibits many of the same properties as those displayed by complex general systems, as outlined in the previous section.

However, from that discussion, it became apparent that an individual is best understood as a component in, and in relation to, a larger framework of systems, so as to remain mindful of their biological and cultural environments by which they are shaped, and which they in turn influence (Wachs, 2000). Bronfenbrenner (1979), provided a similar perspective with the formulation of his model of nested systems within which individuals function and develop. While the individual is placed within a family system for instance, the family in turn needs to be viewed with respect to wider systems in society created by social, economic and government policies that all affect the family, and ultimately the individual within it, in many aspects of life.

From a contextual stance, disability is recognised as a systemic concept that can be defined based on the fit between the individual's needs and their respective physical, social and legal environments. Challenges related to a disability may be equally attributed to deficiencies in the environment than to the disability itself, and failures of larger system supports – rather than the disability per se – may be responsible for challenging interpersonal dynamics between individuals with disabilities and their caregivers (McDaniel & Pisani, 2012). Murray (2007) points out a variety of inequalities pertaining to opportunities, income, work, leisure and family quality of life, experienced by families caring for children with disabilities. In addition, Breen (2009, p. 18) suggests that these disparities, along with inadequate service delivery, potentially *"reinforce, rather than reduce social, cultural and economic injustices…rendering the family as disabled"*. Both caregivers and individuals with disabilities are thus set in a multilayered biopsychosocial system, wherein ideally, economic and legislative concerns can direct public policy to the development of systems that promote the welfare of persons with disabilities and their caregivers (McDaniel & Pisani, 2012).

Since this study is primarily concerned with persons with disabilities, their primary caregivers, and the interrelationship between them and their religious community, specific attention will now be given to the family and the church as social and community systems, and their exchanges with the individual.

### 2.3.3 The family as a system

It is widely recognised that the majority of primary caregivers of persons with disabilities are family members (Giallo, Gavidia-Payne, Minett, & Kapoor, 2012; Maes, Broekman, Došen, & Nauts, 2003; Markey, 2015; McDaniel & Pisani, 2012; Murray, 2007; Norlin & Broberg,

2013) with mothers mostly bearing the caregiving responsibility (Breen, 2009). For this reason, the topic of caregiving and disability readily lends itself to a systemic approach for understanding family dynamics, since family systems theory highlights the interconnected nature of relations within a family, where the interaction between the caregiving parent and the child with a disability (irrespective of age) is best understood in the context of other related subsystems within the family. This type of relationship intimates interdependence and requires a fine balance between the often opposing needs that exist between persons with disabilities on the one hand, and that of their caregivers and other family members on the other, and involve decisions that directly affect both parties (McDaniel & Pisani, 2012).

An authority in the field of family systems theory, developmental psychologist and family therapist, Patricia Minuchin (1985), describes a family as a complex system, which comprises many naturally occurring subsystems that interact and influence one another, such as the mother-father, mother-child, father-child, or child-child subsystems. Each member is seen as an active participant in these interacting subsystems and forms part of the process that creates and maintains the patterns that regulate behaviour. In this way, the quality of the relationship between the mother-father system for instance, may affect the mother-child and father-child systems, and similarly, all the relevant subsystems within a family network ultimately shape one another (Minuchin, 1985). Applying the theoretical principles of general systems theory discussed earlier, a family is thus more than a mere compilation of isolated individual members; instead, a family has unique structures, wherein the hierarchies, boundaries, roles and connectedness between the individual members generate patterns of interaction, expectation and support (McDaniel & Pisani, 2012; Wachs, 2000). It is therefore important to consider the entire family system, its subsystems and their exchanges, before a clear understanding of an individual's developmental path, behaviour and functioning can be gained (Mussen, Conger, Kagan, & Huston, 1990). Linking Mussen et al.'s (1990) notion to the current study, it is argued that religious engagement and participation of persons with disabilities, or the lack thereof, also necessitate thorough exploration of their entire family systems, among the other interplaying social and political systems.

Referring to systems and their boundaries in a general sense, Gregory (2012) advises to describe systems according to their degree of openness or closedness because they mostly display characteristics of both. For Minuchin (1985) though, the family is an open system,

which undergoes periods of stability and periods of change. On the one hand, well-established interaction patterns among members keep the family functioning in stable, adaptive ways, while on the other, changes in circumstances, such as illness or disability, disrupt the established patterns and bring about changes in emotional reactions that necessitate the restructuring of roles and relationships, causing its various subsystems to become reorganised. Nevertheless, family systems are generally inclined toward growth, development and well-being (McDougall et al., 2010) and in difficult circumstances, tend to produce compensatory actions which drive the system back to its previous equilibrium, or homeostasis (Laszlo et al., 1974). Accordingly, families who experience disruptions in the form of a diagnosis of disability, for instance, may employ self-regulatory behaviours which help them return to their previously established patterns, where they experience stability once again.

In response to the stress experienced by families during such times of adversity, Walsh (2012) proposes a conceptual framework for promoting family resilience through targeting key family processes that can diminish strain and vulnerability, encourage healing and growth, and empower families to overcome even prolonged hardship. These processes for resilience have been identified in three basic domains of family functioning, by which family dynamics and processes can be understood and improved. They include flexible organisational patterns, cultural and spiritual family belief systems, and open communication processes.

For optimal functioning, families who care for persons with disabilities need to develop *organisational patterns* that are flexible enough to adapt to the demands produced by the disability, but also sufficiently stable to allow for steadiness, predictability and growth. By allowing the boundaries between the family system with its core family members, and those of their extended family connections and social networks to become semipermeable, a system of care can be produced in their outside world that will support successful family caregiving (McDaniel & Pisani, 2012). The value of this process is accentuated by the results of a recent study (Erasmus, Bornman, & Dada, 2016), which suggest that, among adequate social services, systems and policies, parents of children with intellectual disabilities most highly esteem relational support from their friends and families. Above all, however, the study showed that parents desire for their children to be treated with love, respect and acceptance. Since disability can easily isolate those affected by it from their loved ones, it is important to reinforce

communion – the spiritual and emotional bonds with family and friends – that are so easily broken by disability and inadequate healthcare systems (McDaniel & Pisani, 2012).

Resilience also involves the potential of the family to grow, make repairs and ultimately recover in the face of challenging life circumstances. What is regarded as difficult or distressing for one family may very well be embraced by another (Walsh, 2012). To illustrate, a couple with a child with Autism Spectrum Disorder may limit their participation in their local congregation, and eventually withdraw altogether from church involvement and attendance because of other congregants' inadequate awareness of their child's condition, and judgement coupled with a lack of tolerance for their child's challenging social behaviour, over which the parents have no control. Feeling misunderstood and unsupported is a yoke heavy enough on its own, and parents may feel that they cannot cope with the additional weight of negative attitudes, especially from a community where they expected the opposite. The abovementioned study by Erasmus et al. (2016) also highlighted parents' perceptions that underscore the importance for attitudes to be addressed as part of human rights.

In contrast to the family's evident experience of distress in the former example, the adult children of an elderly woman who suffered and survived a stroke that had subsequently radically limited her capacity to perform her everyday responsibilities, may feel such deep gratitude for their mother's second chance at life that they remain optimistic and encouraged, viewing her survival as an opportunity for closer connection with God and with one another, despite the glaring challenges that lie ahead. Even in the midst of the stresses of reshuffling roles and responsibilities after their mother can no longer fulfill her pivotal role in caring for their frail father, the support received and continuously offered by their parents' church community, can help ease the burden that was so suddenly thrust upon them. If Christian congregations can fully appreciate the impact exerted on the family system that cares for a family member with a disability, they can discern the appropriate measures necessary to adequately support such families (Möller, 2012).

Apart from the level of support available, such dissimilar reactions to life stressors and change will depend on the meaning and value families ascribe to the challenges they face, as their responses, including their narratives, result from the *shared beliefs* and worldviews of the family system in which they operate. Levels of stress are increased in families where parents perceive the disability of a child as punishment for wrongdoing and religious failure. With the

combination of incongruous theological explanations, generally held societal perceptions of disability, and limited integration of spirituality into healthcare, issues of problematic attitudes re-emerge. Negative messages from the abovementioned arenas are often internalised by persons with disabilities and their families, and may contribute to their rejection of God and religious beliefs and practices that could in fact be beneficial to them (Treloar, 2002). On the other hand, spiritual beliefs and practices often promote acceptance and become the link between the painful realities of disability and some greater purpose. With faith-based hope, no matter how grim the present circumstances, many families manage to foresee a brighter future, where deep faith, prayer, meditation and church involvement are all recognised and relished as reliable sources for resilience (Walsh, 2012). In addition, when families draw close in the face of difference or disability, they become enabled to increase agency, while maintaining optimism and growth, as well as building a group identity that includes, but surpasses the disability (McDaniel & Pisani, 2012).

In the midst of challenging circumstances, where stress tends to escalate and interpersonal conflicts erupt easily, it is important for families to experience a sense that they are loved, cared for, and supported within their relationships, without any judgement (McDaniel & Pisani, 2012). In the domain of *communication processes*, resilience is facilitated by clear communication and collaborative problem solving and awareness, in a space that invites and facilitates truthful expression of thoughts and feelings (Walsh, 2012). McDaniel and Pisani (2012) add that direct messages through open emotional expression in a collaborative environment also lead to increased communion in the individual and the family system. Faith communities have unique opportunities to further foster this sense of communion, or, koinonia (Leshota, 2015) among family members and the rest of the congregation, by creating a safe environment for authentic emotional sharing, subsequently enlarging their support system through the quality of the communication among them that connects and empowers them (Walsh, 2012).

Given that the dynamics of caregiving change and are typically different at different times in the family life cycle, roles and responsibilities continuously evolve as individuals develop within the context of the family and other systems, which in turn, change in response to the different needs of each individual, and to external pressures exerted on the system (McDaniel & Pisani, 2012). A study undertaken by Murray (2007) serves as an example of the pressure

under which families often succumb and highlights the subsequent limited participation of persons with disabilities and their families in their wider communities, including their faith communities, as a result of inadequate support systems, which have impeded their engagement in activities that other families take for granted. Breen (2009) contests assumptions that families' care for children with disabilities have negligible outcomes on the family system and disproves this notion with research evidence, including that of Murray (2007) cited above, and numerous others. Interestingly, with specific reference to the impact on the siblings of persons with disabilities, Lamorey (1999) and Rossiter and Sharpe (2001) cite research findings from systematic reviews that claim only minimal negative impact on households caring for children with disabilities. In contrast however, the results of the study conducted by Giallo et al. (2012) corroborate with the sentiments of Murray (2007) and Breen (2009), accentuating that siblings of persons with disabilities are at higher risk of developing emotional and behavioural difficulties due to the additional stress placed on their family units. Their study also underscores the need to consider the characteristics of the broader social system that may strengthen or weaken the well-being and overall functioning of the family, including system supports, such as access to healthcare and disability services, as well as attitudes and acceptance of persons with disabilities in their local communities, counting in their religious communities. For this reason, it is important to consider how practices involving persons with disabilities could assist, or potentially hurt families (McDaniel & Pisani, 2012).

It is thus an unjust society, with its social structures, systems, policies and attitudes that disables not only the person with an impairment but also their entire family unit, where the families of individuals with disabilities commonly experience inequality and discrimination – or so-called *"disablement by proxy"* (Murray, 2007, p. 216).

### 2.3.4 The church as a community system

Laszlo, et al. (1974), contend that all social systems are essentially complex dynamic living systems, and therefore fit into the domain of general systems theory. Given that the current study is particularly concerned with how religious systems impact the functioning and quality of life of persons with disabilities and their families, it seems fitting to discuss the church as one such social structure.

In his first letter to the Christian congregation in Corinth, the Apostle Paul undoubtedly had no inkling of the striking similarity he would make between the metaphor he used to describe the church – *The Body of Christ* – and the modern-day definition of a system. He wrote, *"The body is a unit, though it is made up of many parts; and though all its parts are many, they form one body"* (1 Corinthians 12:12). This is reminiscent of Boulding's (1956) definition quoted earlier, where general systems theory is imaged as a living, unified body of knowledge held together by a core, or skeletal structure. Paul continues the body analogy in verses 24 through 27.

> *But God has combined the members of the body…so that there should be no division in the body, but that all its parts should have equal concern for each other. If one part suffers, every part suffers with it; if one part is honored, every part rejoices with it. Now you are the body of Christ, and each one of you is part of it.*

While the term *inclusion* is not originally Biblical, Paul's account presents a theological basis for viewing every member of a congregation as an active participant, and for receiving the gifts of all Christian members, regardless of their differences. Furthermore, within this framework, every person is seen as an equal member who offers diverse but indispensable contributions to the whole, where the individual believer is not merely a body part, but a *functioning* member of the body, with a unique purpose (Brock, 2011). The importance of understanding disability from this perspective is reiterated by studies such as those reported by LoBianco and Sheppard-Jones (2007), where the perceptions of others toward persons with disabilities have been investigated. Results highlighted that, once integrated into social settings, persons with disabilities felt less perceived as having a disability, and generally, people's perceptions of disability changed with increased contact with persons with disabilities. It can thus be inferred that the intentional inclusion of persons with disabilities in society and in churches will yield a reciprocal recompense for all involved, helping all people discover their likeness, interdependence and need for each other (Gurbai, 2014; Leshota, 2015). From a systems perspective, grasping that the whole surpasses its interrelated parts, this realisation is essential, not only in the interest of persons with disabilities, but also – and perhaps more

importantly – for the sake of the church's health and welfare. As it is at present, however, without the inclusion and full participation of persons with disabilities, the church, in its corporeal representation, can be conceived as missing a few vital body parts where it has inflicted both impairment and disability upon itself in its neglect of proper self-care. This is illustrated through misguided theological understandings that have typically denied persons with disabilities any involvement in the life of their church (Haythorn, 2003). An issue briefly raised in an earlier section, individuals with cognitive and communication impairments are – by no choice of their own – often restricted from sharing in sacraments such as Holy Communion because they supposedly cannot understand or verbally express its meaning, the former being a prerequisite for participation in some faith communities. In an 800-year-old tradition, still thriving in many denominations, Holy Communion is reserved only for those who can confess their faith. Taken out of context, this conviction is based on 1 Corinthians 11 where Paul admonishes the congregation for using the communion elements of bread and drink in an *"unworthy manner"* (v 27), by misconstruing that not *"recognizing the body of the Lord"* (v 29), equals not comprehending the meaning of the sacrament, thereby desecrating the communion elements. Those warning passages in actual fact follow from Paul's charge in verse 18, where he explicitly addresses the problem of division among church members and encourages corporate unity through fellowship and communion among them, and are not related to the ability to conceptualise the sacrament (Peters, 2009).

Not only is this exclusion practice a serious violation of human rights but also a gross misconstrual of scripture. In John 6:53-54, Jesus, in His initiation of Holy Communion, taught that anyone who does not eat and drink from His body (i.e. share fellowship with Him and His Body, the church), cannot attain eternal life. Who then, apart from the *"…Head, from whom the whole body, supported and held together by its ligaments and sinews, grows as God causes it to grow"* (Colossians 2:19), decides which body parts are needed and which ones should be severed from the Body (1 Corinthians 12:21)? If the church is the Body, with Christ as the Head, should not the Body follow the direction of the Head, and ultimately do what He desires and causes it to do? The answer to both questions is simple. Regardless of hierarchical order, no created being is in the place of God to choose the elect at will, and therefore have no authority to decide who should and should not share in this fulfilling life that Christ freely offers to *all*. Neither are they allowed to set lesser standards for Christian living.

The above scenario exemplifies persistent theological fallacies as accurately as it exposes human rights infringements. Extending the obligation of freedom of expression to provide information in understandable and accessible formats, Article 21 of the CRPD recognises the sharing of thoughts, feelings and beliefs through all forms of communication, as a fundamental human right (United Nations, 2006). Restrictions on freedom of expression can affect everyone in many ways but more so persons with disabilities, and often in more subtle ways, especially those with communication disabilities. Failures to make reasonable accommodations to enable persons with disabilities to partake in matters that they consider important, implicitly contradict the person's freedom of expression (McEwin & Santow, 2018) and subsequently deny their right to participation (Articles 29 and 30) (United Nations, 2006). Similarly – influenced by cultural values, family beliefs and interactional styles – some families consciously hide children with disabilities and so prevent their societal and religious participation because of perceived social curse and shame (Möller, 2012; Treloar, 2002), a dogma detained in the medical model, with its victims still haunted by ghosts from the past.

Derived from the adapted definitions of disability, new policies have been implemented in religious settings to advocate and enforce the principles of non-discrimination and equal access for all (Lid, 2017). Respect for inherent dignity, non-discrimination and difference is highlighted in Article 3 in the CRPD (United Nations, 2006), which South Africa ratified in 2007 (Kamga, 2016). Nevertheless, religion scarcely features in the CRPD (Silecchia, 2013). Without affording it a stand-alone article in the document, religion is only briefly stated in the CRPD's preamble, where it is listed, amongst other areas, as a layer of identity within the context of disability and human rights (Degener, 2017). Accordingly, no basic rights in the pursuit of religious freedom, nor any questions concerning religious exercise, are addressed anywhere in the treaty (Silecchia, 2013). This brings to mind Eiesland's (2002) and Creamer's (2009) critiques, discussed earlier, on the failure of religious and human rights groups to acknowledge and engage with each other's concerns. Likewise, an example of the absence of disability discourse in religious policy can be taken from the laws and discipline of the *Methodist Book of Order* (Methodist Publishing House, 2016), the official constitution of the Methodist Church of Southern Africa. Without stipulating any regulations to promote their participation, perfunctory references to persons with disabilities are made twice in the 247-page document, in a laissez-faire appeal to church circuits to aspire toward the provision of adequate access for

persons with disabilities to church properties. Then, in an addendum, parenthetically listed among other personal characteristics typically targeted in discriminatory ways, the topic of disability meagrely features once more, this time solely in relation to the prohibition of sexual harassment and the church's calling to respect all people. Duly, Lid (2017) rebukes Christian congregations and argues that the church has not taken seriously its role in the exclusion of and discrimination against persons with disabilities and further holds that it is both the church's political and ethical responsibility to interpret and implement the CRPD in its own work. The church is therefore obliged to partake in civic life in such a way that it becomes sensitive to the community's way of thinking and by incorporating the ideas of the CRPD, so as to correct outdated understandings from the past (Lid, 2017).

With Christianity being the world's largest religious group (Pew Research Center, 2017), making up 33% of the total population by mid-2017, it is estimated that over 2 billion Christians worldwide are active church members (Johnson, Zurlo, Hickman, & Crossing, 2017). While these statistics do not distinguish between persons with disabilities and able-bodied individuals, it is still noteworthy that only a small percentage (5 – 10 %) of the one billion persons with disabilities worldwide (WHO & World Bank, 2011) is involved in the church, where their invisibility in society is also reflected in faith communities (Möller, 2012). One possible contributing factor to low numbers of persons with disabilities participating in South African churches might be inadequate practical guidelines for the inclusion of persons with disabilities. Such guidelines exist in countries like the United States, where organisations like Joni and Friends provide valuable resources for disability ministry and church inclusion with ideas for baptism, worship, communion and church leadership (Dicken, Young, & Baird, 2008). These resources have limited value for imitation in South Africa with its rich contextual and cultural diversity (Möller, 2012). Möller (2012) also points out that a lack of transport and inadequate means to make church buildings accessible largely remain obstacles to access for persons with disabilities living in under-resourced communities.

Both the United Kingdom and the United States have implemented anti-discrimination regulations to protect persons with disabilities from such exclusion (Swinton, 2012). In the 1990 Americans with Disabilities Act (ADA), which suggested changes that resulted in the 2008 ADA Amendments Act (ADAAA) that was signed into law, equal opportunities and access for all is highlighted, and barriers such as the ones discussed in this dissertation are addressed and

ameliorated by implementing civil rights laws in the United States (Feldblum, Barry, & Benfer, 2008). While comparable values of the CRPD are endorsed by the constitution of South Africa, the country has not fully incorporated it as domestic law in the form of comprehensive disability legislation (Kamga, 2016). Even with the adoption of the White Paper on the Rights of Persons with Disabilities (WPRPD) (Department of Social Development, 2016), which makes provision for the accommodation and inclusion of leaders and congregants with disabilities within the religious sector, in Part 7.10 under Roles and Responsibilities, these declarations, along with the CRPD articles, remain mere policies, which hold no value unless the implementation of their statutes are monitored and enforced by law (Kamga, 2016).

But even with strategies for physical access in place, manifold discriminatory attitudes and oppressive theological ideas about disability, faith and healing – as espoused by church leaders and congregants without disabilities, and self-imposed by some with disabilities – raise up rigid barricades that stand firmly in the way of engagement and participation (Leshota, 2015; Möller, 2012). Swinton (2012) articulates these issues aptly in reflecting that the law has much power to change social structures, but none to change the human heart, and while the law can aid inclusion, it cannot facilitate communion and belonging.

The question remains, why, in the face of all the efforts toward inclusion of persons with disabilities in community life, and the importance of spiritual participation highlighted in literature cited throughout this chapter, are persons with disabilities still largely excluded from their faith communities? Apart from the inapplicable practical methods for inclusion, transport issues, poor church access, and unenforced symbolic laws mentioned earlier, it is also necessary to take a closer look at the theology of disability espoused in Christian congregations. The following section includes aspects of disability theology in general but will focus specifically on the Wesleyan tradition upon which Methodism is built.

In an attempt to incorporate inclusion language into Christian theology, Eiesland (1994) utilised scriptures such as 1 Corinthians 12, quoted earlier, to encourage the church to join the pursuit for full accessibility and inclusion, which was by then underway in the secular world (Brock, 2011). Although Eiesland's contributions made giant strides in creating awareness of injustices against persons with disabilities in the church and society, and in the movement toward equality and inclusion, her theology was based on the minority group model, by which she contended that the church system functioned to impede and afflict persons with disabilities. She

also spelled out that her theology was exclusively for persons with physical disabilities (Eiesland, 1994), which is paradoxical to a theology intended to end exclusion, subsequently doing the very same by excluding certain individuals with disabilities (Swinton, 2012).

While Methodist practices attempt to be inclusive of *all* people, as well as persons with disabilities, some Methodist hymnody, much of which was composed by the younger brother of the founder – evangelist and theologian, John Wesley – may be viewed as problematic in that it suggests that the body of the person with a disability serves to exhibit God's miraculous restoration of the body to 'normal' health (Hall, 2011). It is these constructions of what is deemed 'normal' that have led to disability being viewed as 'abnormal' among believers, presuming that persons with disabilities do not reflect the image of God because of their sin, and must therefore be subjected to healing practices to reinstate their 'normality' once they have been freed from their sin and its debilitating effects (Swinton, 2011). Hence, the relationship between Methodism and persons with disabilities has been a conflicting one (Hall, 2011). The issue of healing itself has a contentious history in the church, but where some churches offer healing services, this is not a usual part of Methodist tradition (Armistead, 2006). For Wesley, practical faith had always included paying attention to the body and caring for the ill, and his followers have therefore always made a distinctive link between the soul and physical well-being. Even so, Wesley was adamant that disability was not the result of an individual's sin, yet synchronises its genesis with the Fall – the time when humans rebelled against God, became depraved and in need of God's grace (Armistead, 2006). Hall (2011) explains how disability within Wesleyan theology therefore included a normative understanding of how the body was supposed to look and function and any deviation from these norms were understood against the backdrop of the cardinal sin of Adam and Eve.

Because many people, Christians included, have adopted ideas from the Western culture about external beauty and perfection (Anderson, 2015), Wesley's discourse in his theology of *Christian Perfection* could also be potentially problematic for persons with disabilities, with 'perfection' being a loaded term in disability studies. Wesley, however, conceptualised something very different from the contemporary understanding of the word, asserting that *all* Christians, not a select few, are to move toward a *telos* of perfection, that is, toward an ultimate spiritual end purpose to become like God, by grace, through faith in Christ (Hall, 2011). Deeply aware of cultural perceptions, many persons with disabilities may become demoralised by

society's bias toward able-bodiedness (Anderson, 2015). For that reason, Creamer (2012) cautions that persons with disabilities may erroneously associate Wesleyan terminology of perfection with flawlessness of the body, that is, internalising the able-body as the ideal and worthy of God's grace, and therefore impairment, the result of God's disapproval and punishment. It is possible that these perceptions are held not only by persons with disabilities but also by other members of the family and church systems, who inadvertently perpetuate such views in alignment with the moral perspective of disability.

From these discussions, it is evident that persons with disabilities face many barriers to inclusion, engagement and participation in their congregations. Whether physical, attitudinal or theological in nature, concerted efforts from all members of the Body are needed to remove these obstacles. Perhaps a starting place is to enhance congregations' conscience and Biblical responsibility toward one another. This will hopefully lead to a sober, unmitigated appraisal and urgent remedy of the church's incomplete status without its vital body parts. Revisiting the theoretical principles of system functioning, it is important to remember that interactions in a system are multidirectional, between all the different individual components within the system, and among the subsystems within the larger context. Combining theoretical and Biblical constructs, if all the elements of the individual, family, church and wider social systems function in an organised, integrated manner, the congregation as an embodiment of Christ, will itself move toward *telos* to fulfill its purpose and learn what it means to be the body of Christ as He intended it. From the top down, church leaders imparting theology, and policy makers protecting human rights, should be held accountable at their levels of management and engage attentively with those on the ground, to ensure the welfare of *all* within the system (Creamer, 2009; White, 2014).

This chapter also revealed the resistance wielded by the inert conceptual models of thought and perceptions concerning disability that lie beneath the social structures that persons with disabilities face on multi-system levels, including their faith communities. Since the context plays an important part in understanding a phenomenon such as the above (Leedy & Ormrod, 2015; Leshota, 2015), it is necessary to engage with the personal experiences and interpretations that have constructed people's perceptions regarding a specific social situation. Therefore, this study aims to explore and describe the perceptions of persons with disabilities, primary caregivers of persons with disabilities, as well as church leaders, in order to determine

what they consider to be barriers and facilitators to meaningful participation in their Christian congregation.

## 2.4 Conclusion

Focusing on the social participation of persons with disabilities, specifically within their Christian faith communities, this chapter provided a detailed review of the literature concerning disability inclusion. The most prominent models of disability, as deliberated by both scholars of disability studies and theology, were unpacked and related to their influence on the church's stance on disability throughout history. Concluding with insights into Wesleyan theology in a Methodist faith-based system, this chapter offered a theoretical framework for understanding the interactive nature between the individual and their wider systems. It also highlighted the importance of appreciating disability and societal participation based on the experiences and perceptions of individuals within their unique social situations. With this being the goal of the research, the next chapter will explore the practical steps for obtaining the study's aims.

# CHAPTER 3
# METHODOLOGY

## 3.1 Introduction

The previous chapter presented an appraisal of the literature concerning disability inclusion in a religious context and provided a basis for considering how socio-cultural constructions of disability may influence the inclusion and participation of persons with disabilities within their Christian faith communities. This chapter discusses the research methodology – including a description of the aims, design, pilot study, participants, materials and equipment, as well as the procedures followed for the collection and analysis of data in an attempt to answer the following research question:

> *What are the perceptions of persons with disabilities, primary caregivers of persons with disabilities, and church leaders regarding barriers and facilitators to participation in ceremonies, activities and events in the church?*

Before ending with a conclusion of the main points of the chapter, ethical aspects pertaining to the research procedures are discussed.

## 3.2 Aims

In order to address the research question, the following main aim and sub-aims have been set.

### *3.2.1 Main aim*

The main aim of the study is to determine the perceptions of a triadic participant group, comprising persons with disabilities, primary caregivers of persons with disabilities, and church leaders, regarding barriers and facilitators to the participation of persons with disabilities in ceremonies, activities and events in the church, as an example of a human activity within a specific environment.

### *3.2.2 Sub-aims*

Four sub-aims delineate the main aim of the study, namely:

i. To explore and describe what persons with disabilities, primary caregivers of persons with disabilities, and church leaders regard as ceremonies, activities and events in the church

ii. To explore and describe the perceptions of persons with disabilities, primary caregivers of persons with disabilities, and church leaders regarding barriers to the participation of persons with disabilities in ceremonies, activities and events in the church

iii. To explore and describe the perceptions of persons with disabilities, primary caregivers of persons with disabilities, and church leaders regarding facilitators to the participation of persons with disabilities in ceremonies, activities and events in the church

iv. To explore if the perceptions of persons with disabilities, primary caregivers of persons with disabilities, and church leaders regarding barriers and facilitators to the participation of persons with disabilities in ceremonies, activities and events in the church can be linked to the contextual factors in the ICF as a theoretical framework

### 3.3 Research design and phases

A constructivist paradigm was adopted in this study. From a social constructivist point of view, knowledge and reality are constructed by individuals, who form their own understanding of life and give meaning to the world in which they live, based on their personal and social observations and experiences. It is the meaning they give to their constructed worlds that informs their actions, thoughts and feelings (Carter & Fuller, 2015; Mackay & Petocz, 2011). This implies that reality – and along with it, the constructed meaning of disability – can change and can be perceived differently by different individuals (Pritchard & Woollard, 2010), and in different contexts (McEwan & Butler, 2007). Since disability is best understood within the context in which persons with disabilities exist (Leshota, 2015; Möller, 2012), this study aimed to describe the lived experiences of persons with disabilities and two additional stakeholder systems within the unique contextual reality of a particular Christian congregation.

Accordingly, a qualitative, descriptive case study design was employed. The detailed account produced by this design effectively captured the distinctive features of the participants' natural context (Qi, 2009), and provided the opportunity to discover the experiences and perceptions of this community of people of which little was known before. To understand their context thoroughly, three participant focus groups were included in the sample, which engendered profound insight and a wealth of detailed information from them (Leedy & Ormrod, 2015; Naudé & Bornman, 2018).

Focus groups are considered useful since several individuals can be interviewed simultaneously, saving time and creating comfortable environments promoting interaction among participants (Leedy & Ormrod, 2015), and stimulating one another's thoughts and sharing (Naudé & Bornman, 2018). Through exploration, the researcher was thus able to gain a deeper understanding of the contextual significance the participants' perceptions bear (Klopper, 2008). The triadic participant group contributed their views in their respective focus groups, from which rich, in-depth descriptions and comparative aspects of their perceptions were obtained (Leedy & Ormrod, 2015; Qi, 2009).

However, given the relatively small number of participants, the sample may not necessarily be representative of the wider population, and the results may therefore not be generalised to other situations and other congregations (Leedy & Ormrod, 2015; Zaidah, 2007). Moreover, given that this specific design is susceptible to bias, in that the researcher may have guided the results and conclusions in the direction of her own preconceptions (Zaidah, 2007), trustworthiness has become a key element of this research, and specific measures (outlined in section 3.7.3) were employed to ensure the credibility and trustworthiness of the findings.

Figure 3.1 shows a schematic overview of the three phases of the research process.

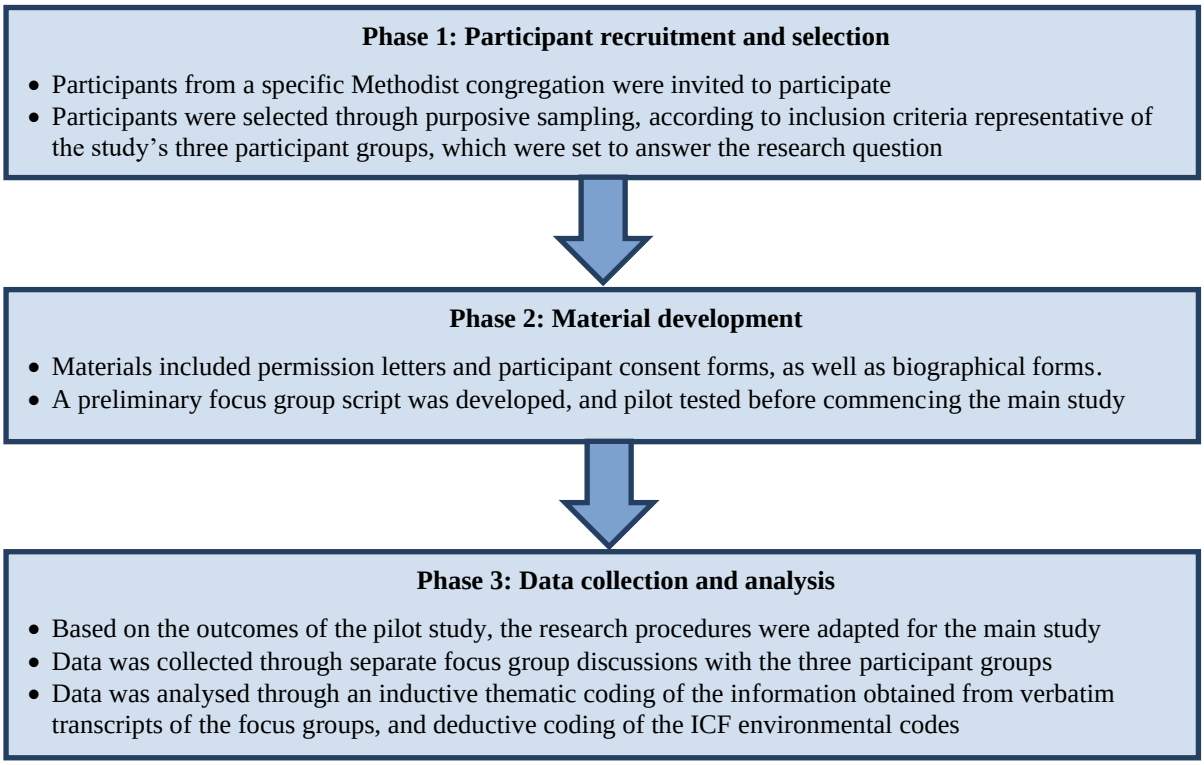



Figure 3.1 *Phases of the study*

### 3.4 Pilot study

Although the main study has been planned thoughtfully, it was considered essential to pilot test the methodology and research instrument (Naudé & Bornman, 2018), since such pre-testing can forewarn of areas where the main research project may fail (van Teijlingen & Hundley, 2002). In addition, it can timeously reveal some unforeseen practical challenges that are likely to appear, despite all well-planned efforts (Hassan, Schattner, & Mazza, 2006). A pilot study was therefore conducted to ensure that the materials and equipment, and all the procedures proposed for the main study, were appropriate and adequate, so as to ensure that it will deliver the results aimed by the study (Leedy & Ormrod, 2015).

While pilot studies are necessary and useful in guiding researchers' next steps in their own projects, the manner in which they report on their pilot studies is considered to have equal importance for other researchers (Arain, Campbell, Cooper, & Lancaster, 2010). In fact, researchers have an ethical duty to provide detailed accounts of their pilot studies as part of their research experiences – not only on the processes and outcomes of their main studies – as it may hold valuable directives for other researchers planning to use similar methods and instruments (van Teijlingen & Hundley, 2002). In compliance with this principle, the following section contains a comprehensive description of the pilot study, including the participants, aims, materials and procedures used, the issues that arose, and the improvements proposed for the main study.

#### 3.4.1 Participants

Due to the limited number of potential participants for the main study, participants were recruited from a different population, and therefore, their characteristics are not consistent with the selection criteria for any of the participants in the main study, as described in section 3.5. Similarities between the pilot and main study participants were, however, not deemed necessary, given that only the research instrument and the method of data collection were tested, and not the outcomes of the participants' responses.

The researcher invited ten final year Master's students in Psychology, who were halfway through the process of completing their internship programme. They were selected based on their suitability to critically reflect on the researcher's facilitation of the focus group discussion, as it is a research methodology that forms part of their training, and also to offer feedback in terms of weaknesses in the procedures and to make suggestions for improvement.

Eight of the ten participants who were invited consented and participated. The remaining two were on leave on the scheduled day of the focus group. Snacks and beverages,

which were enjoyed by the participants before and after the focus group, were provided in a meeting room at the participants' workplace.

Once written informed consent was obtained and the biographical questionnaire completed by all participants, the focus group discussion, which was conducted in English, commenced. The whole discussion was audio-recorded. Immediately after the focus group discussion, the participants were asked to reflect on their experiences in the group discussion. Once the proceedings ended, the researcher expressed her gratitude for their contributions through giving each of the participants a small token of appreciation.

The biographical information of the eight participants who formed part of the pilot study is presented in Table 3.1.

Table 3.1

*Biographical Information of Pilot Study Participants (n=8)*

| **Participant** | **PP1** | **PP2** | **PP3** | **PP4** | **PP5** | **PP6** | **PP7** | **PP8** |
|---|---|---|---|---|---|---|---|---|
| **Sex** | Male | Female | Female | Male | Female | Female | Female | Female |
| **Age** | 27yrs | 24yrs | 26yrs | 25yrs | 27yrs | 25yrs | 28yrs | 25yrs |
| **Race** | White | Black | Black | White | Black | Indian | Indian | Indian |
| **Home Language** | English | English | Setswana | English | Sepedi | English | English | English |
| **Religious affiliation** | Christian | Christian Pentecostal | Christian | Christian Roman Catholic | Christian | Christian | Islamic | Hindu |
| **Experience with PwD*** | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| **Family member(s) who is a PwD*** | Yes | Yes | No | No | No | Yes | Yes | Yes |
| **Awareness of church participa-tion of PwD*** | Yes | No | Yes | Yes | No | Yes | No | No |
| **Awareness of disability inclusion policy in any church** | Yes | No | No | Yes | No | Yes | No | No |

* Person(s) with Disability

On the one hand, Table 3.1 suggests a diverse group, with three Black and three Indian females, as well as two White males, whose ages range between 24 and 28, with a median age of 26 years. Three different religions are represented, with two participants belonging to the Islamic and Hindu faiths respectively, and the rest, Christianity – further differentiated by two specified denominations. The participants were equally divided in terms of their awareness of the participation of persons with disabilities in church activities.

On the other hand, the group shares more similarities than differences, the most striking being their level of education and chosen profession as Psychologists. In addition, all the participants, except one, are South African, and six participants live in the residential suburbs of Johannesburg, while only two reside further North in the Gauteng Province.

Barring two participants, English is the home language shared among everyone. Table 3.1 also shows that all the participants have had some experience with persons with disabilities, either through work, or personal encounters, such as at their places of worship. Five also have at least one family member with a disability, and only three were aware of any existing disability inclusion policies in any given church.

### *3.4.2 Aims, materials, procedures, results and recommendations*

Table 3.2 gives and overview of the aims of the pilot study, the materials and procedures used, as well as the results and the subsequent recommendations.

Table 3.2

*Pilot Study Aims, Materials, Procedures, Results and Recommendations*

| | |
|---|---|
| **Aim 1:** | To test the timing of the administrative procedures, such as completing the consent forms and biographical questionnaires, prior to the focus group discussion. |
| **Materials** | Participant Consent Forms; Biographical Questionnaires (Appendix B); Clip Boards; Stationery |
| **Procedures** | Informed consent was obtained from all eight participants, once they read the forms and signed the reply slips. The Participant Consent From for the pilot study was adapted from the approved participant consent form for the Church Leaders of the main study. Similarly, the Biographical Questionnaire for the pilot study (Appendix B) was adapted from the approved Biographical Questionnaire for Church Leaders (Appendix G) of the main study. The participants' chairs were arranged in a circular configuration with a small table in the middle. The researcher was seated amongst the participants. To ensure maximum comfort, each participant was provided with a clip board on which to press whilst completing the consent forms and biographical questionnaires. They were each given a black pen, which they could keep. |
| **Results** | It took approximately 5 minutes for the whole group to read and sign their consent forms. The biographical questionnaire took between 5-8 minutes to complete. Extra time was taken, given that some participants were uncertain how to engage with the question: *"Do you have any experience with persons with disabilities? If yes, please specify."* Their hesitation was caused by an uncertainty of the scope of the term 'disability'. Four participants initially answered 'no' to the question, and then self-corrected after one participant clarified whether disability could include injury resulting from an accident, and another, whether intellectual difficulties, such as barriers to learning, can be included in the study's definition. It was subsequently explained that disability might be understood in a very broad sense. Possibly fearing disapproval in a workplace environment that encourages professionals in psychology to look beyond disability labels and diagnoses, most of the participants initially considered only obvious visible physical impairment as disabilities (e.g. wheelchair-users), and assumed that it excluded intellectual, social and psychiatric challenges, such as learning difficulties, autism spectrum disorder, Alzheimer's disease, depression, etc. |
| **Recommen-dations** | Whilst the procedures should remain unchanged for the main study, it is recommended that additional time is allocated for the completion of the biographical questionnaires for the main study, given that their forms are somewhat longer and more detailed than the one used for the pilot study. Additionally, given that disability in this study is understood in a very broad sense, the term, as it is used in all the custom-designed biographical forms for the main study, could be delineated with more precision, and elaborated to include intellectual, physical and sensory difficulties, and whether the disability was from birth, or acquired after an accident, for instance. |
| **Aim 2:** | To test the focus group script to determine how comprehensible the questions are. The questions were thus screened for ambiguity, so as to rephrase any problematic questions in such a way as to clarify, yet maintain their meaning. |
| **Materials** | Preliminary Focus Group Script (Appendix C); Sticky notes; Flip Chart and Whiteboard Markers |
| **Procedures** | In following the preliminary focus group script, the researcher facilitated a discussion around the participants' contributions to the pre-prepared focus group questions, including one introductory, and two key questions. For the introductory question, participants were given sticky notes on which to write down their responses before sharing it among the group. Once everyone had given some thought to the question, they contributed their responses, which were noted on the flipchart in point form by the researcher. Although the researcher's seat was incorporated into the discussion circle, she had to rise frequently throughout the procedures, to write down responses on the flip chart, which was positioned just outside the circle, at an angle where everyone could see the written responses. Once the discussion was underway, the two key questions were added. After the focus group, the participants were asked to reflect and identify difficult, vague, or ambiguous questions. |

| | |
|---|---|
| **Results** | The wording in the introductory question, *"What comes to mind when you think about participation in church ceremonies, activities and events?"* proved problematic and produced response error, as it did not capture the information it was designed to obtain. Some participants wrote down abstract responses, such as emotions – an understandable response, given the vagueness of the question in hindsight. They felt hesitant to share their considered responses after hearing other participants respond with different, more concrete examples, such as, worship services, weddings, Bible studies, funerals, etc. Some participants disclosed feelings of discomfort because their responses were so different from the others and admitted that they felt discouraged to share their thoughts for this reason. This unintended hiccup interrupted the participants' spontaneity and thus the flow of the discussion early on. However, given the group members' familiarity with each other, a relatively quick recovery was made, and once the confusion was resolved, clarity of the question was achieved, and the discussion gained momentum. No problems were experienced with the two key questions. |
| **Recommen-dations** | It is recommended that the introductory question be rephrased in a manner that is clear-cut and unambiguous in meaning, such as, *"What are the different ceremonies, activities and events that people attend at church?"* This should avoid participants feeling confused and holding back their valuable contributions. The key questions should remain unchanged. |
| **Aim 3:** | To test if it is feasible to complete the focus group discussion within the allocated time (90 minutes). |
| **Materials** | Preliminary Focus Group Script (Appendix C); Sticky notes; Flip Chart and Whiteboard Markers |
| **Procedures** | The provisional focus group script was strictly adhered to and administered in the exact manner proposed for the main study. The total time of the focus group discussion was recorded to decide whether it was reasonable. |
| **Results** | The focus group discussion lasted 99 minutes, which means that it exceeded the allotted time by 9 minutes. |
| **Recommen-dations** | While 9 minutes over time may not seem serious, it is important that this time factor is reckoned in the main study. It is likely that a more clearly defined introductory question would prevent any confusion, and hence facilitate a smooth, uninterrupted discussion, without any waste of time. |
| **Aim 4:** | To test if the audio-recording equipment is adequate in clearly capturing all the participants' comments. |
| **Materials** | Olympus Digital Voice Recorder (VN-240PC) and iPhone 5S (Model A1530) Voice Memo as a backup recording device. |
| **Procedures** | Before any of the pilot study procedures commenced, the researcher briefly tested the sound quality in the room by recording parts of the informal conversations between the participants whilst they enjoyed refreshments. To ensure the best audio quality for the recording of the focus group discussion and the subsequent reflections, the digital voice recorder was optimally set to the High Quality (HQ) recording mode and to High-sensitivity (HI) mode for microphone sensitivity. As a backup plan in the event of an unforeseen technical malfunction, the researcher used her own cellular phone's voice memo function to record the session. Both devices were placed on the small table in the middle of the circle of participants in order to maximise the quality of the recordings. |
| **Results** | In addition to delivering results concerning the audibility of the recording, additional lessons were learnt and problem areas exposed, that could not have been known unless the equipment was pilot tested. On its selected High Quality (HQ) setting, the digital voice recorder did not produce a good sound quality, as it was only audible with the use of earphones. It was also discovered that the voice recorder, in its selected HQ mode, did not record the entire discussion. Only 88 minutes of the session was captured. The total time of the meeting, which included the focus group discussion and the reflections, was 115 minutes, which means that 27 minutes of the discussion / reflections would have been lost, had there not been a backup preparation for the recording equipment. The backup recording on the cellular phone produced adequate results, both in terms of audio quality and duration of the recording. |

| | |
|---|---|
| **Recommen-dations** | Given the unpredictable nature of technological devices, a similar backup strategy as the one used in the pilot study, is recommended for the main study. The recording mode of the digital voice recorder should be set on Standard Playback (SP), as it provides a longer recording time; however, the extended time is gained at the cost of the sound quality, which is already poor at the highest setting. Even so, the digital voice recorder can be implemented as the secondary device performing the backup duty, while the iPhone 5S's voice memo function can be used as the primary device. The researcher is aware of the ethical implications of collecting confidential information on her cellular phone. Once the recordings are digitally transferred and stored onto her secured laptop, the recordings will be deleted immediately from both devices. This is the same procedure approved by the Ethics Committee for using the digital voice recorder, and this same procedure was followed in the pilot study. |
| **Aim 5:** | To gain participants' reflections on their overall experiences of being part of the study, so as to receive feedback and suggestions for improvement. |
| **Materials** | Reflections |
| **Procedures** | In addition to contributing their perceptions on the appropriateness of the focus group questions, participants were asked to reflect on their overall experiences on participating in the focus group and to suggest recommendations for improvement. This procedure lasted 16 minutes. Directly after the focus group discussion, the participants were invited to openly share their thoughts on the procedures, specifically paying attention to any problematic areas that needed improvement. They were subsequently asked to suggest recommendations to resolve the issues they have identified and were reassured that there would be no negative consequences to them if they commented on any negative aspects. |
| **Results** | In addition to the abovementioned recommendations made regarding the clarity of the introductory question and the backup audio-recording, the participants identified the researcher's interaction with the participants as another important area that needed attention and modification. The participants commented on their perception and appreciation of the relaxed manner in which the researcher remained seated throughout the time they shared their reflections on their experiences. This was contrasted to the behaviour they observed while the researcher was writing down their responses during the focus group discussion. The participants also made the researcher aware that she was missing out on some valuable non-verbal cues from the participants at the times she was writing. They also thought that she wrote too much, especially considering that the discussion was recorded, with backup. They further expressed the ease with which they were able to communicate with her and share their thoughts when she was engaging with them face-to-face, instead of turning aside to write down their comments on the flip chart. |
| **Recommen-dations** | It is recommended that an assistant is employed for the task of writing down the participants' responses, while the researcher remains seated, allowing her to fully connect with the participants and to facilitate the flow of the discussion. With an independent person doing the writing, the participants suggested that the researcher can more successfully engage the reserved participants to contribute their views, by using simple gestures, such as direct eye contact, or a nod of the head in their direction. |

Table 3.2 provides evidence that the pilot study was indeed a useful and indispensable step that helped to inform the important required changes to the materials and procedures for the main study. In summary, all the aims set for the pilot study were met with valuable suggestions for improvement, some even with unexpected additional recommendations. For instance, while it was not specifically the aim to determine the precision of the terminology used in the biographical questionnaire, the pilot study shed light on the importance of clearly defining disability in such a way as to promote broad thinking, thus helping to elicit rich data from participants on the topic (Shenton, 2004). The pilot study also revealed that an assistant, in the role of a note-taker (Prior, Waller, & Kroll, 2013), will be a crucial additional resource to the main study.

### 3.5 Participants

In coherence with a case study method, a limited number of individuals from a specific geographical area (Zaidah, 2007) in Johannesburg, South Africa, were selected as subjects for the study. Instead of focusing on disability inclusion in the church in general – which is too broad for a case study that does not aim to generalise the results to the wider population (Leedy & Ormrod, 2015) – the focal point of this study was narrowed down by restricting it to a specific Methodist congregation familiar to the researcher. The selected congregation is situated in an affluent residential suburb in the north of Johannesburg and is attended by individuals and families who reside in the area, as well as neighbouring suburbs and townships.

As a member of the selected congregation, the researcher employed non-probability, purposive, convenience sampling, where only a few individuals from a suitably accessible homogeneous context, who yielded the most information about the topic, were included in the study. Originally, the study proposed to include participants with disabilities from a nearby adult residential care facility, who regularly attend events at the congregation. While permission was positively granted to recruit participants from the Methodist congregation's leadership team, permission to recruit participants from the residential care facility was denied. No specific reason was provided.

Alternatively, additional permission was given by the church leadership to formally invite caregiver participants, as well as participants with disabilities from the congregation. This was arranged by allowing the researcher opportunities to address the congregants in person at the various Sunday services, where written information about the study was also projected electronically. In addition, the researcher handed out information flyers at the

doors, as well as displaying these on the notice boards in the church foyer. After a poor response of interest, follow-up invitations were printed in the church bulletins for two consecutive Sundays, and included in the congregation's newsletter, reaching a wider population of potential participants.

The selected sample consisted of a triadic participant group, each unit considered to best portray the characteristics of the larger population they represent, based on their knowledge and ability to describe disability inclusion with the unique perspectives they brought regarding their own contexts (Leedy & Ormrod, 2015).

The first unit of the triad included persons with disabilities, while the second unit comprised primary caregivers of persons with disabilities. The third unit consisted of ordained clergy, pastors, society stewards and other individuals representative of the congregation's leadership. Some of the participants in the first two units had not been attending the congregation for some time, but were notified of the study by means of the church's communication network or by family members. Other participants were directly approached by the researcher and invited to participate. Both male and female adults with a Christian faith orientation and proficiency in English, and who matched the rest of the selection criteria, were included in all three focus groups. All participants included in the study provided written consent.

The participant selection criteria are presented in Table 3.3.

Table 3.3

*Participant Selection Criteria*

| **Criterion** | **Theoretical Justification** | **Measure used** |
|---|---|---|
| Unit 1: Persons with disabilities who presently attend, or have attended the selected Methodist congregation as members or visitors | Leshota (2015) mentions the *"oft-missing voice"* (p.2) of persons with disabilities in theological discourse and encourages church leaders to create spaces for heeding the desires of those with disabilities. | Biographical Questionnaire |
| Unit 2: Caregivers of persons with disabilities who presently attend, or have attended the selected Methodist congregation as members or visitors | Parents and families of children with disabilities usually form the primary support system to persons with disabilities, and can act as either a barrier or facilitator to participation (Breen, 2009; Murray, 2007). It is therefore important to involve them and gain their perspectives on inclusion in the church. | Biographical Questionnaire |

| Criterion | Theoretical Justification | Measure used |
|---|---|---|
| Unit 3: Church leadership team from the selected Methodist congregation | In relevant literature, religious leaders are urged to address issues of justice and human rights more widely by finding ways for worship and faith communities to become models of inclusion and access for persons with disabilities (Creamer, 2012). | Biographical Questionnaire |
| Christian faith orientation | Perceptions are sought regarding inclusion within a Christian faith community. | Biographical Questionnaire |
| Geographical area: Connection with the Methodist congregation in the Northern suburbs of Johannesburg, either as visitors, members, or leaders | Given that this is a case-based study, the triadic participant group is comparatively homogeneous in terms of each unit's concern and connection with the congregation (Leedy & Ormrod, 2015). | Biographical Questionnaire |
| Language proficiency | Participants were required to communicate intelligibly in English to ensure adequate participation and contribution to focus group discussions. | Established through the researcher's prior knowledge of participants |

Information obtained from three custom-designed biographical questionnaires made it possible to describe the participants comprehensively according to personal characteristics such as age, race, sex, education, and their level of involvement and participation in the congregation. Participants' knowledge and endorsement of existing disability inclusion policies in the congregation were also probed. Specific questions to church leaders involved role descriptions, service duration and experience with persons with disabilities. From primary caregivers and persons with disabilities, specific information regarding the nature of the disability, their Christian faith denomination and customary church attendance was obtained.

The abovementioned information, together with the findings of the focus groups, have therefore contributed to providing a thick description of the contexts that surround each participant group; thus elevating the credibility of the results (Shenton, 2004).

Each of the three units will now be described according to characteristics additional to the selection criteria.

### *3.5.1 Focus group unit 1: Persons with disabilities*

Six of the eight participants, who communicated their interest in participation, consented and participated in the focus group discussion. One of the two potential participants sent an apology afterwards. While the other potential participant, who has Down's syndrome, is not a member of the congregation, she was invited to participate given that she is familiar with the church and has attended several events hosted there before. She is also the daughter of a participant from the caregiver focus group. Her mother, in collaboration with the researcher, decided that it would be best for her not to participate, as she became increasingly emotionally stressed as the time for the meeting drew closer.

Although the researcher eventually managed to convene this group of participants with greater ease than the other two groups, this was not the situation from the start. Due to a poor response from the congregation to the initial invitation process, the researcher had to consider recruiting participants from a different community altogether. Alternative avenues were explored to no avail, since no other suitable participant group, who met the participant inclusion criteria, was accessible. These challenges caused a significant delay in the research process, as several months had passed since the initial recruitment process.

Given the fact that the World Health Organisation estimates the disability prevalence at 15% (WHO & World Bank, 2011), this congregation, with an average of 950 people in attendance during the Sunday services, should have approximately 143 persons with disabilities, that is, one in every seven people. Therefore, it was surprising how difficult it was to recruit participants.

As the primary participant group, and thus the linchpin of this study, the researcher made further appeals to the congregation, and with the help of church staff members, more participants were reached through different communication channels. It transpired that some of the participants were not attending church, while two others were visiting different churches, during the period of the initial recruitment process, and were unaware of the study. Two other participants disclosed that they were too fearful to come forward with their true views about disability inclusion in the congregation.

The biographic information of the six participants in the first unit of the triadic participant group is presented in Table 3.4.

Table 3.4

*Biographical Information of Unit 1 Participants: Persons with Disabilities (n=6)*

| **Participant** | **P1-1** | **P1-2** | **P1-3** | **P1-4** | **P1-5** | **P1-6** |
|---|---|---|---|---|---|---|
| **Sex** | Female | Male | Male | Female | Female | Female |
| **Age** | 30yrs | 54yrs | 69yrs | 41yrs | 75yrs | 51yrs |
| **Race** | Black | White | White | White | White | White |
| **Education level** | Master's Degree | Doctoral | Bachelor's Degree | Grade 12<br>Mainstream | Matric<br>College credit | Grade 12 Mainstream<br>College credit |
| **Type of disability** | Major Depressive Disorder | Deafness | Parkinson's Disease | Epilepsy | Parkinson's Disease | Cerebral Palsy |
| **Difficulties experienced** | Depressed mood<br>Anxiety<br>Poor concentration | Hearing | Moving and walking independently<br>Short-term memory loss | Seizures<br>Photosensitivity | Tremors<br>Hearing<br>Anxiety | Moving and walking independently<br>Anxiety & depression |
| **Severity of disability** | Severe | Severe-to-Profound | Moderate | Moderate | Moderate | Mild |
| **Duration of disability** | 1½yrs | Since birth | 15 years | 23yrs | 13yrs | Since birth |
| **Attendance period** | ±1yr | 30yrs | 32yrs | 22yrs | 22yrs | 20yrs |
| **Attendance with someone** | Alone | Alone mostly | Wife and occasionally children | Mom | Daughter | Alone |
| **Attendance regularity** | More than once weekly | Once-twice monthly | Once monthly | Weekly | Weekly | Weekly |
| **Additional attendance apart from Sundays** | Women's Manyano | None | None | Special services<br>Ladies' mornings | Small group<br>Special events | None |
| **Know of other PwD* in congregation** | No | Yes | No | Yes | Yes | No |
| **Awareness of disability policy** | No | No | No | No | No | No response |
| **Support of policy** | Yes | Yes | Yes | Yes | Yes | No (No reason) |
| **Attend another church** | Yes | Yes | No | No | No | No |

* Person(s) with Disability

Table 3.4 provides a detailed description of the participants from the focus group for persons with disabilities and reveals a participant profile that varies fairly in terms of age, education level, type, duration and severity of their disability, and the difficulties they experience as a result. While two participants were born with their disability, two others' were acquired during childhood, and two later in adulthood. Two participants described their disability as severe, three as moderate and one as mild. Difficulties associated with their disabilities include physical, neurological, sensory, cognitive and psychological challenges, such as difficulties with mobility, tremors, seizures, hearing, impaired concentration and memory, and anxiety. All participants indicated that they have to manage their conditions with medication, psychological treatment and/or assistive devices. One participant, who is Deaf, made use of an assistive listening device during the focus group, which allowed sound to be transmitted to his hearing aid through wireless Bluetooth technology. This enabled him to hear and interact with everyone during the discussion.

All participants, apart from one who is isiXhosa-speaking, share English as a home language and one participant also uses South African Sign Language. The one Black and five White participants in this group – only two of whom are male – are all South African and are affiliated to the Methodist denomination as full members of the congregation in this study. Only one participant is relatively new to the congregation, while all the other participants have attended this church for a time period between 20-32 years. While all participants are able to attend church on their own, one participant relies on a lift for transport. Three of the participants usually attend alone, where the three other participants – two of whom are blood relatives – always attend church with a family member. Some participants are also occasionally joined by their children at some services.

In terms of their regularity of attendance, four participants usually attend church at least once weekly, with one participant attending once or twice per month, and another participant only once monthly, at most. While three participants attend other church activities and events specifically for women, none of the other participants attend any church activities in addition to weekly church services. Barring two participants, none of the other participants attend any other churches. Although the participants were equally divided concerning their awareness of other persons with disabilities in the congregation, none of them were aware of any disability inclusion policy or training programme endorsed by the congregation. However, all participants, except one, indicated their support in favour of this. Out of the five participants who indicated their support, only three participants provided reasons, while the other two participants verbally expressed that their reasons were obvious.

The researcher thus inferred that they felt no need to explain their answers. The three participants who motivated their positive responses gave the following reasons: one participant commented that it would help persons with disabilities, and another participant shared that nobody in the church leadership seemed to understand the negative impact the poor maintenance and faulty lighting equipment in the church had on her health condition earlier in the year. Finally, one participant expressed the need for increased disability awareness and education to the church staff, stewards, music groups and the congregation in general. The evident perceived appeal in a prospect of the congregation's attempt at intentional inclusion of persons with disabilities may thus potentially result in a sense of feeling understood, more regular attendance, as well as increased participation in other church activities as well.

### *3.5.2 Focus group unit 2: Caregivers*

From the outset, very little interest in participation was shown for the second unit of the triadic participant group. Again, approximately 143 persons with disabilities should be in the congregation. It was therefore interesting how few caregivers came forward. Since only one participant from the congregation spontaneously communicated her interest, the researcher approached other prospective participants personally. Although they all expressed their appreciation and recognised the value and necessity of the study, two people explained that time away from their family responsibilities and the persons with disabilities in their care was not feasible for them. These responses were empathetically discerned in light of McDaniel and Pisani's (2012), and Breen's (2009) validation of the onerous burden that family members – mostly mothers – who assume the role of primary caregivers, often bear alone or with little support.

While five participants confirmed their attendance of the focus group beforehand, only three participants eventually participated. One of the participants in this focus group is the spouse of a participant in the focus group for persons with disabilities, while the other two participants each care for one disabled child. A potential participant withdrew 45 minutes before the discussion, sending an apology through a text message to the researcher's cellular phone. Another potential participant, the mother of one of the participants in the focus group for persons with disabilities, fell ill on the morning of the focus group, and only reached the researcher telephonically 15 minutes before the meeting time, to notify of her withdrawal. By then, two of the three remaining participants had already arrived at the venue, signed consent and started completing their biographical forms. Although the researcher was

concerned that fewer participants in an already small focus group may possibly compromise the outcomes of the discussion, she decided to continue with the meeting, unaware of the earlier text message, and expecting a new total of four participants. Another reason the researcher did not reschedule the meeting, is that she was aware of one of the arrived participant's scheduled departure to a neighbouring country the following week, only to return to South Africa a month later at the end of her son's school holiday.

The biographic information of the three participants of the second unit of the triadic participant group is presented in Table 3.5.

Table 3.5

*Biographical Information of Unit 2 Participants: Caregivers (n=3)*

| **Participant** | **P2-1** | **P2-2** | **P2-3** |
|---|---|---|---|
| **Sex** | Female | Female | Female |
| **Age** | 43yrs | 76yrs | 67yrs |
| **Race** | Black | White | White |
| **Nationality** | Swazi | South African | South African |
| **Education level** | Master's degree | Diploma | College credit<br>Vocational training |
| **Age of PwD* in their care** | 11yrs | 40yrs | 69yrs |
| **Type of disability of PwD* in their care** | Autism Spectrum Disorder<br>Generalised Anxiety Disorder | Down's Syndrome | Parkinson's Disease<br>Diabetes<br>Foot Disability |
| **Difficulties experienced** | Speech Understanding<br>Behavioural challenges | Developmental delays<br>Special learning needs | Moving and walking<br>Speech |
| **Severity of disability** | Moderate | Moderate | Moderate |
| **Duration of disability** | 7yrs (diagnosed at 4yrs) | 40yrs (since birth) | 15yrs |
| **Duration as primary caregiver** | 11yrs (since birth) | 40yrs (since birth) | 15yrs |
| **Duration of attendance** | 8yrs | Occasional visitor | 36yrs |
| **Regularity of own attendance** | Weekly | Weekly with daughter | Bi-monthly |
| **Regularity of PwD* joining** | Weekly | Weekly | Special occasions |
| **Additional attendance apart from Sundays** | None | Ladies' Bible study | Senior's ministry<br>Church pre-school |
| **Additional attendance from PwD* apart from Sundays** | None | Ladies' Bible study<br>Special events | None |
| **Know of other PwD*** | No | Yes | Yes |
| **Awareness of disability policy** | No | No | No |
| **Support of disability policy** | Yes | Yes | Yes |
| **Attend another church** | No | Yes | No |

*Person(s) with Disability

Table 3.5 gives an overview of three participants who are each the primary caregiver of a person with a disability, with varying periods of duration in fulfilling this particular role. The information tabled above gives the impression of a participant group that is diverse in many respects, including their education levels, the participant's ages, as well as the ages of the persons with disabilities in their care. While all the disabilities were described as moderate in severity, the types of disability, and the difficulties experienced by the person with a disability in their care, vary somewhat. However, they also share some similarities, most markedly that all the participants are female, share English as a first language, and are all in support of a disability inclusion policy or training programme, the existence of which they are unaware in this congregation and others. Reasons for their support of such a programme include two participants' comments about the potential benefit of building awareness and fostering inclusion for persons with disabilities. The other participant motivated her support based on the view that, unless one has a medical background, very little training is available for the understanding of and caring for persons with disabilities.

Although one of the participants is not a member of the congregation, she was included in the study as she is known to the researcher and has attended many events and visited the congregation's services before, and is therefore familiar with the church's structure. This particular participant is of the Presbyterian denomination but currently mostly attends a United church, in close proximity to the Methodist congregation of the study, where her daughter has joined as a member 14 years ago, and where they both belong to a Ladies' Bible study group. The other two participants are both Methodist and full members of the congregation in the study. Apart from one of the latter two participants who are involved with other church-related activities, neither of the persons with disabilities in their care attends any other activities or events apart from church services, which one of them usually attends weekly, and the other on special occasions only.

### *3.5.3 Focus group unit 3: Church leaders*

Eight of 12 potential participants, representative of the congregation's leadership, consented and participated in the third and final focus group. Due to a tight work schedule, one clergy member declined participation from the start. In contrast to the first two units, no problems with participant interest or recruitment were experienced, given that permission was granted early in the research process, and that the individuals exhibited a keenness and commitment to participate in the study. However, owing to the nature and amount of church-related interests at this congregation, challenges were experienced in assembling all the

potential participants on a single day and time that was suitable for everyone. Altogether, six staff members and five volunteers who serve on the congregation's leadership team were pursued for participation. At the time of the setting of the original meeting date, one of the pastoral staff members, who would eventually become a participant, was unavailable after recovering from surgery. The irregular work schedules of the staff members, and numerous church activities during weeknights and over weekends, as well as other personal and work engagements of the staff and volunteers, complicated the coordination of the focus group.

When the researcher finally managed to establish and confirm a meeting date and time with seven of the remaining potential participants, the focus group needed to be postponed at short notice before the set date, seeing that an urgent ad hoc meeting among the church's leadership and the rest of the congregation was scheduled on the same evening, with the time slot overlapping with that of the focus group. The result was that three of the prospective participants – one ordained minister and two Society Stewards – who originally confirmed their attendance for the initial meeting, were no longer available for the rescheduled focus group. Providentially, a different clergy member and the abovementioned pastoral staff member became available for the postponed meeting, resulting in one more participant than confirmed for the original focus group.

The biographic information of the eight participants of the third unit of the triadic participant group is presented in Table 3.6.

Table 3.6

*Biographical Information of Unit 3 Participants: Church Leaders (n=8)*

| **Participant** | **P3-1** | **P3-2** | **P3-3** | **P3-4** | **P3-5** | **P3-6** | **P3-7** | **P3-8** |
|---|---|---|---|---|---|---|---|---|
| **Sex** | Female | Female | Male | Female | Female | Male | Female | Male |
| **Age** | 58yrs | 47yrs | 50yrs | 31yrs | 60yrs | 60yrs | 46yrs | 30yrs |
| **Race** | White | Black | White | White | White | White | White | Black |
| **Home Language** | English | isiXhosa & English | English & Afrikaans | English | English | English | English | Setswana |
| **Education level** | Honour's degree | Master's degree | Bachelor's degree | Master's degree | Matric | Doctoral degree | Master's degree | College credit |
| **Role description** | Worship coordinator | Society Steward | Pastoral care | Children's pastor | Circuit Steward | Pastor & Teacher | Local preacher Volunteer | Youth & young adults pastor |
| **Additional training related to role** | Music qualifications | None | Counselling | Godly Play & Leadership training | Steward responsibilities | Seminary training | Spiritual Director's training | Youth Pastor's training |
| **Duration of current role** | 12yrs | 6mths | 11yrs | 8mths | 2½yrs | 3yrs | 8yrs | 4yrs |
| **Duration at current congregation in any role** | 12yrs | 9yrs | 11yrs | 8mths | 22yrs | 3yrs | 8yrs | 4yrs |
| **Duration served at any congregation** | 12yrs | 12yrs | 16yrs | 15yrs | 22yrs | 40yrs | 8yrs | 7yrs |
| **Experience with PwD*** | No | Yes | Yes | No | Yes | Yes | Yes | Yes |
| **Family member who is PwD*** | No | No | Yes | No | No | Yes | No | No |
| **Awareness of PwD* in congregation** | Yes | Yes | Yes | Yes | Yes | Yes | Yes | No |
| **Awareness of policy** | No | No | No | No | No | No | No | Yes |
| **Support of policy** | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |

* Person(s) with Disability

Table 3.6 depicts a participant group that vary significantly in terms of education level, as well as age, with the youngest participant at 30, and the oldest at 60 years of age. The group was made up of mostly White, English-speaking participants. Two participants have additional home languages of isiXhosa and Afrikaans respectively, while one participant's home language is Setswana. All but one participant received additional training pertinent to their current church leadership roles.

The table also shows that the duration of the church leaders' service in their current roles in this congregation (at most 12 years), is relatively brief compared to the duration of membership and attendance of some of the participants in the other two focus groups, making this a comparatively new leadership team.

Two of the participants have family members with a disability. While six participants indicated that they have experience with persons with disabilities, one participant has none, and two participants gave no response to this question on the biographical questionnaire. Seven participants were aware of persons with disabilities attending the congregation, and only one participant indicated knowledge of a disability inclusion policy in the church. The participants all gave unanimous affirmation to their approval of a disability inclusion policy or training programme, which was discussed amongst them in greater depth during the focus group, with suggestions for implementing next steps. Interestingly, these strategies were initiated without consulting any persons with disabilities in the congregation, and before receiving any feedback of their perceptions about a way toward disability inclusion.

### 3.6 Materials and equipment

Materials for this study include the Formal Letter of Approval (see Appendix A1) from the Research Ethics Committee in the Faculty of Humanities at the University of Pretoria, which permitted the commencement of the data collection process. It furthermore comprised the Permission Letter to recruit church leader participants for unit three from the Methodist congregation, and an additional Letter of Permission from the same congregation to recruit participants with disability, and caregivers for units one and two. The materials for the pilot study included the Participant Consent Forms, the Biographical Questionnaires (see Appendix B), and the Preliminary Focus Group Script (see Appendix C). Based on the recommendations of the pilot study, the Focus Group Script was modified for the main study (see Appendix D).

Further materials include the Participant Consent Forms for units one, two and three of the main study (see Appendix A2), as well as the custom-designed Biographical Questionnaires for units one to three (see Appendix E, F and G). Additional materials used during the study consist of stationery items, such as pens, sticky notes, clipboards, a flip chart and paper, as well as whiteboard markers. The focus group discussions were audio-recorded, using the researcher's iPhone 5S's voice memo function as the primary recording tool, and were digitally transferred and stored onto a secured laptop, before being erased from the recording device.

## 3.7 Procedures

### *3.7.1 Data collection*

Permission was granted by the congregation to use private meeting rooms on its premises and subsequently, all the focus groups were held on the church campus. The focus groups for the participants with disabilities, and caregivers of persons with disabilities, were held on the same day (a Saturday) and were conducted in the same venue – unit one during the morning, and unit two in the afternoon – with one hour between the two meetings. This arrangement was made for a number of logistical reasons, including the availability of the participants, the note-taking assistant, and the designated venue. In addition, this arrangement served as a measure to prevent participants from the two units conversing and potentially influencing each other, especially since the researcher was expecting relatives and spouses in each unit. Moreover, given the church context, some of the participants in these two units knew each other, and may thus have shared their experiences with one another before the next focus group could be held.

For the focus groups for units one and two, participants' chairs were arranged in a circular formation around a small table, on which the recording, and back-up devices were placed. Given that the focus group with church leaders was arranged on a week-day evening after work on a day and time most suitable for the participants, the same venue that was used for the first two units was not available. The focus group was thus held in a different venue, but a similar set-up was achieved, albeit around a sizable boardroom table. Although the researcher was initially concerned that the distance between the participants and the recording device would impact the sound quality, the audio-recording was not compromised.

Participants for all focus groups were provided with beverages and something light to eat, and each received a token of appreciation for their participation afterwards. Once written

informed consent was obtained from all participants and the biographical questionnaires completed, the separate focus groups commenced. For all three focus groups, the help of a note-taker was enlisted.

Lively participation was achieved particularly during the two larger focus groups, that is, persons with disabilities and church leaders. Included in the informed consent forms, the researcher restated that the discussions were audio-recorded for transcription purposes. The researcher and the note-taker acted as scribes and helped complete the biographical forms for participants from the disability group who needed assistance with writing.

The purpose and procedure of the focus group was explained and ground rules for participation established at the start of each group. Participants were reminded that their participation was voluntary and that they could withdraw from the study at any point with no expectation to supply an explanation and without any negative consequences. To further enhance the trustworthiness of the study, the researcher established rapport from the onset, so as to encourage open and uncensored responses (Shenton, 2004).

Following the amended focus group script and the other recommendations ensuing from the pilot study, the researcher assumed the role of the moderator and, seated amongst the participants, facilitated their discussion, while the note-taker captured the important discussion points on the flipchart, further stimulating the participants' ideas (Naudé & Bornman, 2018; Prior et al., 2013). The focus group script consisted of three semi-structured, open-ended questions, which aimed to explore the perceptions of each participant group based on their interpretations of barriers and facilitators to meaningful participation in ceremonies, activities and events in the congregation. The researcher meticulously followed the same script and format for each group, ensuring that all participants received the same questions to obtain consistency in the results. Given that there were no participants with intellectual disabilities, none of the questions needed rephrasing and no props were needed as concrete visual aids.

Response validation from participants, (i.e. member checks) were included during the course of the discussions to ensure the accuracy of the information, where the participants had an opportunity to verify whether or not the researcher's impressions match their words and what they intended to communicate (Naudé & Bornman, 2018; Shenton, 2004). The audio-recordings were transcribed verbatim for the purpose of data analysis, after which a summary of the main points was also sent to the participants via email for further member checking.

Additional observations and impressions about behaviours and emotive aspects that appeared to guide the participants' responses were recorded by the researcher and note-taker after each focus group, when they shared reflections about the different moods in each group, and highlighted preliminary ideas about apparent themes from the discussions. These reflective notes became an integral part of the research process, and added fullness to the data, which allowed for achieving rich descriptions.

### *3.7.2 Data analysis*

Following a verbatim transcription of the three focus groups, the data was analysed through open thematic coding applying an inductive approach, by which emergent themes were constructed and described first, and then linked to the codes in the Environmental Factors component of the ICF, using the linking rules suggested by Cieza, Fayed, Bickenbach, and Prodinger (2019).

To ensure that meaningful patterns in the data were accurately identified, analysed and conveyed, the researcher applied Braun and Clarke's (2006) six-phased framework as a step-by-step guide for conducting thematic analysis, so as to arrive at a truthful and persuasive account and interpretation of the information. Within this method of thematic analysis, the first phase involves familiarisation with the data, followed by the second phase, during which the coding of the data items occurs. Phases three, four and five relate to the searching, reviewing, and defining of themes respectively, and concludes with the final phase of telling a credible story about the data in the write-up. While these specific steps were meticulously followed, the researcher moved back and forth between the different phases of this non-linear method of analysis (Braun & Clarke, 2006; Clarke & Braun, 2013).

During the first phase, the researcher familiarised herself thoroughly with the entire data corpus by becoming fully immersed in the data. This process was advanced from the outset, since the researcher transcribed the verbal data herself, and was thus able to deeply connect with the data early on. This step was concluded after the researcher listened to the audio-recordings and read the transcripts from all the focus groups several times while making notes of her observations. During phase two, initial codes were generated, where the researcher labelled all the meaningful units of the data relevant to the research question, and then compiled all the codes with their corresponding data extracts. In a natural progression, the coding phase

overlapped with the third phase of actively searching for preliminary themes, where the focus was on identifying broader patterns of significance within the data. The coded data and relevant preliminary themes were then collated. During phase four, the researcher considered whether or not the reviewed data in fact supported the identified themes, and made the necessary modifications so that the themes made sense and could be substantiated with sufficient data. It was during this phase that the researcher started collapsing some preliminary themes that were originally separate, and combined others into new themes, using the initial themes as sub-themes (Braun & Clarke, 2006; Clarke & Braun, 2013). Aiming to *"…identify the 'essence' of what each theme is about"* (Braun & Clarke, 2006, p. 92), the final tweaking of the themes occurred in phase five, where the researcher considered what each theme is saying about the data overall, how each sub-theme relates to its main theme, and how all the main themes relate to each other (Maguire & Delahunt, 2017). In the sixth and final phase, the researcher integrated the theme-derived *"story line"* (Vaismoradi, Jones, Turunen, & Snelgrove, 2016, p. 107), incorporating insights from the reflective notes, with the data extracts in such a way as to make meaning of the data, and to present this result as a convincing answer to the research question within the context of existing literature (Braun & Clarke, 2006).

In addition to implementing the solid data analysis framework outlined above, researcher bias was curbed, and confirmability promoted by employing two independent coders, who each followed a process of authentication. To strengthen dependability, the first coder verified that the audio-recordings were accurately transcribed, and the script followed, by listening to a percentage of random audio-recording segments. The second coder confirmed that the identified themes reflect the participants' perceptions, and not the researcher's own ideas (Shenton, 2004). Given the single data collection instrument of the study – focus groups – comparisons drawn between the findings from the three different data sources served as a form of triangulation, which is essential for reducing researcher bias, the establishment of credibility, and thus the trustworthiness of the study (Shenton, 2004).

Once the inductive thematic analysis process was complete, the deductive phase of coding was applied as a final step in the effort to understand and describe the data in relation to the theoretical framework of the study. To enhance trustworthiness of the linking results, this procedure was executed by employing Cieza et al.'s (2019) most recently revised linking rules as guidelines to direct the process of connecting meaningful concepts in the data to the ICF. In this

context, Cieza, Geyh, Chatterji, Kostanjsek, Üstün, and Stucki (2005) describe a meaningful concept as a unit of information that contains enough detail to determine which ICF category to link.

Accordingly, all the pertinent ICF environmental categories and codes represented in the participants' perceptions concerning barriers and facilitators to the participation of persons with disabilities within their congregation, were documented. Given the study's aim to identify and describe the presence or absence of barriers and facilitators, and not the degree, no qualifier codes were applied to establish or indicate the extent to which the identified barriers and facilitators in any of the categories were perceived as such. Therefore, by applying an interpretive approach (Cieza et al., 2019), meaningful concepts in the data were frequently linked to more than one ICF code and category to ensure that the full range of connections between the data and the environmental factors is recorded.

### *3.7.3 Establishing trustworthiness*

As an alternative construct for validity and reliability used within a positivist research paradigm, Guba (1981) suggests using the term *trustworthiness* in qualitative research. Trustworthiness refers to the trust that can be placed in the notion that the researcher followed all the necessary procedures to ensure that the data was collected, analysed and reported appropriately and ethically (Carlson, 2010). Given the current study's qualitative design, and that the trustworthiness of qualitative research is often questioned (Shenton, 2004), careful attention was given to demonstrating that the entire research process is in fact trustworthy. Several references to the variety of measures employed by the researcher in pursuing trustworthiness have been interweaved throughout this chapter. Using Guba's (1981) four closely associated criteria for establishing the trustworthiness of qualitative studies, this section provides a consolidating summary of the specific aspects that were considered. These criteria, which correspond to the criteria used in a positivist approach, include *credibility* (internal validity), *transferability* (external validity / generalisability), *dependability* (reliability), and *confirmability* (objectivity) (Shenton, 2004). An outline of the criteria, the techniques used, and its application to the current study is provided in Table 3.7.

Table 3.7

*Criteria for Establishing Trustworthiness*

| Criterion | Technique | Application to the study |
|---|---|---|
| *Credibility: Demonstrating that he findings of the study are a true picture of the participants' real-life situation* | Triangulation | Data was obtained from three different focus groups, treated as three separate data sources. By triangulating the findings from all three data sets, the experiences and perceptions of individuals were corroborated against others. |
| | Tactics to ensure openness in contributing to the discussion | To uphold the integrity of the data, unfiltered responses were gained from the participants from the outset through the establishment of rapport. Participants were also assured of their anonymity and the confidentiality of their contributions. They were reminded that there were no right or wrong answers to the questions. |
| | Member checking | Summarising statements, functioning as member checks during, and at the end of the discussions were made. After transcribing the audio-recordings verbatim, further member checking occurred by providing a summary of the respective discussions to each participant group, allowing them an additional opportunity to confirm their input. |
| | Reflective annotations | Reflective notes, containing the researcher's impressions of the participants' moods and behaviours recorded after each focus group, as well as the patterns that emerged, were considered and incorporated with the findings, contributing to ascribing contextual meaning to the results (see Chapter 4, section 4.3). |
| *Transferability: Providing sufficient detail of the context of the study for readers to apply the findings to their own situations* | Rich descriptions of participants' context and views | Conveying the actual context of the study, the participants from the three focus groups were described in detail. Additionally, their perceptions captured during the focus groups yielded rich, in-depth descriptions of their situation. |
| | Detailed description of data collection and analysis procedures | The data collection and analysis procedures are discussed in detail in sections 3.7.1 and 3.7.2 respectively. While the case study's findings may not be generalisable to wider populations, the case under study can be considered a microcosm of a wider system, |

| Criterion | Technique | Application to the study |
|---|---|---|
| | | allowing the results to be transferable to other settings, where other researchers and readers with similar experiences may potentially see their application. |
| *Dependability: Enabling another researcher to repeat the study* | Research design and procedural implementation | Chapter 3 provides an extensive description of the research methodology to allow the study to be repeated. As such, the research design and phases are discussed in section 3.3, followed by a comprehensive account of the pilot study, its aims, materials, procedures, findings and recommendations in section 3.4. Section 3.5 offers an in-depth description of the participants of the main study, which is trailed by section 3.6, explaining the materials and equipment used for this phase. Section 3.7 contains the procedures for data collection and analysis. |
| *Confirmability: Demonstrating that the study's findings emerged from the data and not from the researcher's own biases* | Audit Trails | By introducing audit trails, the processes of data collection and analysis were authenticated. The audio-recordings and verbatim transcriptions were checked by an independent proofreader before the data was analysed, verifying the consistency in the focus group procedure for all three groups, as well as the accuracy of the transcriptions. Researcher bias was reduced by an independent coder, who confirmed that the themes identified by the researcher represented the participants' perceptions, and not the researcher's own predispositions. |

### 3.8 Ethical aspects

Given that qualitative research frequently involves human beings as the focus of the study, it lends itself to moral and ethical challenges and the researcher needs to take special care to ensure that ethical standards are met through obtaining institutional ethics approval and by protecting the participants' rights (Klopper, 2008; Leedy & Ormrod, 2015). This also applied to the current study. Consequently, formal ethics approval from the University of Pretoria's Faculty of Humanities Research Ethics Committee was obtained before participation was solicited, whereby the researcher respected and agreed that the participants' interests remained a priority throughout the entire project. As two principles that go hand in hand, the researcher ensured that beneficence and non-maleficence were in place. Beneficence refers to *doing good*, while non-maleficence denotes *avoiding harm* (Tangwa, 2009). By upholding these complementary principles, the study was designed in such a way that it would benefit and enhance the welfare of the participants, and at the same time, prevent intentional hurt or harm, and minimise any adverse effects.

Further to the above, the researcher followed guidelines for ethical consideration outlined by Leedy and Ormrod (2015), and ensured that all procedures were in accordance with the ethical principles of the most recent amendment of the Declaration for Helsinki (World Medical Association, 2013). Accordingly, prospective participants received sufficient information in the consent forms concerning the nature, purpose, procedures and duration of the study, as well as specific details about their expected participation. Thus, participants were able to make informed judgments as to whether or not they wanted to participate. Those who agreed were reminded that their participation is voluntary and that they could withdraw from the study at any point without negative consequences. Informed consent for participation and permission for audio-recording was solicited in writing before data collection, whereupon participants were invited to join in the proceedings. Along with verbal announcements, a written statement concerning confidentiality was included; guaranteeing the elimination of identifying information from the transcripts, dissertation and presentations. The researcher's name and contact details were also issued should any questions arise about the study.

## 3.9 Conclusion

The study's methodology was discussed in this chapter, with specific attention given to the description of the procedures followed within the design, including a thorough report on the pilot study and the ensuing recommendations for the main study. A detailed account of the participant selection and recruitment process, as well as a rich description of the sample was offered. Together with the above, discussions concerning the data collection and analysis procedures, as well as the establishment of trustworthiness and ethical considerations, have laid the foundation for the presentation of the results of the three focus groups in the next chapter.

# CHAPTER 4
# RESULTS

## 4.1 Introduction

This chapter presents the outcomes of the applied research methodology described in Chapter 3, where the procedures for data collection and analysis were detailed. Added features of the three focus groups are included as a prelude to the presentation of the research findings. The results are reported with reference to the study's four sub-aims, which encapsulates the main aim of the study, namely, to determine the perceptions of persons with disabilities, caregivers of persons with disabilities, and church leaders regarding barriers and facilitators to the participation of persons with disabilities in ceremonies, activities and events in their congregation. Emergent themes from the integrated perceptions from this triadic participant group are arranged first, after which links to the relevant ICF environmental codes are made to connect the findings of the study to its theoretical framework.

## 4.2 Trustworthiness of results

As a crucial component of this study, the trustworthiness of the results was secured by utilising specific measures to ensure that the integrity of the data was upheld. This was achieved in several ways, one of which included gaining candid, unfiltered responses from the participants from the outset through the establishment of rapport. Another way involved meticulously following the focus group script containing the pre-prepared questions in triplicate, which ensured that the researcher maintained uniformity in the procedure for all three focus groups, and accordingly, reach consistency in the data. The different types of questions for the focus group script were also structured in such a manner that would invite and promote optimal participation from all the participants.

To prepare and stimulate the participants' thoughts for the main discussion, an introductory question was posed prior to asking two key questions, which were founded upon the research question, respectively concerning barriers and facilitators to the participation of persons with disabilities in church-related activities. Probing and follow-up questions were used throughout to encourage further sharing among the participants and to perpetuate the discussion. The researcher tracked her summarising statements with further questions, which functioned as member checks during, and at the end of the discussions.

Figure 4.1 demonstrates the structure and flow of the verbatim questions. For the full focus group script, please refer to Appendix D.

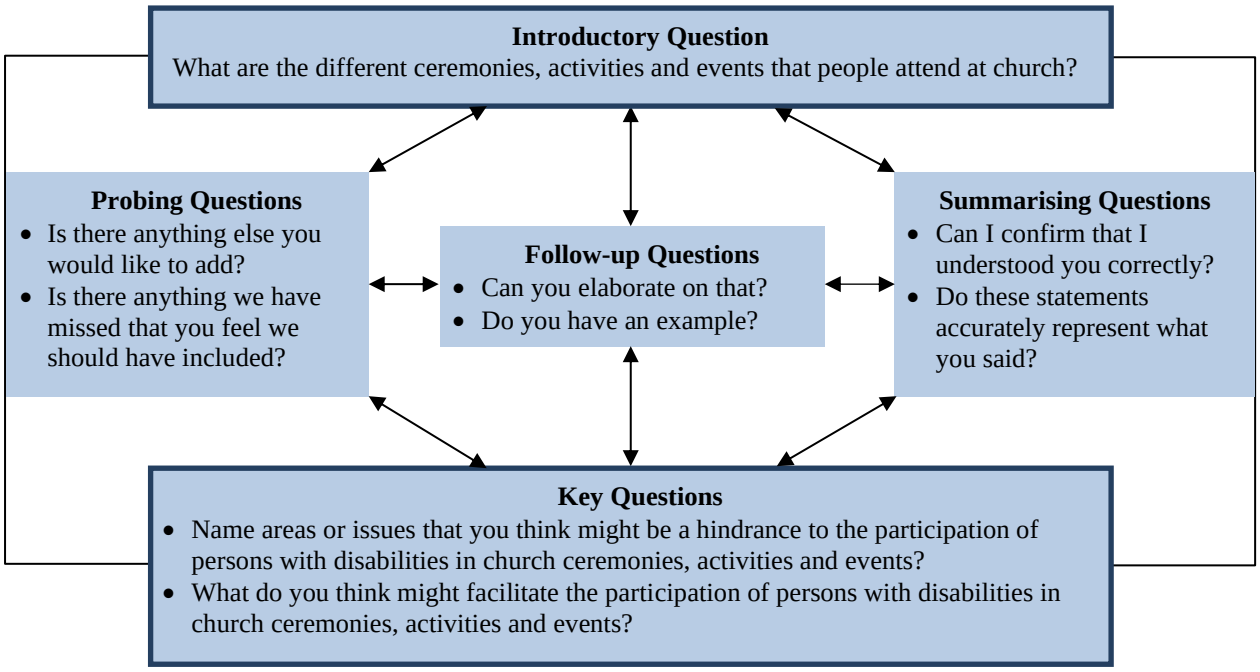



Figure 4.1 *Structure and flow of the focus group script questions*

Once the audio-recordings were transcribed verbatim, further member checking occurred by providing a summary of the discussions to the participants, allowing them an additional opportunity to confirm their input. Before the transcripts were analysed, a process of authentication was initiated by having the audio-recordings and transcriptions checked by an independent proofreader, who verified the consistency in the focus group procedure for all three groups, as well as the accuracy of the transcriptions. This was done by reviewing 20% of randomly selected verbatim transcriptions of the audio-recordings, with 100% agreement.

To ensure that the research findings could be accepted as trustworthy, the researcher conducted a systematic thematic analysis of the data, by applying Braun and Clarke's (2006) rigorous and well-documented six-phased framework. The authentication process was continued and researcher bias minimised by an independent coder, who confirmed that the themes identified by the researcher represented the participants' perceptions. Moreover, by triangulating the findings from all three data sets generated by the three focus groups, the trustworthiness of the study was increased.

In addition to the abovementioned measures, the reflective notes, containing the researcher's impressions of the participants' mood and behaviours recorded after each focus

group, were considered and incorporated with the findings, contributing to ascribing meaning to the results.

**4.3 Researcher's annotations**

Before presenting the derived themes, a descriptive backdrop is staged, portraying the observed subconscious affective displays that appeared to underlie the participants' perceptions and determined the emotional climate within each focus group.

High in energy and quick in tempo, the focus group for persons with disabilities was characterised by lively conversation. It was the rising solidarity among the participants that seemed to relieve the early apprehension and encouraged the sharing of personal accounts. "*I'm exactly like her. Two peas in a pod"* (P1-6), marked the end of one participant's initial nervousness and reluctance to speak out. An air of annoyance and resentment toward the congregation's leadership filled the somewhat tense atmosphere, where a demoralised 'been there, done that' disposition swayed the group toward cynical expressions, as uttered in this example by one participant, whose recent experience mirrored that of her fellow participants' own thwarted attempts at changing the current system: *"But you see on that perspective, also, if going to someone sometimes doesn't help… I spoke to every minister, I spoke to [Name], I spoke to everybody. Eventually we stopped coming to church"* (P1-4). As the discussion developed, further laments continued. Yet, growing anticipation among the participants seemed to give new impetus to instigate the desired changes in their congregation, and motivated the following statements: *"…I'm glad there's another focus group coming up about the ministers, so everything that they need to talk about, but also what we feel of these things and they don't know"* (P1-2), and, *"…I mean, you're going to collect your data but for us, this has started. When you do your research, hand it in, I'm not that patient to wait for your research to come in… So, the fact that you've spoken to us [clicks fingers], I want movement… I want action"* (P1-1).

Although no less engaged in the discussion, the caregiver participants were less animated in offering their contributions. In contrast to the mood in the focus group for persons with disabilities, the caregivers exuded a longsuffering acceptance and tolerance in the tone with which they shared their personal experiences and perceptions, without any sense of agitation or reproof. For instance, one participant's observation, *"…people who don't have those problems don't understand…and they don't tolerate it"* (P2-3), was made not with indignation, but instead with an empathic understanding of people's typical misconceptions of disability. The same spirit was evident in the next two comments, where

two participants recalled times when they themselves were once unaware and inexperienced regarding disability: *"…'Cause people are not aware. I wasn't until I got my child. I wasn't, so I'd look at them as naughty children"* (P2-1), and, "*I also taught. I had a child with dyslexia in my class. I had no idea how to handle her; I hadn't been trained… Now, I always go back to my daughter 'cause she's the one I understand."* (P2-2). While the caregivers extended empathy to ill-informed church leaders and congregants, they were still forthright in revealing the ensuing challenges they face in a system seemingly unmindful of disability. Dimmed by the failures of a faith community from whom they presumed support, the caregiver participants did not have the same urgency and expectancy for change as the participants with disabilities.

Well acquainted with one another, as well as with the dynamics of their congregation, the church leader participants were high-spirited and took a light-hearted, yet considered approach to their discussion. Compassion was stirred up and expressed in an *"ag shame"* chorus, followed recurrently after one participant shared his personal encounters with persons with disabilities. As the conversation progressed, reminders of their own good intentions and perceived incapacity to meet all the needs of persons with disabilities in their congregation seemed to prompt feelings of frustration and helplessness in offering them the affordance to access and participation. The impression of self-defence in the notion that their hands are tied, is implied in the following example: *"Um, it would be nice if they came and told me 'cause I might be able to do something about it… there are people sitting in those pews that we don't even know are disabled in some format… but as I've said before, it's not because we don't wanna help… we have, we have tried very hard to fix that"* (P3-1). With most of the church leader participants being relatively new to the congregation – compared to the lifetime most participants from the other two focus groups have been in attendance – the church leader participants appeared to feel burdened by challenges they inherited from the previous leadership, and that with ever-diminishing resources to make the amendments they deem necessary.

The above descriptions bring together different elements from three diverse participant groups, each playing an equally important part in the overall functioning of their congregation as one faith-based system. Moreover, it informs how the actions of one part of this system is reliant upon and influenced by the actions of all the other components within the system, highlighting that the whole is indeed greater than the sum of its parts.

## 4.4 Thematic structure

The data from the three focus groups was integrated and significantly reduced so as to capture the essence of the findings, whilst still providing a comprehensive account of the participants' perceptions. The results are presented according to the four sub-aims of the study, the first being aligned to the introductory question of the focus group script, grounding the main discussion, from which the predominant themes developed. Several areas for participation in church-related activities were identified and sorted into categories and are presented separately from the predominant emergent themes derived from the participants' responses to the two key questions, aligned to the second and third sub-aims of the study respectively.

Themes were developed inductively based on the content, as well as the underlying processes of the participants' contributions, some more explicit than others. The researcher thus mused beyond the actual spoken words and searched for the deeper meaning their comments conveyed. Finally, through deductive coding, the relevant ICF Environmental Factors that are represented in the data corpus address the study's fourth sub-aim.

### *4.4.1 Participants' identification of church-related ceremonies, activities and events*

Participant responses discussed in this section relate to the first sub-aim of the study, namely, to explore and describe what persons with disabilities, caregivers of persons with disabilities, and church leaders regard as ceremonies, activities and events in the church. In answer to the introductory question, the participants offered responses that were mostly consistent across the three focus groups. The participants' responses were coded and grouped into seven categories, as depicted in Table 4.1. Only the most salient data extracts per category are included as examples listed by the participants.

Table 4.1

*Church-related Ceremonies, Activities and Events Listed by Participants*

| Category | Codes | Data extracts from all participant's responses |
|---|---|---|
| **Spiritual practice and formation**<br>(31 comments) | • Weekly services | *"…Sunday services, which includes adults, children and youth"* (P3-2) |
| | • Liturgical services | *"And then you get special event services like…"* (P3-1)<br>*"Ja, Christmas, Easter…"* (P3-7), *"Ash Wednesday…"* (P3-6) |
| | • Small group activities | *"There's also Bible studies"* (P1-6) |
| **Church ministries** | • Community outreach | *"…the feeding scheme for the poor"* (P1-3)<br>*"Prison ministry… outreach"* (P2-3) |

| Category | Codes | Data extracts from all participant's responses |
|---|---|---|
| (26 comments) | • Pastoral care<br>• Support groups | *"Ja, the cancer care"* (P1-4)<br>*"…support groups that meet"* (P3-6) *"Addiction support groups"* (P3-4) |
| **Social and recreational activities**<br>(21 comments) | • Social gatherings<br>• Leisure & sport<br>• Fund-raising activities | *"Thursdays Seniors' group"* (P3-6) *"Ja, that's another social gathering"* (P3-3)<br>*"... and church sports, they have soccer days"* (P2-1)<br>*"And then there's…fund raising activities, fetes"* (P1-5)… *"When they did the boerewors rolls and all those kind of things"* (P1-4) |
| **General ceremonies, rites and sacraments**<br>(10 comments) | • Ceremonies & rites (e.g. weddings, funerals, confirmation)<br>• Sacraments (e.g. baptism & communion) | *"Funerals… I went to one yesterday"* (P1-2)<br>*"Confirmation"* (P3-8) *"Weddings..."* (P1-3)<br>*"...baptisms"* (P1-3) *"Communion"* (P1-1) |
| **Organisational meetings**<br>(10 comments) | • Church meetings<br>• Women's / Men's' Methodist groups | *"...AGM's…"* (P3-3P)<br>*"And then there are organisational meetings, which are different to small group meetings. So, like YMG [Young Men's Guild], Manyano…"* (P3-4) |
| **Education and training**<br>(9 comments) | • Workshops, courses, seminars & conferences | *"There's workshops, …events"* (P3-2)<br>*"Well… conferences…put conferences"* (P1-5) |
| **Public and workplace activities**<br>(7 comments) | • Church amenities for public hire<br>• Pre-school on church premises<br>• Workplace activities in offices | *"What you do need to realise is that we get used as a venue quite often, by other churches"* (P3-1)<br>*"And then we've got our school next door, that nobody knows… It's the best kept secret"* (P2-3)<br>*"And then of course, what isn't there, all of us who happen to be staff…it's an office"* (P3-1) |

Table 4.1 gives an overview of the different church-related ceremonies, activities and events identified by the participants. All participant groups seemed to follow a trend, starting off with broad, occasional rites and ceremonies, such as confirmations, weddings and funerals, as well as sacraments, including Baptism and Communion, before narrowing down their responses by naming the activities and events that have particular reference to their congregation. While the participants in the focus group for persons with disabilities did not specifically state any liturgical services, such as Christmas, Ash Wednesday, Easter, and Ascension Day, as was listed by the other two participant groups, all three groups mentioned the regular weekly services for children, youth and adults, including the congregation's customary birthday and Heritage Day celebration services. Other references ranged among a variety of engagements related to spiritual growth through small group activities (including Bible study and prayer groups), education and training through course presentations,

seminars and conferences, as well as activities related to church ministries, such as pastoral care and community outreach, and social interests for recreation and fund-raising. The church leader participants added the congregation's amenities being used as a workplace and a venue frequently hired for public use, while all three groups made mention of the church's pre-school facility on the property.

### *4.4.2 Participants' perceptions regarding barriers and facilitators to participation*

The second and third sub-aims of the study are addressed jointly in the presentation of the predominant emergent themes, derived from the participants' perceptions elicited during the main discussion, which developed in response to the two key questions of the focus group script. The second sub-aim was to determine the perceptions of persons with disabilities, caregivers of persons with disabilities, and church leaders regarding barriers to the participation of persons with disabilities in church-related ceremonies, activities and events, while the third sub-aim, contrariwise, was to determine the three participant groups' perceptions of facilitators to the participation of persons with disabilities.

Concerning the first key question, the participants from each focus group identified many obstacles to the participation of persons with disabilities in the congregation's various ceremonies, activities and events that they have listed. In a unanimous verdict, all the participants from all three focus groups concluded that, in many respects, their congregation is not a disability-friendly one and acknowledged the need to reform the status quo. In response to the second key question regarding facilitating factors, the participants appeared to struggle to veer their thoughts away from the identified barriers. Their views about aspects that they initially considered to be existing facilitators, soon changed as they recognised that the said enablers were in fact insufficient in meeting the needs of persons with disabilities. They subsequently stipulated many conditions for inclusion and meaningful participation and offered suggestions for improvement.

Pervasive throughout the data corpus, four predominant themes, with a total of nine sub-themes, were identified. While the themes are interrelated and entwined, the overarching theme, from which all the others seemed to develop, is that of *Social Status*. The next theme is *Addressing Needs*, followed by *Awareness and Understanding*, and *Access*. The main themes, delineated in relation to the specific context of this study, are outlined in Table 4.2, including their respective codes and sub-themes (indicated in italics), and concise data samples relevant to each.

Table 4.2

*Theme Development and Descriptions*

| **Themes and sub-themes** | **Codes** | **Data extracts from the three participant groups** | **Theme description** |
|---|---|---|---|
| **Social Status**<br>*Conformity*<br>*Belonging*<br>*Reciprocity*<br>(73 Comments) | Majority rule<br>Mainstream criteria for inclusion<br>Fitting in<br>Dependent minority<br>Mutual benefit | *"We're a minority"*; *"…'cause you're different"* (P1-1)<br>*"…they never thought about what I need, or you need…"* (P1-2)<br>*"…they had a child who was autistic and could…not sit still… So, we then made a plan for them to go to a different venue…"* (P3-3)<br>*"… where do we fit in?"* (P1-2)<br>*"...come to us if you have needs that we can meet for you"* (P3-4)<br>*"Those with disabilities teach those with abilities. Each benefits"* (P2-2) | Guided by underlying conceptual models of thought, social status refers to the sense of worth and agency bestowed upon an individual based on their level of conformity to the set norms and identity of the congregation, their perceived membership, as well as their perceived benefit to the congregation (Brock, 2011; Cabrera, Cabrera, & Powers, 2015; Meininger, 2008; White, 2014). |
| **Addressing Needs**<br>*Communication of needs*<br>*Accommodation of needs*<br>(121 Comments) | Ownership to reveal needs<br>Asking for help is futile<br>Uncovering and meeting needs | *"But anyone with a need…you identify yourself…if you don't, there's nothing that can be done for you"* (P1-1)<br>*"I spoke to everybody…"; "…eventually, you'll keep quiet"* (P1-4)<br>*"…we don't always know…what their needs are"* (P3-4) | Aspects of ownership regarding the communication and resulting accommodation of personal needs (Bell & Clegg, 2012; White, 2014). |
| **Awareness & Understanding**<br>*Social constructions of disability*<br>*Education*<br>(150 comments) | Stigmas related to disability<br>Raising awareness through education<br>Personal transformation | *"…the congregational reaction to the person…can be a deterrent to whether they want to come back again"* (P3-4)<br>*"…the way to deal with the ignorance is to educate"* (P1-2)<br>*"… there's education and awareness, and then there's actual experience…and our own personal work"* (P3-7) | The level of awareness and understanding of disability as a result of oblivion, socialisation and stereotypes, the impact it has on interpersonal relationships, and ways to increase awareness to promote accurate understandings of disability (White, 2014; Yong, 2009a). |
| **Access**<br>*Accessibility of the physical environment*<br>*Access to necessary resources*<br>(152 Comments) | Restricted access on church property<br>Technological resources<br>Financial resources<br>Human resources<br>Transport resources | *"I don't think the church is geared for wheelchairs"; "They've got odd ramps here and there, but…not all over"* (P2-3)<br>*"…control the technology and make sure it works"* (P1-2)<br>*"…we didn't have the bucks to spend…on a proper loop system"* (P3-1)<br>*"…it's very difficult to get volunteers"* (P2-3)<br>*"I can't drive"* (P1-4) | Includes the accessibility of the physical environment of the church premises within which ceremonies, activities and events occur, as well as the affordance of access to the necessary means to enable involvement and participation, including technological, financial human and transportation resources (Bell & Clegg, 2012; White, 2014). |

Table 4.2 portrays the progression of the data reduction process and the refinement of the inductive thematic analysis, showing extracts from the data, as well as the codes and sub-themes from which each of the four main themes were derived and defined. Together, these themes encapsulate the participants' perceptions in response to the study's research question. From here onwards, each theme and its subsequent sub-themes are presented individually, including more detailed verbatim data excerpts that illustrate the pertinence of each theme.

**Theme 1: Social Status**

Three related sub-themes, namely *Conformity*, *Belonging* and *Reciprocity*, fit into the overarching theme of Social Status.

*Conformity*: Frequently referring to their awareness of being different, and that persons with disabilities do not conform to the so-called norm, the participants in the groups for persons with disabilities and caregivers presented themselves as the underrated minority and reported feeling outweighed by a substantial majority in respect of the numbers, value and power they occupy within their congregation. For example, a participant with a disability remarked, *"I think the problem is more of…'there is one or two people with the problem. We've got 300 in the service, so when it affects 50 or a 100, we'll look into it'…"* (P1-4). A caregiver participant echoed in accord: *"I mean, are you going to get a person to come and sign the services for five people? Or 10 people? …Are you going to do a whole…new electronic system to facilitate…five people?* (P2-3).

Concerning the accommodation of their differences and needs, further expressions among the participants with disabilities and caregivers revealed a general sense of being disregarded, as a participant from the group for persons with disabilities frankly captured her own and her fellow participants' perspectives: *"It's a 'majority rules and minority'; it's not a 'stuff you', but it basically boils down to that… 'you're in the minority, so…we'll kind of ignore it and hope the problem goes away, or you sort it out yourself'…"* (P1-4). A caregiver participant confirmed this stance from her own viewpoint as she shared how her son's needs are overlooked, which led to his reluctance to attend children's church because he is unable to join in with the usual activities: *"…in terms of just the concentration, …you have to do certain things over a prolonged period, yet his concentration…span is quite short… After 15 minutes, it's just too long, then he needs to do something else. So obviously that's structured in a way for people without any disability… the problem is that it caters for only mainstream"* (P2-1).

Disclosing feelings of social pressure within their congregation, participants from the group for persons with disabilities also addressed the spiraling adverse emotional effects they experience for having to conform to standards they described as unattainable, along with the influence this has on their motivation for participation. They also explained how conditions for participation in their congregation's various activities increases their anxiety, which often results in their withdrawal and non-participation, leaving them with an ensuing sense of inadequacy and guilt. One participant expounded these views by objecting: *"…if I've got a disability that doesn't make me volunteer or showing you've got faith that moves mountain[s], what happens, must I fake it until I make it?"*, and, *"…there's additional requirements for confirmation… I knew I would not make the criteria"* (P1-1). Whilst sharing experiences of low motivation to participate in relation to their anticipation of anxiety-provoking encounters, another participant remarked, *" I look forward to doing stuff… and then at the last minute, I think, oh my word, I'd rather sit at home"* (P1-6), before pointing to the entire list of the congregation's ceremonies, activities and events identified by the group earlier, affirming that *"…anxiety…can affect…all those things"* (P1-6). Her statement was validated and expanded in the follow-up dialogue, *"It becomes maybe too much to do, in your head, to do it in the first place, so then you don't go"* (P1-4),*"And then you get frustrated with yourself"* (P1-6), and trailed by another participant who described her own hindrance to participation this way: *"One of my frustrations, thinking on that line, is going to Bible study, and with Parkinson's, I also get anxious…and the person taking the Bible study jumps around the Bible. Now, I know my Bible quite well, but in…my anxiety state and in my shaking…I can't flip backwards and forwards… it puts me off going… I can't do it, so I sit there"* (P1-5). Sharing his own exasperation with the demands for participation, another participant openly acknowledged, *"I don't want to be involved in Bible studies, simply because to me it's a struggle"* (P1-2). Additional references to the participants' perceptions of a cause-effect relationship between their compelled non-participation and their lowered sense of self-worth were made throughout the discussion, for instance, *"And then there's the pressure of, you know, you're gonna let people down and then you feel bad about yourself… you've got a lot of self-loathing"* (P1-1).

Consistent with these sentiments of participation being contingent on imposed conformity, all three participant groups also spoke about social norms and attitudes operative in their congregation that tend to highlight the misfit between conduct considered socially appropriate and behaviours exhibited by persons with disabilities, that do not conform to those standards. A statement from a participant in the group for persons with disabilities

epitomises this perception: *"They've got a lot of church decorum…'Cause they've got a lot of expected behaviour of the person in the church"* (P1-1). This comment was preceded by another participant in the same group, who described the disapproving glares she receives from congregants' in reaction to her attempts to prevent the impending onset of a light-induced epileptic seizure owing to camera flashes during some services: *"It's like when I put my sunglasses on in church sometimes during the Baptisms…and people look at you as if to say 'what are you doing?'…but people don't understand that there might be a legitimate reason… and what happens is…I'll go out…"* (P1-4). A caregiver participant represented her groups' view by saying, *"…if there's an autistic child that has an episode in the middle of Sunday school, the other parents would have quite a lot to say about it, I'm sure"* (P2-3). Referring to her son's widely misunderstood behaviours, another caregiver participant explained that he *"…acts in a way that he'll have everyone going, 'what's happening'?"* (P2-1). A church leader participant denoted her group's stance as follows: *"Our programmes… necessarily have moments of silence, which can be problematic for people who are unable to keep quiet. Um, it draws attention to yourself if you are unable, either physically or psychologically, to keep quiet in moments of silence. People notice that. Um, which can be a deterrent 'cause it can make you feel like you're disturbing people… It's behaviour that doesn't always meet the requirement of that particular moment"* (P3-4). Among other comparable observations, another comment summarises the church leaders' perceptions on the prevailing attitudes toward persons with disabilities: *"So, when they come into a church environment, people think 'ag no, look how that guy is drooling', or um, 'they're in my personal space all the time'… and people are uncomfortable with it…"* (P3-3).

In addition to the behavioural differences identified, the church leader participants also emphasised how congregants' negative attitudes toward bodily deformities may prevent persons with physical disabilities from church attendance and participation: *"I think disfigurement also can be a barrier… So, anything, basically from something like polio, or someone who's been burnt, or who has scars, or…who just doesn't look the same as, in inverted commas, 'normal' people look… people stare and people are cruel, so I think that could put people off coming…"* (P3-5).

<u>*Belonging*</u>: Based on their non-conformity to the perceived set norms for participation in their congregation, the participant groups for persons with disabilities and caregivers expressed uncertainty as to their membership status, not in terms of their addition to the data base, but concerning their assimilation into their congregation. One participant from the

group for persons with disabilities articulated it this way: *"So, what is the identity of the church, and therefore, what is our identity within it? Do we fit in as disabled people…? What is the church saying about us, and what is the church not saying about us? …Who are we? …And what is the church saying about how I should fit in?* (P1-2). Referring to the involvement of children with special needs in the congregation's current setup for children's church, a caregiver participant candidly noted, *"They can't really be integrated with the other children"* (P2-3). An example of this situation was illustrated by another caregiver, who explained her child's situation as follows: *"For some of the services, I have to take him with me because he'll be complaining that 'there's too much noise, they're making too much noise'… he was saying he doesn't want to come to church"* (P2-1). A related comment by a church leader participant corroborated this scenario, when she explained how a child in her care on Sunday mornings is excluded from the group because the *"…worship songs…are loud and they're active and it makes him feel very uncomfortable… he has to go and sit where it's quiet"* (P3-4).

Participants from the group for persons with disabilities also questioned their worth after enduring incidents of scorn: *"I even got joked at"* (P1-4), as well as their sense of belonging, on account of their basic needs not catered in their congregation: *"…my question is, why am I here?"* (P1-2). Similar perceptions were demonstrated in the following dialogue excerpt: *"And they always say… 'we'll help you'…but where is the help?"* (P1-6), *"…so they'll say, 'go to her', you go to her, she forgets… It was such a struggle for me…'cause I spoke to this one lady. I didn't get communication"* (P1-1).

Sharing experiences of rejection, others' lack of understanding and acceptance, as well as their fears of judgement toward their own differences, and that of the persons in their care, participants from the focus groups for persons with disabilities and caregivers have respectively alluded to their desire for increased involvement in their congregation's activities and a deeper sense of belonging, as encapsulated by these statements: *"I'm very ambitious about going up the ranks of church leadership and I sometimes worry that my disability will get in my way"* (P1-1), and, *"…we end up not attending a whole lot of things. You see in church we only come for Sunday, because I'm thinking, 'God, if I come for this, then, what do I do to my child?' Can't even attend the sports because he'll be running around… I mean, we've had nasty experiences, so we prefer to be home"* (P2-1). From the church leader participants, references corresponding to comments such as *"…there's a desire for them to…participate with our community"* (P3-7), and, *"…those people want to be touched as well… once you get to know them, you realise that, inside of that little body, is*

*someone who just need[s] to be loved"* (P3-3), were made as they communicated their recognition of an existing unmet basic need for acceptance, inclusion and belonging. They also expressed their awareness of the difficulties faced by many persons with disabilities known to them in the surrounding community, who do not have any means to get to church. Building onto one another's ideas, suggestions were made to appeal to congregants who discerned a calling for disability ministry, to *"create friendships"* (P3-5) with these individuals, with the purpose of lifting them to and from church, as echoed by one of a few examples: *"Yes, then we could also somehow try and solve the transport issue… pick them up and…bring them to church"* (P3-2).

*Reciprocity:* Linked to the views captured by the former data extract, the church leader participants made ample references to a moral responsibility toward persons with disabilities that they and the rest of the congregation ought to share. A comment by a church leader participant captured the group's perception that the key role to be performed by them and the congregation in relation to persons with disabilities, is to minister to them: "*…they're part of the Body…and I think…they've got a purpose here as well – how did we care for them?"* (P3-3). They further conveyed this sense of duty by suggesting that congregants should be encouraged to perform more acts of goodwill toward persons with disabilities and their caregivers, and to offer them assistance, adding the forewarning: *"…we need to make the congregation aware that when you do step into that space…forget about you. Know that you are here to give a service"* (P3-2). Additional comments from this group illustrate the church leaders' intent of benevolence by their proposal of providing aid and liberating salvage to persons with disabilities, as shown in one sample: *"…if you have particular needs…we'll try and solve them for you"* (P3-4). This offer was also extended in an invitation to caregivers of children with disabilities as follows: *"…if they have special needs, then speak to us about it and we'll see if we can accommodate them…"* (P3-4).

In contrast to the church leaders' perceptions presented above, the discourse among the participants from the groups for persons with disabilities and caregivers reveal that they regard both child and adult persons with disabilities as potential active ministering members to the church leaders and other congregants, and not only as recipients of attention, care and support from them. For instance, comments from two caregiver participants demonstrate how their perceptions promote the advantages of interdependence, where they recommended instilling principles of reciprocity early on. One participant suggested offering collaborative socio-moral learning experiences *"…to the children themselves; they're very smart, you*

*know, and clever and aware and kind… those with disabilities teach those with abilities. There's always a lesson to learn… Each benefits"* (P2-2). The other caregiver added, *"It's just also to teach…other children to be, you know, more patient… So, it's a two-way, inclusivity helps with that"* (P2-1). With a strong sense of purpose to edify the leadership and congregants through her spiritual gifting, a participant from the group for persons with disabilities paralleled this notion of mutuality by expressing her desire for collaboration with church leaders, who seem to be perceived as unreachable and unyielding to minority petitions: *"I wanna have the conversation with someone high up who can make decisions to say, 'here's my challenge, I want to participate in church leadership and here are my, my problems, how can we work together to ensure that you understand my illness and you understand my calling, so to speak, for God, and when my illness interferes with my calling, you understand very well that it's just that'… It's access to senior leadership…to find out what our ambitions in the church are, not just participation but ambitions"* (P1-1).

Roughly midway through their discussion, the church leader participants' views were also swung in the direction of the previous example from the group for persons with disabilities, where one church leader participant made a suggestion (seconded and elaborated upon by his peers) for disability representation within the congregation's leadership: *"I think also you can look at creating systems where, even in our leadership, or people who serve, we have people with disabilities because it's one thing to say, we are…disability-friendly, but it's another thing for someone to see that, okay, we've got like ten youth leaders and three of them are disabled, so it means we are inclusive, because they see that, they don't just hear about it. They see it in action"* (P3-8).

**Theme 2: Addressing Needs**

The second theme, Addressing Needs, comprise two sub-themes, *Communication of needs* and *Accommodation of needs.*

<u>*Communication of Needs*</u>: All three participant groups considered the matter of communication of high importance when it comes to addressing the specific needs of persons with disabilities. They all recognised that persons with disabilities have basic needs that must be met (further detailed in the themes *Awareness and Understanding,* and *Access*) before they can be included in their congregation, and that participation would be perpetually restricted if these needs remained overlooked and subsequently unaccommodated.

Apart from the perceived barriers to participation reported in the theme *Access*, the church leader participants conveyed the impression of an awareness of a few other needs they

are not addressing. One of the main reasons offered by the church leader participants as to why basic needs remained unmet, is that persons with disabilities and caregivers *"don't always…take active responsibility for their needs and say, 'I have these problems, and these are the things I need'…"* (P3-4). The same participant later added, *"…some of the problem is…we don't always know who's sitting in church and what their needs are… I mean, I don't know because nobody ever says anything"* (P3-4). In affirmation of this objection, the statement *"Good comment"* (P3-6) was added. Joined to these opinions, the church leader participants frequently reiterated their willingness to assist throughout the discussion but repeated that they cannot help someone with a special need if they do not understand their circumstances or know exactly what their requirements are, reaffirming their stance with statements such as, *"We just wouldn't know"* (P3-7).

The participants with disabilities broached this subject from an entirely different angle. Although they acknowledged the importance of conveying their own needs, they expressed that sharing their requests with the church's leadership was futile, with the consequence, *"…eventually, you'll keep quiet"* (P1-4). They added that the congregation lacked a proper communication system whereby their needs can be known, and stated that they did not trust that their requests verbalised to the leadership were honoured, and equally so, the ones they submit in writing. One participant explained her own experience as follows: *"I often worry about just talking. That's why recording and writing is important, 'cause they give us the slips every Sunday about anything you need, but I've never heard anyone announce where you must drop them off. They're just there. Last week Sunday I had to ask: 'I actually have a prayer request, where must I take this?' So, it's almost like you have to ask for yourself"* (P1-1). On the same topic, another participant sarcastically retorted, *"Sometimes the ministers are deaf, there, I've said it"* (P1-2), and yet another, *"It's a lack of the powers [that] be, that they're not listening"* (P1-6).

Confirming the empowering effects it would have on their own participation, the focus group for persons with disabilities supported the contributions one of their participants made in sharing positive experiences he had at another congregation, as he expressed how much he appreciated the caring and humble attitudes of individuals who were bold enough to ask him outright what he needed, and who would readily and patiently learn from him precisely how he wanted his needs to be met. Recounting one such occurrence, he reported, *"At least he has the bravery, or courage to say, listen, uh, let's try this. I don't mind. I'm not offended. And he's not afraid that I might be offended…",* before remarking, *"…they're afraid to ask questions"* (P1-2) with reference to his own congregation. Another participant

from this group added the importance of church leaders and congregants *"…being…able to say, 'I'm out of my depth… can I get back to you?' 'Cause there's a lot of pressure for them to respond there and then… and that's very dangerous"* (P1-1). The participants with disabilities concluded that this is how the communication of their needs will become viable and others can discover how to help. They also expressed that this approach will increase the understanding of disability and/or illness. Although the discussion progressed to the prospective facilitating difference it can make when someone actively listens to their needs, and understands with empathy how they feel, their perceptions reverted to an existent hindrance in how they view their own church leaders having *"…the heart to heal, the heart to help, the heart to talk, but not the heart to listen…"* (P1-2).

In addition, the participants with disabilities seemed to be in two minds about accepting ownership for addressing their needs and expressed that communicating with the church leaders had become too arduous, owing to the frequent reshuffling in the leadership over the past decade. For instance, one participant protested that the congregation *"had seven…ministers in charge of it in eight, in six years. Now, how can you hope to get any continuity…with leadership changing all the time. It seems silly"* (P1-3). The regular staff turnover also claimed its toll on the caregivers, as one participant mentioned how her child's needs are perpetually obliviated in the children's ministry, "*Like when they changed the Sunday school teachers, then…he can't cope"* (P2-1). The participants in the disability group added that, with every change, they constantly had to repeat their needs, as one participant denoted his own and the other participants' ambivalence in saying: *"…sometimes we need to advocate for what we need, otherwise it doesn't get done"*, yet shortly thereafter vacillated in stating, *"…advocating all the time is exhausting… And especially with someone new, and I, then I've got to tell them who I am all over again. That's a schlep"* (P1-2). In contrast to the church leaders' perceptions that the onus of communication is on the person with the need, or on their caregivers, the participants with disabilities asserted that this responsibility is not theirs alone: *"…sometimes, don't wait for us to say, offer… That's the problem, it's so hard to speak up"* (P1-1). Another participant with a disability added that they *"…also need somebody to take responsibility for it"* (P1-3). By this, they implied the need for a representative to advocate on their behalf, as another participant clarified, *"You need someone with passion for this… Somebody with a heart for it and experience. You know, you don't have to be a disabled person"* (P1-2).

The caregiver participants expressed similar views to the persons with disabilities and agreed that it is useful when parents or caregivers contribute to informing the church leaders

of the support needs of the individuals in their care. However, with an outlook that nowadays *"…every second child is Special Ed…"* (P2-3), they pointed out that the church leaders, especially those involved with the children's ministry, ought to be abreast with this reality and that, by this time, they needed to be prepared to cater to the needs of children with special needs. One participant expressed her disappointment at the idea that the leadership is not proactive in making allowances for disability, and that the church environment and activities are not set up from the outset in such a way that barriers are removed, and everybody's needs considered. She explained: *"You think of a church, you think of that place that will open up its gates for everyone, so…for a person to miss these in churches, then, I mean…it's the first place you run to, so when you only go there, then to find that you're not catered for, it's just, it's disheartening"* (P2-1).

<u>*Accommodation of Needs*</u>: Welcomed by all three participant groups, one of the suggested ways to uncover the existence and extent of specific personal needs, is to create forums for open discussions between persons with disabilities, caregivers and church leaders, where the communication between them can be facilitated and sustained. The church leader participants' ideas included: *"I wonder if an open invitation, that is reiterated every now and again, that…'we are willing…to make a plan, but you need to let us know'…might make it be a more welcoming environment?"* (P3-4). The participants with disabilities recommended, *"We need a group…a disability group, or whatever you want to call yourselves, and this is what we picked up, and minute it… but the minister is here to listen"* (P1-2). A suggestion from the caregiver participants was to encourage the *"…communication between the parent and… whoever's in charge… there must be the mother, the father and they must tell them, 'my child has this, and…this sort of behaviour could come up, treat them like this'…"* (P2-2).

The participants in the groups for persons with disabilities and caregivers also expressed their wishes that the church leaders would take active responsibility to employ practical measures to ensure the fulfilment of their needs once they have been communicated. The persons with disabilities group's appeal to how they hope the church leaders would respond to their plea is summarised by the comment: *"…when they hear it from me and I say, 'this is my challenge…and this is what I would like', then someone has a face to it…"* (P1-1), while the caregivers agreed: *"I think all of this also goes back to, 'where there's a will, there's a way'… I think it's massive will on the part of…management, of leadership"* (P2-3). The suggestion for the development of a policy as a formal structure for enforcing the necessary regulations to ensure the accommodation of their needs was strongly supported by

the participants with disabilities, as seen in the example, *"And maybe have a church policy… If there's a policy, no one gets to wing it"* (P1-1). Both the persons with disabilities and caregivers cautioned that the objectives to meet their needs will be attainable only through the congregation's leadership *"…putting services in place"* (P1-1) that are powered and steered by them, as denoted in two comments from a participant with a disability and a caregiver respectively: *"It needs to be managed"* (P1-5), and, *"I mean, if anything's gonna happen, it's gotta be driven… once again…it's drive and it's leadership"* (P2-3).

The obvious lack of disability accommodation within their congregation was targeted and explored by all three focus groups while reporting many relevant instances. With concurrence of opinion among the participants of the group for persons with disabilities, one participant contended: *"But why is it if you ask…the church to assist you…they don't sort it out with immediate effect? 'Cause if you don't sort it out with immediate effect…this is the reason why they are losing members, because people are getting fed-up"* (P1-6). For the caregiver participants, a particular area of concern surfaced regarding the complex nature of the content of some Bible study materials. For example, one participant expressed her reservations about her adult daughter's wish to attend an upcoming Bible study series, on the grounds that she may not be able to keep up with the group, given her intellectual disability. Comparing the absence of provision for her daughter's needs to the manner in which Jesus overcame this challenge, she uttered, *"I'm not sure, you know, it's too advanced…and maybe she wouldn't understand… Jesus managed to speak to the simple and the advanced and the intellectual, by making it…understandable, but some of them are highly advanced, so they can't attend all those studies"* (P2-2). On the accommodation of her son's special needs and learning style at children's church, another caregiver added that a *"…picture is explained much better for him, but…they just talk to it quickly… the pace, or the language used…is for a higher IQ"* (P2-1). The church leader participants also acknowledged their congregation's shortcomings in disability accommodation. The outcome of this limitation is seen in the following example: *"…we had a couple with a son, he was about 12…when they stopped coming… we didn't…really have people trained among the Sunday school workers that could properly look after him… So, that was a point which would have been good if we…had someone trained, or knowledgeable to be able to, to just focus on that, because they needed one person just for him, and understand him"* (P3-3).

Referring specifically to the children's ministry, which is held in a different venue and runs concurrently with the congregation's other morning services, a caregiver participant expressed her concerns about the effect the absence of disability accommodation has on

caregivers: *"I'm just sitting wondering how many parents don't come to church because their children cannot go to Sunday school"* (P2-3). In a similar vein, a church leader participant remarked: *"In terms of children's church, it's a barrier for the parents who are hesitant to send their child because they're constantly getting feedback about their disruptive child, who won't listen"* (P3-4). Another church leader participant illustrated this scenario by reporting an actual incident: *"…he would make noises and spastic movements and…some of the kids were scared of him but the parents couldn't come to church because there would always be a disruption and they would be called out of church"* (P3-3). Using a different example, the same participant also illustrated how the rationale: *"…so, we then made a plan for them to go to a different venue…and we said that…'if you're uncomfortable, take your child there'…"* (P3-3) barred inclusion and participation during family services, since persons with disabilities and their caregivers were removed from the rest of the congregation. Both the caregiver and church leader participants shared similar perspectives on the necessity of accommodating children with disabilities and their caregivers through the provision of a specialised assistant, skilled in the recognition and service of special needs, that is, *"…somebody qualified to understand"* (P2-2).

**Theme 3: Awareness and Understanding**

Two sub-themes, *Social constructions of disability*, and *Education* are contained in the theme Awareness and Understanding.

<u>*Social constructions of disability*</u>: There was consensus in the perceptions among the three participant groups concerning the lack of awareness and understanding of disability in their congregation. It was especially the socially constructed misconceptions about disability, including spiritual fallacies, that they perceived to largely contribute to hindering the participation of persons with disabilities in their congregation. In a summarising comment, a participant from the church leader group remarked: *"Sometimes the disability is in our eyes, that we are disabled in being able to just see the person who is within that…shell"* (P3-3). Regarding the congregation's perceived connotations between sin and disability, a participant with a disability asserted: *"People must read Job. Job did nothing wrong"* (P1-1).

The church leader participants openly admitted their own lack of awareness and experience with disability and mentioned that they do not necessarily possess the practical know-how to treat persons with disabilities with dignity, and in a manner that does not demean them. One participant said: *"… you don't know if you're doing the right thing, or then you overcompensate, and then it borders around you patronising them and then they can*

*see that and then, you know, there's a friction there already…"* (P3-2). Another church leader participant expressed her view as follows: *"It's a lack of understanding of what your perceived non-acceptance means to that particular person. Because sometimes you do something, you're not even aware of it"* (P3-1). A participant from the group for persons with disabilities affirmed this notion by saying, *"…sometimes people don't realise what they're doing wrong"* (P1-1).

For the church leaders, it was also the *"…lack of knowledge about how to be inclusive…of people with disability*" (P3-7), and more specifically, the reactions of uninformed people, that were perceived to make persons with disabilities feel unwelcome and unlikely to return to their congregation. An example of this view was given by a church leader participant who witnessed the discomfort in the reactions of a group of adolescents, when a girl with albinism joined their youth group: *"…I mean, she could tell…because she walked in and everyone stared… at times, people don't know how to act, or behave"* (P3-8). Referring to the conspicuous differences persons with disabilities sometimes display in their appearance or behaviour, the subsequent question contemplated among the church leader participants was: *"Do you ignore it, or don't you ignore it?"* (P3-4).

The participants from all three focus groups also mentioned social stigmas, negative attitudes, as well as fear of disability, and gave other examples of hurtful reactions toward persons with disabilities that marginalise them. A participant from the caregiver group expressed: *"… people are so overprotective of their children… they don't want their child to experience somebody having [an] epileptic fit…"* (P2-3). In their own discussion about erroneous beliefs regarding epilepsy, this perception was echoed by the persons with disabilities, as one participant emphasised: *"That's exactly what it's about, the church is afraid of disabilities"* (P1-2). The church leaders' view that people typically feel particularly awkward about engaging with people with specific types of disability, was captured by the statement: *"…I think…it's easy to…accept, or interact with someone that's got…sight loss, than someone with a disability when you struggle to hear what they say. And you're not able to communicate with them, so you rather avoid them"* (P3-3). A participant from the group for persons with disabilities, who is Deaf, shared his actual experience of such avoidance, when a congregant, who initially approached him, turned silent and walked away from him upon noticing his hearing aids. In a wry comeback after recounting his encounter, he uttered: *"That doesn't help… You know, I'm not going to make you sick. Yes, you can touch me. It's ignorance!"* (P1-2).

The participants in all three groups appreciated the important role that socialisation plays in forming perceptions about disability. The church leaders mentioned how people may want to assist someone with a disability but that they may be unsure of the kind of assistance or interaction that is acceptable and that which is not, for instance, *"…if someone is autistic, they might not want to be touched"* (P3-4). The participants with disabilities also shared their own previous uncertainty regarding how to respond when they came across disability symptoms and behaviours that were unfamiliar to them before, and described the influence their own upbringing had on their behaviour: "*We, we were taught as kids that you shouldn't look at…the people who aren't properly formed and so on because it was, it was very rude…"* (P1-3). However, having lived with impairment in their own bodies, the participants' painful experiences of social rebuff caused them to question this belief, as articulated by the comment: *"I think the worst is acting like you can't see a disability. There are people who do that… so, you see, and then you 'unsee' them, but it's almost like you're 'unseeing' the human being."* (P1-1). Suggested as an alternative to internalising the norms and values of secular society as a model for interpersonal relationships, a caregiver participant stressed the importance of cultivating and nurturing a deeper "*…understanding that God made us in His image…and that includes [the] disabled, it includes…everybody"* (P2-2).

Onto stereotypes and classification of health conditions, a caregiver participant said, *"Today they're labelling children, autism, Asperger's, um, Down's syndrome… they understand children more, I think, but I don't know if they're better…at handling them"* (P2-2). The participants in the groups for persons with disabilities and caregivers questioned whether labelling was at all helpful to promote understanding of disability, if it did not also inform interventions for disability accommodation in social environments, such as churches. One participant with a disability cautioned sternly, *"…don't put me in a box…or change the box"* (P1-1). In addition, the participants in the group for persons with disabilities also expressed their concerns about the misinterpretations of disability symptoms and diagnoses among church leaders and congregants, which they explained largely impact the extent to which their needs are understood and accommodated. For instance, they emphasised the prevailing underplaying of the severity of certain disabilities, as illustrated in the following extract: *"When I came to the church, I was 'hard of hearing', and that's the wrong term. I'm not hearing impaired…I'm Deaf, I can't hear"* (P1-2). Emphasising that *"…there's a big difference between Deaf and hearing impaired"* (P3-7), one of the participants in the church

leader group corrected her fellow group members forthwith on this very matter, as they discussed the needs of persons with disabilities during their focus group.

Regarding the true nature of their disabilities and inaccurate theological interpretations thereof, the participants with disabilities also asserted that depression and epilepsy are respectively clinical and neurological conditions that require medical intervention, and not spiritual maladies that are primarily prayed over for deliverance, and healed. One participant explained: *"A lot of people think depression is a spiritual illness, which is just nonsensical. So, if you think it's a spiritual illness, you think you're gonna pray for me"* (P1-1). Sharing an incident that occurred at a different congregation, another participant reported how his disability was assumed to be the mark of demonic possession: *"They said 'well, you have the demon of being deaf' and they put their hands on me to heal me"* (P1-2). Referring to the theology espoused in his own congregation, and the starting place for the social reconstruction of disability, the same participant continued, *"…the church leadership's understanding of it [disability] needs to change from that model"* (P1-2).

<u>*Education*</u>: The participants from all three groups noted the importance of raising awareness among the congregation to address the issues reported in the previous sub-theme, as affirmed by a participant with a disability in the statement, *"…the way to deal with the ignorance is to educate"* (P1-2). Through the promotion of disability awareness and education, the participants from all three groups expressed their hopes that everyone in the congregation would gain a correct understanding of disability and related behaviours that may otherwise be misunderstood.

Different ideas on how to address the congregation on these matters were also made by all three groups, with suggestions for disability awareness services led by the leadership, and testimonies volunteered by persons with disabilities and caregivers. A synthesis of all the participants' comparable recommendations is provided in the following excerpts, the first two presented by persons with disabilities: *"If the minister at the end of his…sermon said um, 'I'd like you to understand there are a couple of people in the…congregation who are Deaf, do you know what Deaf means?' That…could…spread the word…from the top down, rather than trying to get from the bottom up"* (P1-3). Another participant added: *"You, know, they could do it beautifully. They could bring it in to like a testimony thing, that if [Name] was brave enough, and he is, to stand up and say, 'I'm a person with this disability', [and] 'I need this around me'…"* (P1-5). Representing the caregivers' perspectives, a participant from that group said, *"You build awareness…to the…wider church… So that, you see my child*

*screaming, 'oh yes, that's something they told us about, okay', and there's that understanding… We just ask for them to just be aware"* (P2-1). A church leader participant suggested that *"…you can do a testimony-type thing, where someone…with a problem comes and speaks to people, gives their testimony on 'what it feels like when you do this and what I would like instead'… if you do a testimony in a service, people hear stuff differently"* (P3-4). In line with the first idea offered by the disability group, the church leader participants agreed that the best way to address the congregation is to *"…preach it from the pulpit…[because]… that is the only time they [congregants] listen"* (P3-1), tracked by a follow-on comment by another church leader: *"And I do think P3-1 is right. We need teaching, and sermon series' help do that. Help raise awareness"* (P3-6). The same participant suggested that this can be done alongside national and international initiatives commemorating disability, by plugging into similar global activities.

Participants from the groups for caregivers and persons with disabilities have also emphasised the importance of extending this awareness and education to the children in the congregation. A caregiver participant suggested *"…you train even the children, in the Sunday school. If there's somebody…that suddenly does this, you know…this one can go and do that, help that child in this way…or the child who's…misbehaving…maybe even another child can go and help that child because you've trained them"* (P2-2). In addition, the caregiver participants discussed potential benefits to the congregation if specialised training can be provided for teachers and volunteers within the children's ministry. According to the caregivers, the ultimate gain is that disability in children will be accommodated, the child's needs met, and parents of children with and without disabilities can attend the main service in the sanctuary, and *"…with peace of mind leave [their] child…"* (P2-3), without any concerns about their child's safety and well-being. They added another advantage, in that the trained individuals can impart important prosocial interpersonal skills for the development of tolerance, empathy and collaboration among all the children. Furthermore, if special needs are to be accommodated in their congregation's children's ministry, the caregiver participants maintained that *"You will see a lot of people coming through. 'Cause…one in every two children now has a special need"* (P2-1). This comment was supported by another caregiver with the affirmation that *"…it will attract members to the church…"* (P2-3).

The church leader participants offered further ideas by which disability education and inclusion can be facilitated, and the congregants can be invited to discern a calling for a ministry with this purpose, as one participant advised, *"…we all understand in church that there are some things that we are called to or gifted for. There will be people sitting in the*

*congregation who may not even be aware of the fact that they are called to or gifted for this particular ministry… But if we don't tell them that, 'A', the ministry is needed, and, 'B', give it a try, they may have a gift that they're not even using"* (P3-1). Along with the promotion of increased understanding and sensitivity to disability and the individuals living with it, the church leader participants highlighted the necessity to inform the congregants of an important personal transformation they need to undertake, should they wish to be involved in such a disability ministry and make personal connections with persons with disabilities. They stressed that part of this education to the congregation must include the preparation that they will be *"…compromising [their] own personal space and [their] own comfort"* (P3-7). The same participant added, "*…and that, even for people who are willing to try…that is tough, that is really, really tough"* (P3-7). Another participant from this group confirmed this perception in saying about themselves and the congregants: *"…you have to overcome your own problems as well"* (P3-3).

**Theme 4: Access**

The final theme, Access, features two sub-themes, namely *Accessibility of the physical environment* and *Access to necessary resources.*

<u>*Accessibility of the physical environment*</u>*:* In an all-embracing statement concerning the poor accessibility of the physical spaces on their congregation's property, a comment by a caregiver participant consolidated all three participant groups' perceptions in this regard: *"So, it's the whole infrastructure…which needs to be more accessible…the toilets, the ramps… parking"* (P2-1).

The participants from the focus groups for persons with disabilities and church leaders made specific mention of the number of stairs on the church property that impede the physical access of persons with disabilities. For instance, a participant from the disability group explained, *"…I have…Cerebral Palsy, so I find it difficult to climb up and down the stairs and so, if there's any activities that we have to climb up stairs, or hold two things at the same time, I find that awkward"* (P1-6). Another participant with a disability also commented on the many stairs around the church campus, as well as within the different buildings on the property, protesting: *"Well, if you've invited me when I was in a wheelchair, how do you think I would've got here? Got up and walked? No ma'am. There's no ways I would've got down there"* (P1-3). On the same topic, a church leader participant addressed one of the other participants in her focus group about the unsuitable nature of the venue designated for the congregation's youth gatherings, saying, *"If you have physically disabled*

*youth, they cannot come to you"* (P3-1). After contemplating this observation, the addressee concurred, *"I think it's seven stairs down, plus another seven, so it's 14, just to get to the room"* (P3-8).

Concerning the staff work spaces, the church leader participants also noted that, apart from using stairs, there is no alternative access to the upstairs and downstairs offices in the main office block. One church leader participant warned: *"If we ever had a disabled minister, we're in trouble* (P3-1). Another participant from this group added: *"Or any other employee who has a disability because we only have one floor accessible…and the toilet on that floor is not accessible. So, even if somebody…worked in here, you can't get into the toilet. The one floor that is accessible to someone with a disability…the toilet is up two stairs, or down two stairs. So, if we ever did employ someone, it would be an added issue"* (P3-4).

With reference to the availability of ramps to ease the access of wheelchair users or others who cannot use stairs, the church leader participants remarked that the quality of the existing ramps on the church property is very poor, with uneven surfaces and unexpected drops, especially the one leading into the sanctuary: *"But even the ramp going down, as you get to the bottom, it suddenly slope[s], and you almost go into the garden… we'll have to even it out because, even if you walk down there, the elderly, I have to always caution them to stay on the other side"* (P3-3). A participant from the group for persons with disabilities described her own experience as follows: *"…it looks nice when you come in that there's a wheelchair ramp…but having brought someone…in a wheelchair… let me tell you… coming down that ramp in the church…is a nightmare… Trust me, it, it looks lovely, that it's wheelchair-friendly; this church is not very wheelchair friendly"* (P1-4). Expressing similar perceptions, the caregiver participants also pointed out that the ratio of ramps to building entrances were insufficient for providing wheelchair users access to most of the venues on the church property, for example: *"…there's the one going into the main church…but to get to…the meeting rooms, down stairs and whatever, they couldn't, and up to the offices…they can't do that"* (P2-3). The church leader participants proposed evaluating the user-friendliness of the church environment by *"…taking a wheelchair and checking if you can get around… Speaking to those who actually use our facilities to find out what problems they do have. What could be changed? Because there are people who do use the ramps. Are they okay for them, do they need a different ramp?"* (P3-4).

Onto parking spaces reserved for persons with disabilities, a church leader participant pointed out, *"…they're all the one's there next to the ramp. There's six of 'em"* (P3-1). However, despite the availability of disability parking bays, the church leaders aired their

concerns about able-bodied congregants' inconsiderate use of these designated spaces, as one participant explained: *"…we do have a couple of reserved parkings, but we do have congregants who don't have a disability…and park in it anyway"* (P3-4). Later in the church leaders' discussion, another participant returned to this issue, advising, "*I do think we…need to keep reminding people about our handicapped parking area… we need to remind them it's there for a purpose. There're people who actually need it"* (P3-6). The church leaders subsequently proposed closing off the parking bays, to be made accessible for legitimate users only: *"You get those very big…life-size cones. They're massive and it's up to the security guard…to move them, and her alone"* (P3-1).

The participants with disabilities pointed out an additional matter that encumbers their ease of access, namely inadequate signage. They expressed that, with all the alterations made on the church property, some of the signposts had been removed and some of the existing signage do not correspond to the buildings, which is confusing and causes them to easily lose their way on the campus. One participant captured her group's frustrations in this regard by saying, *"…there were no signposts either. That got me ticking. I didn't know where I was going to…because some of the places [have] been changed totally…it's not well signposted"* (P1-6). Some of the participants also mentioned that they struggled to find the venue where the focus group was held, because it was not signposted near the entrance, as one explained: *"…once you get down here, there is a sign that says this is where it is, but I mean, you gotta know…"* (P1-3). Approved by all the participants in the group for persons with disabilities, one participant suggested reinstating an updated scale drawing of the campus, indicating the location of all the different venues to aid their orientation: *"Do you know what will help… that little map… There used to be one at the top by the church that said…'the main office building, the sanctuary'… they…probably took it down because they changed it but there used to be that site map"* (P1-4). Another participant suggested offering this guide in printed form: *"You know that area map of how to exit the place on a Sunday, they should give you a map like that to tell you where everything is… They should hand that out to everybody when they do the…sermon notes"* (P1-6).

The reservation of seats in the sanctuary also surfaced among the participants' contributions from the focus groups for church leaders and persons with disabilities. Explaining that there are no additional seats made available for people in wheelchairs to sit with their families during church services, a church leader participant stated: *"Another thing that could be a hindrance [is] seating arrangement. There's a lady who's in a wheelchair… if she comes maybe and it's already full, then she can't sit because she's with her family, so*

*now they've got to run around, trying to grab maybe a chair there but you know, the service is on, and it's just, you know…it's awkward, so maybe if we could cordon off, even if it's three or four chairs?"* (P3-2). A participant from the group for persons with disabilities shared his own initial apprehension concerning this type of reserved seating arrangement, along with its discovered benefits, when he recounted a personal experience: *"I went to church…down the road…and they always reserve seats for me, but they welcomed me with like four, five rows, and Deaf people, and that's where I started learning sign language from. At first, I thought, 'huh? I don't want to be in front!'…But…they're allowing people to come; then people will come"* (P1-2). While the participants from the groups for persons with disabilities and church leaders agreed that seating provisions were necessary, the participants with disabilities cautioned that *"There needs to be sensitivity"* (P1-2), and that the person with a disability must be given a choice as to whether or not they want a seat reserved for them, and if they want to sit in that particular space at all: *"There must be an option. We don't all have to take it"* (P1-1).

<u>*Access to necessary resources*</u>: The participants from all three focus groups pointed out the necessity of specific resources without which the participation of persons with disabilities in their congregation are obstructed. These include technological, financial, human and transportation supports.

Aspects pertaining to acoustic, or sound quality in the sanctuary received much attention among the participants in all three focus groups, as a Deaf participant in the group for persons with disabilities described, *"…sound…for me is fundamental. That's my primary one"*, and added the importance of *"…having someone to control the technology and make sure it works"* (P1-2). Regarding hindrances to sound transmission in the sanctuary, the church leader participants explained that the acoustic design of the building was conceived *"pre-microphones"* (P3-1) and that the current electronics cause the sound to bounce, producing slapback. Living with hearing impairment himself, a participant from the church leader group described his own challenges in the following way: *"…having lost some of my hearing…there's dead areas in parts of the church where I cannot hear, or where there's a…reverbing, and I have to move to another place…to be able to hear"* (P3-3). Another church leader participant corroborated this experience, saying, *"…you would sit in a spot…and the sound just feels dull…its's a complete damp, as though somebody's turned the volume down"* (P3-7). The participants from the caregiver group also highlighted poor sound quality as a deterrent to participation during church services when the message preached

cannot be received, for instance: *"…one of my friends has stopped coming to church because she couldn't hear"* (P2-3).

The participants from the focus groups for persons with disabilities and church leaders further reported challenges that arise when those operating the sound equipment do not use it properly. One participant with a disability insisted that *"…the people in charge of sound must…know what they're doing…to keep it controlled"*, adding that they must *"…make sure that the person using the mic knows what they're doing"* (P1-5). Participants from the church leader group made congruent statements, for example, *"…when you get up there to pray…you're not bowing your head and praying quietly to God by yourself… you actually need to produce good projection. You need to use clear articulation because otherwise, people with hearing disability are not gonna hear a word of your prayer… anybody who's going to be addressing from the pulpit needs to be aware of that"* (P3-7). Another church leader followed up this comment by suggesting, *"You would have to have some mic training because not everybody knows how to use the mic"* (P3-1).

In addition, the participants in the groups for persons with disabilities and church leader raised concerns about persistent audio-visual delays, as both groups perceived this as having a substantial impact on people who are Deaf or hard of hearing, who cannot follow the message that is preached, or the songs that are sung when there is insufficient visual input on the projection screen. From the perspective of the group for persons with disabilities, one participant explained, *"…if you don't know the song, and the…slides are sometimes out, that can be a problem"*, and subsequently proposed the potential resolution of *"…updated technology"* (P1-4). In an objection against the congregation's audio-visual support team, another participant in the group for persons with disabilities observed, *"…those guys are so slow. Like to change from one hymn to another, sometimes the song starts from start to finish, and they haven't even changed it"* (P1-1). The church leader participants shared their own frustrations and challenges with audio-visual lags, for instance, *"I am not disabled in any of those forms and I cannot look at the screen when there's no synchronisation"* (P3-1). In addition, the church leader participant with hearing impairment explained: *"…I learnt to read lips to compensate… the difficulty is, if I look at the projection, there's a delay, so the lips and the sound [don't] correspond as well"* (P3-3). The Deaf participant from the group for persons with disabilities made a parallel comment saying, *"…when you're talking, I need to be able to see you. If I…can't see your lips, I'm gonna battle"* (P1-2). In their discussion of facilitators to the participation of persons with disabilities, a participant from the church leader group pointed to the identified list of barriers and stated, *"The AV syncing needs to go*

*on there. We've got it as a problem, but we haven't got it as a solution"* (P3-7). Confirming the priority of addressing the audio-visual issues, another participant from this group assured, *"…it's right on top of my to-do-list"* (P3-1).

In addition to resolving the audio-visual challenges, and apart from assistance through electronics and technology, the participants in the groups for persons with disabilities and caregivers recommended the facility of a sign language interpreter during the different church services, since there is no such provision at their congregation. With reference to the congregation's existing audio system, a participant in the group for persons with disabilities said, *"I found I wasn't happy with the way it was working, so I said to them, 'well then, please, I would like an interpreter, a sign language interpreter then'… I would like to come to church if there's an interpreter here"* (P1-2). While not expectant that it will materialise, support for this gesture was expressed by a participant in the caregiver group, who said, *"…somebody to sign the services would be fantastic"* (P2-3). In recognition of the advantage of an interpreter, yet faced with the present reality that they *"…don't have people…signing"* (P3-6), the church leader participants discussed the complications of having their multilingual services sign interpreted, and as another church leader advised, *"…we'll have to get somebody who understands most of the languages to sign"* (P3-2). After some deliberation regarding the provision of sign language interpretation, the initial response from one of the church leaders, *"I don't have an answer for it…"* (P3-6), remained at that for the church leader group.

On a visual level, the participants from the caregiver and church leader groups pointed out that their congregation does not provide access to Braille services, and that, as a result, people who are blind cannot participate in singing unfamiliar lyrics, or follow Bible texts. A caregiver participant explained it as follows: *"Well, obviously blindness is…a disability throughout the whole church service…whatever you come to… I mean, there's no Braille"* (P2-3). In a corroborating statement, a church leader participant said, *"…there's no Braille…for people who don't see, for them to be able to follow…at least the scripture… I think that will also make people not want to come"* (P3-2). Some of the other church leaders also discussed a time when a blind person, who used to attend the congregation, made arrangements with them prior to the Sunday services to familiarise himself with the upcoming proceedings. One church leader participant described how she used to assist him: *"… he did ask me to send him the songs before Sunday and then his wife would go through them with him, so that, when he got there on Sunday, he wasn't completely lost on the songs that he'd never heard before*" (P3-1).

During all three focus groups, availability of finances was mentioned as a prime barrier, the presence of which was said to make for an excellent facilitator to address many of the barriers they have identified. For instance, when discussing the question on factors that may facilitate participation, one caregiver participant stated, *"It's always economics, obviously… it governs our lives, I'm afraid"* (P2-3). Realising that they had not identified access to finances as a hindrance to participation earlier, all the caregivers agreed when the same participant added, *"Finance absolutely…should be at the top… Huge barrier"* (P2-3). The church leader participants also made recurring references to a shortage of funds, as one of them explained why they were unable to update their electronic systems, and were still experiencing issues with acoustics in the sanctuary: *"…short of spending many thousands of Rands to re-thingy…the venue, we would have to put…sound and all sorts of very expensive stuff in it… that's why we haven't done it because it's a money issue"* (P3-1). Further discussing the necessity of a specialised assistive sound system and the limitations in affording it, another church leader participant stated, *"If money were no object, a good loop system"* (P3-7), followed by the prospective, *"But I'm saying, who knows? Somebody might be willing to sponsor it. People sometimes take on particular projects that they can see"* (P3-6). While one participant in the group for persons with disabilities reasoned that *"It's finance"* (P1-5) that may be preventing their needs from being met, the other participants in her group had dubious views, for instance, *"…the only excuse I would accept is that there's no budget. But…if you say there's no budget, I want to see three quotations"* (P1-1). Expressing thoughts that they are unimportant and ignored in their congregation, another participant from this group muttered, *"You can get three quotations, it doesn't make any difference, believe you me"* (P1-3). In terms of *"getting better technology"* (P1-2) to improve the sound system, an added comment depicts this perception, where yet another participant with a disability explained: *"…to get it properly fitted in, a R130 000, okay, so that would fit for one – for me and who else – so why are we going to do it?"* (P1-2).

With reference to the various volunteers and staff members who previously fulfilled essential roles in assisting the leadership during the congregation's services and activities, the participants from all three focus groups also identified human resources as an area that is currently lacking. A participant in the group for persons with disabilities stated, *"So, I think it's boiled down to under-staffing, because they haven't got those individual people anymore. And at the church office it's the same"* (P1-5). The same participant shared that, in the past, *"…there had to be 12 people available on a Sunday morning to run that service… there were helpers, there were stewards, there were people even watching where people had disruly*

*children"* (P1-5). As a suggestion, a participant from the caregiver group mentioned: *"…obviously, I think a person in a wheelchair, if they haven't got an assistant…if there's some caregivers offered by the church, to meet them at a certain point and take care of them, get them into church, get them to a toilet, get them to have tea, whatever"* (P2-3). Additionally, the caregiver participants placed specific emphasis on the need for more volunteers to support the pastor during children's church activities. In fact, they stressed the importance of the children's ministry being managed by an entire team, and not only one person as it is currently done, so that the children do not have to deal with the disruption of unforeseen changes in staff and volunteers: *"…the minute the teacher is not there, she's got the flu, or she goes overseas, or whatever the reason… If it's just one person running that, then there's no flexibility… Because for your child, you know, walks in and immediately sees the teacher's changed, that's that child one way"* (P2-3). Devising ideas for marshalling more volunteers for service, the participants from the church leader group described the need for *"Mobilising the broader community to actually meet a need for inclusion"* by asking the congregants: *"…is there someone who's willing to pick someone up? Is there someone who's willing to sponsor a driver, um, once a week, to drop people off"* (P3-4).

Linked to the above, access to transportation was considered a barrier to church participation for the participants from all three groups, not only to persons with disabilities, but also the elderly. One church leader participant gave the following example: *"There are old folk sitting there whose children are in all other parts of the world, who don't come to church. They may not be disabled in the strict sense of the word; all they need is someone to pick them up. Like, [Name], if somebody doesn't pick her up every Sunday, she would not be here, you know, if someone didn't do that"* (P3-1). Another participant from the church leader group added that persons with disabilities may want to attend church services and other activities but *"…there is that, 'but how can I, I'm not mobile…I don't have that choice to actually, you know, get there myself'…"* (P3-7). The need to assemble volunteers to provide transport to those who cannot get to church on their own was also raised by the caregiver participants, who suggested an arrangement of *"…people who go and pick up this one, and that one and that one and bring them to…the services"* (P2-3). Similar suggestions were made by the participants in the group for persons with disabilities. One participant proposed, *"…with epilepsy, I can't drive…so if there's…maybe some kind of…a social group…let's go together…or we meet somewhere. You know, we can even all Uber together or something…"* (P1-4). Another participant with a disability suggested that *"…transport needs to look at car pools and things like that"* (P1-3).

The preceding section concludes the presentation of the results from the inductive thematic analysis. As a brief review of the extensive descriptions of the emergent patterns in the data given above, the participants' responses were organised into four predominant themes related to barriers and facilitators to the participation of persons with disabilities in their congregation's various ceremonies, activities and events identified by them. The themes included perceptions concerning the social standing of persons with disabilities, aspects related to addressing their needs, disability awareness and understanding, as well as access to the physical spaces and resources, that affect their involvement and participation in their congregation. The subsequent section presents the abovementioned findings in relation to the deductive coding process that was followed as a final step in the data analysis. Conceptualising functioning and disability in line with the biopsychosocial model of the ICF (WHO, 2001), the following segment of the results connects the participants' perceptions to the interaction between the health conditions of persons with disabilities, and the external influences on their functioning (or disability) within the unique context of their congregation.

### *4.4.3 ICF contextual factors represented in the participants' perceptions*

The fourth and final sub-aim of the study was to explore the relevant ICF contextual factors that were represented in the participants' perceptions in the three focus groups. Using Cieza et al.'s (2019) refined linking rules, this section highlights the corresponding ICF classified environmental codes and categories implicit in the participants' responses concerning factors featuring as barriers and facilitators to the participation of persons with disabilities in the physical, social and attitudinal spheres of their congregation. Since the aim of the study was to identify the participants' perspectives on the presence or absence of barriers and facilitators to participation, and not the degree, no qualifier codes were applied to establish or indicate the extent of the participants' functioning or disability in any particular category, or the degree to which the pertinent environmental factors were barriers or facilitators. The ICF environmental codes represented in the participants' perceptions are documented in Table 4.3. Limiting the code listings to the context of the *Religion and spirituality* code (d930) of the ICF's Activities and Participation component, the details of the coded categories in the table are abbreviated and modified to fit the church-specific context of the study and do not include the full code descriptions related to other broader environments as included in the ICF.

Table 4.3

*ICF Environmental Factors Represented in Participants' Perceptions*

| ICF Code | ICF Category description | (No. of data links per category) | No. of ICF codes per category |
|---|---|---|---|
| **Chapter 1:** | **Products and technology** | **(146)** | *three e1 second-level codes**; five e1 third-level codes |
| *e145* | *Products and technology for the practice of religion and spirituality* | | |
| e1451 | Assistive products and technology for the practice of religion or spirituality | | |
| *e150* | *Design, construction and building products and technology of buildings for public use* | | |
| e1500 | Design, construction and building products and technology for entering and exiting buildings for public use | | |
| e1501 | Design, construction and building products and technology for gaining access to facilities inside buildings for public use | | |
| e1502 | Design, construction and building products and technology for way finding, path routing and designation of locations in buildings for public use | | |
| *e165* | *Assets: Products or objects of economic exchange, e.g. money, goods, property and other valuables that an individual has rights of use* | | |
| e1650 | Financial assets | | |
| **Chapter 2:** | **Natural environment and human-made changes to environment** | **(27)** | *two e2 second-level codes**; three e2 third-level codes |
| *e240* | *Light: Electromagnetic radiation by which things are made visible by artificial lighting* | | |
| e2400 | Light intensity: Level or amount of energy being emitted by either a natural, or an artificial source of light | | |
| *e250* | *Sound: A phenomenon that is or may be heard, such as banging, ringing, thumping, singing, whistling, yelling or buzzing, in any volume, timbre or tone* | | |
| e2500 | Sound intensity: Level or volume of sound determined by the amount of energy being generated | | |
| e2501 | Sound quality: Nature of sound as determined by the wavelength and wave pattern of the sound | | |
| **Chapter 3:** | **Support and relationships** | **(147)** | *four e3 second-level codes**; zero e3 third-level codes |
| *e325* | *Acquaintances, peers, and community members who are familiar to each other and share religious creed* | | |
| *e330* | *People in positions of authority with decision-making responsibilities for others and who have influence or power based on their religious roles* | | |
| *e335* | *People in subordinate positions whose day-to-day life is influenced by people in positions of authority, such as members of a religious group* | | |
| *e340* | *Personal care providers and personal assistants: Individuals who provide support services to individuals on a remunerated or voluntary basis* | | |
| **Chapter 4:** | **Attitudes** | **(170)** | *four e4 second-level codes**; zero e4 third-level codes |
| *e425* | *Individual attitudes of acquaintances, peers, colleagues, neighbours and community members* | | |
| *e430* | *Individual attitudes of people in positions of authority* | | |
| *e460* | *Societal attitudes: General or specific opinions and beliefs held by people of a social group about individuals that influence behaviour and actions* | | |
| *e465* | *Social norms, practices and ideologies: Abstract systems of values and normative beliefs that affect or create social norms of moral and religious behaviour* | | |
| **Chapter 5:** | **Services, systems and policies** | **(60)** | *three e5 second-level codes**; three e5 third-level codes |
| *e515* | *Architecture and construction services, systems and policies for the design and construction of public buildings* | | |
| e5150 | Architecture and construction services: Services and programmes for design, construction and maintenance of public buildings (e.g. building regulations) | | |
| *e540* | *Transportation services, systems and policies for enabling people to move or be moved from one location to another* | | |
| e5400 | Transportation services aimed at moving persons by public or private transport, including those who provide these services | | |
| *e555* | *Associations and organisational services, systems and policies relating to groups of people who have joined together with an associated membership structure* | | |
| e5550 | Associations and organisational services and programmes provided, such as religious services | | |

* Second-level codes are italicised

Table 4.3 reveals that all five chapters of the ICF Environmental Factors were represented in the participants' perceptions concerning barriers and facilitators to the participation of persons with disabilities within their congregation. A total of 27 environmental codes were linked to the data, 16 of which are documented at the second-level (indicated in italics), and 11 at the third-level of classification. The table also draws attention to Chapter 4 of the Environmental Factors of the ICF, *Attitudes*, as the category holding the highest number of data links between the participants' responses and the ICF environmental codes. Given that no statistical analysis was carried out, the frequencies at which these codes occurred as barriers or facilitators were not measured. However, the nature of the environmental factors, that is, whether they were viewed as barriers or facilitators, can be inferred by the qualitative input from the participants' responses. The connection between the ICF and the participants' perceptions is presented in Table 4.4, where links between the environmental codes (e-codes) and the emergent themes are shown.

Table 4.4

*Environmental Codes Linked to Emergent Themes*

| e-Codes | Nature of e-code | Theme / Sub-theme | No. of times stated | Theme # |
|---|---|---|---|---|
| e1451 | Facilitators absent | Access to necessary resources | 19 | 4 |
| e1500 | Facilitators inadequate | Accessibility of the physical environment | 35 | 4 |
| e1501 | Facilitators absent | Accessibility of the physical environment | 46 | 4 |
| e1502 | Facilitators inadequate | Accessibility of the physical environment | 25 | 4 |
| e1650 | Facilitators inadequate | Access to necessary resources | 21 | 4 |
| e2400 | Barriers imposed | Conformity | 3 | 1 |
| e2500 | Barriers imposed | Belonging | 8 | 1 |
| e2501 | Facilitators inadequate | Access to necessary resources | 16 | 4 |
| e325 | Barriers imposed | Belonging | 23 | 1 |
| e330 | Barriers imposed / No facilitators | Addressing Needs / Access | 93 | 2/4 |
| e335 | Barriers imposed | Conformity / Belonging / Reciprocity | 14 | 1 |
| e340 | Facilitators absent | Access to necessary resources | 17 | 4 |
| e425 | Barriers imposed | Conformity / Social constructions of disability | 32 | 1/3 |
| e430 | Barriers imposed | Conformity / Social constructions of disability | 31 | 1/3 |
| e460 | Barriers imposed | Conformity / Social constructions of disability | 48 | 1/3 |
| e465 | Barriers imposed | Conformity / Social constructions of disability | 59 | 1/3 |
| e5150 | Barriers imposed | Accessibility of the physical environment | 15 | 4 |
| e5400 | Facilitators absent | Access to necessary resources | 10 | 4 |
| e5550 | Barriers imposed | Conformity / Accommodation of needs | 35 | 1/2 |

Table 4.4 shows the participants' themed responses in relation to the ICF, and includes the perceived nature of the pertinent environmental factors. Notwithstanding the presence of

environmental factors that may facilitate the functioning of persons with disabilities in the congregation of the study, the ICF constitutes a facilitator that is absent or insufficient (despite its existence) a barrier (WHO, 2001), and in light of this, the nature of the participants' perceptions were fraught with barriers associated with the codes presented in each category. From Table 4.4, it is thus evident that the participants generally considered the environmental factors at work in their congregation to hinder, rather than enable, the functioning and participation of persons with disabilities. Apart from all five environmental chapters being demonstrated in the data, Table 4.4 also shows how the documented environmental codes were evident in each of the four derived themes as well, suggesting a noteworthy resemblance between the participants' perceptions of the wide-ranging external factors that influence the participation of persons with disabilities in the unique setting of their congregation, and that encompassed by the ICF. Furthermore, this comparison confirms the all-embracing comprehensiveness of the ICF as a valuable tool for understanding and describing disability in any context and across disciplinary boundaries.

The documented codes from the first chapter in the Environmental Factors component of the ICF, *Products and technology*, were represented in the sub-themes, Accessibility of the physical environment, and Access to necessary resources, under the fourth main theme, Access. The absence and inadequacy of assistive products and technology, such as Braille (e1451), parking spaces, ramps (e1500), toilets, audio loop systems, accessible seating (e1501), signage (e1502) and finances (e1650), were identified as barriers to the participation of persons with disabilities in the participants' congregation.

In the second chapter, *Natural environment and human-made changes to environment*, the light intensity (e2400) discharged by photographic flashes was noted as problematic and considered a barrier created by the congregation's customs during Baptism services, as reflected in the sub-theme, Conformity, under the first main theme, Social Status. In addition, the environmental code, sound intensity (e2500), is represented in the subtheme, Belonging (Social Status), with specific reference to sound volume in the reported perturbing noise levels during activities at children's church. Next, sound quality (e2501) is linked to the sub-theme, Access to necessary resources (Access), where the participants described the hampering effects of dull sound areas and reverberation in the sanctuary owing to inadequate sound equipment.

The third chapter, *Support and relationships*, which concerns the general physical and emotional support afforded to persons with disabilities, is relevant to the sub-theme, Belonging (Social Status), with reference to the purported barriers inflicted on persons with disabilities through the deficiency in care and assistance offered to them by others who share the same religious interests (e325), and their subsequent exclusion from the congregation of which they are a part. The perception of the church leaders' apparent incapacity to assert their influence and effect the necessary changes to support persons of disabilities (e330) were considered hindrances by all the participants, but for different reasons. While the church leaders attributed their limitations to a lack of resources, the persons with disabilities and caregivers regarded the church leaders' non-intervention as neglect and indifference to engage with the needs of persons with disabilities. Out of all the linked environmental codes, e330 obtained the highest representation in the participants' comments, the majority of which came from the group for persons with disabilities. This code is reflected in the second main theme, Addressing Needs, in both its sub-themes, Communication of needs, and Accommodation of needs, as well as in both sub-themes under the fourth theme, Access. In addition to the above, the presumed subordinate social ranking of persons with disabilities (e335) is evident in the three sub-themes, Conformity, Belonging and Reciprocity (Social Status), which was perceived to determine the level of support provided to persons with disabilities and the types of relationships cultivated with them. Moreover, the provision of personal care to persons with disabilities by staff and volunteers in the congregation (e340) is covered in the sub-theme, Access to necessary resources (Access), where supports such as assistance for wheelchair users and volunteers in the children's ministry were highlighted as lacking.

Environmental codes related to *Attitudes* covered in the fourth chapter, were perceived as barriers to participation, and linked to both the Conformity sub-theme (Social Status), and the sub-theme, Social constructions of disability, within the third main theme, Awareness and Understanding, where congregants' stereotypical views of disability (e425), and the misconceptions of certain disabilities among church leaders (e430) were attributed to a lack of disability awareness and erroneous understandings, including misconstrued theological beliefs about disability. Most prominently, the reported negative societal attitudes (e460) exhibited by congregants, and especially the social pressures exerted to fit in with norms considered

acceptable in their congregation (e465), were perceived to influence the attendance and participation of persons with disabilities adversely.

In the fifth and final chapter, *Services, systems and policies*, the environmental code covering aspects related to architecture and construction services and programmes for the design, construction and maintenance of public buildings (e5150), was captured by the sub-theme, Accessibility of the physical environment (Access), where all the participants described how the related services provided by their congregation imposed barriers to persons with disabilities, despite previous attempts at affording facilitators. In addition, the lack of transportation services to lift persons with disabilities (including the elderly) to and from church (e5400), was attributed to the lack of volunteers to fulfil such roles, and was represented in the sub-theme, Access to necessary resources (Access). Finally, the reported unsuitable services and programmes provided in children's church and Bible studies (e5550) were addressed as barriers to the participation of persons with disabilities in the sub-themes, Conformity (Social Status) and Accommodation of needs (Addressing Needs).

### 4.5 Conclusion

In fulfilment of the study's main and sub-aims, this chapter presented the findings from three separate focus groups for participants with disabilities, caregivers of persons with disabilities, and church leaders, regarding the barriers and facilitators to the participation of persons with disabilities in ceremonies, activities and events in their congregation. Four emergent themes, with nine sub-themes, were developed from the verbatim transcriptions of the participants' responses, and described in detail before the links between the themes and the corresponding ICF Environmental Factors were shown. Environmental codes from all five chapters were represented in all the themes. In the next chapter, these findings will be interpreted and discussed with reference to the relevant literature.

# CHAPTER 5
# DISCUSSION

## 5.1 Introduction

In Chapter 4, the research results were presented in descriptive themes, which were correspondingly linked to the applicable environmental codes of the ICF. Chapter 5 provides a synopsis of the results and focuses on the significance of the findings in relation to the relevant literature in a broad systems thinking approach. Initiating the discussion, the ICF's multi-dimensional framework for describing the process of participation of persons with disabilities in a specific activity, is applied in the congregation used as a case study in the research. This is followed by a social deconstruction of disability, after which disability is described from a systems thinking perspective, which provided the theoretical framework for the study. The focus is thus on the shift from viewing persons with disabilities as *'apart from'*, to *'a part of'* the body of Christ, from inclusion, to belonging and participation, from being *'with'*, not doing *'for'* or *'to'* persons with disabilities and from planning *'with'*, not *'for'* persons with disabilities, as well as breaking down walls, instead of building ramps. Finally, a concluding summary draws the chapter to a close.

## 5. 2 Overview of results

Addressing the research question, the main aim of this study was to determine the perceptions of a triadic participant group, consisting of persons with disabilities, primary caregivers of persons with disabilities, and church leaders, regarding barriers and facilitators to the participation of persons with disabilities in the ceremonies, activities and events that occur at a particular Methodist congregation. Given the trustworthiness of the findings, this study verifies and contributes to the growing body of evidence confirming the immense impact of systemic factors on persons with disabilities' own functioning, societal participation and quality of life, as well as that of their primary caregivers and families, be it in relation to the disability-related supports received, or the lack thereof (Erasmus et al., 2016; Kazou, 2017; Light & McNaughton, 2015; McDaniel & Pisani, 2012; McDougall et al., 2010; Schlebusch, Dada, & Samuels, 2017; Vernhet et al., 2019; Walsh, 2012). The results of the current study corroborate

the latter outcome, where the perceptions of all the participants culminated in the collective observation that their congregation does not yet reflect disability inclusivity that would enable participation and make persons with disabilities and their families feel welcome and accepted.

Four main themes, with a total of nine sub-themes, were identified. The overarching theme, *Social Status*, covered perceptions about the perceived worth of persons with disabilities as contingent on their conformity to the norms within of their congregation, their perceived membership, as well as their perceived benefit to their congregation. The second theme, *Addressing Needs*, included perceptions regarding the ownership for uncovering and accommodating the needs of persons with disabilities. The third theme, *Awareness and Understanding*, dealt with perceived stereotypes and misconstrued notions about disability, as well as the need for raising awareness through education. *Access*, the fourth theme, included perceptions concerning the accessibility of the congregation's physical environment, as well as access to necessary resources to enable the participation of persons with disabilities. The participants' perceptions captured in these emergent themes were associated with profuse hindrances that they considered to obstruct the participation of persons with disabilities in their congregation.

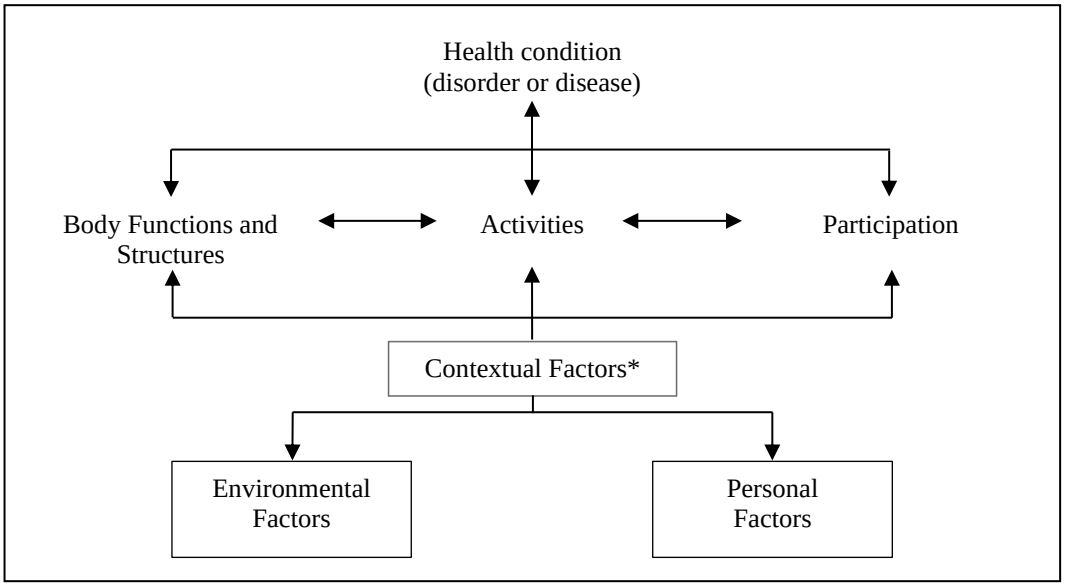
Before interpreting the results in relation to the existing body of knowledge, it is first necessary to reflect on the meaning of the findings as they connect with the ICF, so as to appraise its adoption as a theoretical framework for the study.

### 5.3 The ICF framework of functioning and disability

One of the sub-aims of the study was to explore if the triadic participant groups' perceptions concerning barriers and facilitators to the participation of persons with disabilities in the congregation described in the study, can be linked to the contextual factors described in the ICF. All the relevant environmental factors represented in the participants' perceptions were connected orderly, linking 27 environmental codes with the data, and in turn connecting the four emergent themes with codes in all five chapters of the Environmental Factors component of the ICF. Although the extent to which the environmental codes were perceived as barriers or facilitators was not determined, the significance of the results is in the finding that *no* facilitators were identified in the participants' responses, either owing to the absence, or inadequacy of enabling features in the congregation's environment (WHO, 2001).

Using the ICF as a framework for describing the process of functioning and disability within this faith-based system, the findings provided sufficient evidence to suggest that the physical, social and attitudinal environment of the congregation have a prevailing hindering impact on the participation and functioning of persons with disabilities, their caregivers and families – to the degree of imposing disability on them. The results also reiterate the findings of other research motioning the need for an increased shift in conceptualising disability and functioning holistically, that is, as a dynamic interaction between the health conditions of persons with disabilities and their unique contexts, so that the disabling factors in their environment can be addressed and their participation ameliorated (Leshota, 2015; Möller, 2012; Welch Saleeby, 2016b; WHO, 2001).

While a theoretical description of the ICF framework was outlined in a review of the literature in Chapter 2, this chapter presents an application of this multi-dimensional framework to the results of the current study, where a closer look is given to the interaction among the various components of the ICF to help explore how disability is caused and maintained in this congregation. First, a conceptual map of the multi-directional process of classifying functioning and disability is provided in Figure 5.1.




* Diagram box added

Figure 5.1 *Interactions between the components of the ICF* (WHO, 2001, p. 18)

Figure 5.1 demonstrates the interrelational dynamic between the various components of the ICF. Without repeating explanations covered in the literature review, it is necessary to recollect a few important considerations here. In this framework, functioning and disability are understood as interactionist constructs, in that both result from the interplay among the various components illustrated above, the end product being greater than the sum of the individual and societal contributions made toward either functioning or disability (Bartlett et al., 2006). It is also important to bear in mind that functioning and disability are in turn influenced and altered by an individual's unique context, which involves internal factors (personal characteristics independent of the health condition), and external factors (environmental factors, including physical, social and attitudinal features of the environment), as well as by the interaction among these components (Bartlett et al., 2006; Welch Saleeby, 2016a; WHO, 2001), which, taken together, constitutes an individual's lived experience of health (McDougall et al., 2010).

Positioning this multi-perspective framework within the context of the current study, the *functioning* of persons with disabilities in their congregation would have been achieved if there was a positive outcome arising from the interaction among their body functions and structures (physiological and psychological functions, and anatomical integrity), activities (execution of tasks or actions), and participation (involvement in a life situation). Ultimately, the environment of this congregation has produced the opposite effect for persons with disabilities, where *disability*, the negative outcome flowing from the interaction among their impairments (problems with body functions and structures related to health conditions), activity limitations (difficulties executing activities), and participation restrictions (problems related to involvement in life situations), has become the end product. Since this framework recognises that the occurrence of disability often starts with a health condition leading to impairments, which are perpetually influenced by contextual factors that subsequently contribute to activity limitations and participation restrictions, the occurrence of disability in persons with disabilities in the context of this congregation is thus understood to have resulted from the dynamic interplay between their health conditions and hindering environmental factors (Welch Saleeby, 2016b; WHO, 2001).

Among the participants' responses, examples of a wide range of impairment of body functions and structures that interact with all the abovementioned components included depression, anxiety, hearing impairment, deafness, visual impairment, blindness, dyslexia, speech impairment, epilepsy, Parkinson's disease, Down's syndrome, autism spectrum disorder,

cerebral palsy, albinism and physical deformities as a result of burns or polio. Additionally, several references were made to mobility difficulties and moderate to severe physical and intellectual disability. Concerning the social and built environments in churches, Swinton (2011), concurring with views held in the ICF (WHO, 2001), emphasises that it is not the health conditions of individuals (e.g. mobility limitations, blindness, or deafness, etc.), that cause disability and participation restrictions, since these impairments may not at all produce disability in a different environment. He illustrates that using a wheelchair or being blind only limits one's participation if the built environment is constructed based on assumptions that everyone is physically mobile and able to see. Similarly, deafness is only disabling if there is no provision of assistive devices or sign language in a given environment.

Unequivocally congruent with the above understanding, the findings of this study highlight that constraints on the participation of persons with disabilities in this congregation do not directly relate to their impairments per se. Moreover, although still applicable, it is not primarily the observable built environment or absence of assistive devices in Swinton's earlier examples that hinder the participation of persons with disabilities in the current study. Rather, the most prominent barriers are situated in the invisible social spheres of this congregation, as evidenced in the noteworthy connections between the ICF environmental factors and the participants' responses relating to the categories, *Support and relationships* (Chapter 3), and *Attitudes* (Chapter 4). These strong connections accentuate that it is predominantly perceptions of the church leadership's alleged lack of support (e330), the congregation's apparent preconceptions and negative reactions to their impairments (e460), and the seeming uncompromising normative structures sensed within their congregation (e465), that cause the affected individuals to become disabled, and ultimately excluded from participation. The definition of participation in the ICF *"…brings in the concept of involvement…"*, which incorporates *"…taking part, being included or engaged in an area of life, being accepted, or having access to needed resources"* (WHO, 2001, p. 15). The results of the study yielded numerous examples of the ongoing challenges specifically inflicted by the external contextual factors (environmental factors) that impose limitations on the participation of persons with disabilities in the identified activities of the congregation – in every sense denoted by the above definition.

Examples of the ceremonies, activities and events occurring at their congregation, as listed by the participants, included rites and ceremonies (confirmations, weddings and funerals), sacraments (Baptism and Communion), regular weekly services for children, youth and adults, and liturgical services (Christmas and Easter). Additional engagements that were mentioned, related to activities concerning spiritual formation through Bible study and prayer groups, seminars and conferences, pastoral care and community outreach ministries, as well as recreational and fund-raising events.

Seeing that until now only environmental factors have received attention in the analysis and interpretation of the results, an important note should be made concerning the contextual factors included in the ICF, which has been inserted in Figure 5.1 as an additional diagram box to show its position among the other interactive components. While the Contextual Factors component of the ICF consists of both personal and environmental factors, only environmental factors are classified and coded, whereas the set of personal factors remain unclassified, owing to the wide global social and cultural variability associated with them (WHO, 2001). Personal factors consist of variables such as age, gender, race, social background and education, and represent the person's individuality and the context of their lives. Although Müller and Geyh (2015) consider personal factors relevant and helpful in enriching the understanding of disability, as well as functioning and health for the improvement of services and interventions for persons with disabilities, they also warn about the potential for a counterproductive outcome, where personal factors can be misused against persons with disabilities in a discriminatory manner. This poses serious ethical concerns. Therefore, no health information from the participants' responses were linked to any personal factors.

Since personal factors are intrinsic to the individual, there is a great risk of *"blaming the victim"* (Simeonsson et al., 2014, p. 2192) by labelling and stigmatising persons with disabilities, and saddling the responsibility of disability onto them (Müller & Geyh, 2015). Such documentation of personal attributes are incompatible with the biopsychosocial model of disability upon which the ICF is built, and more fitting to the medical model, which locates disability within the individual (Berghs et al., 2016). It is also counterintuitive to the purpose of a classification system such as the ICF, which aims at objectively classifying the characteristics of health and functioning of people, rather than classifying people themselves (Müller & Geyh, 2015; Simeonsson et al., 2014; WHO, 2001). Even though Cieza et al. (2019) make provision to

connect health information to personal factors in rule number nine of the latest refinements of the ICF linking rules, Simeonsson et al. (2014) caution against this usage, warning of a number of reasons why personal factors, as currently presented in the ICF, should not at all be applied. These reasons include the absence of a formal definition or specific purpose for the use of personal factors, and the lack of inclusion or exclusion criteria and guidelines for its application. Furthermore, there are conceptual and taxonomic challenges, given that personal factors do not meet the standards for classification in the same way the environmental factors meet the requirements as a component in a scientific taxonomy (Müller & Geyh, 2015; Simeonsson et al., 2014).

Given the exclusion of personal factors from the results for the reasons given above, the findings of the current study strongly corroborate Swinton's (2011) stance that disability is indeed a social construct, localising the problem of disability *outside* persons with disabilities in this faith community but *in* the environment of their congregation (Lawson & Priestly, 2017), which, through failures to create ability among those who do not fit the physical, mental and social profile of their typical non-disabled congregants (Wendell, 1996), have excluded persons with disabilities from participating in this crucial area of life (Edwards et al., 2016; Koenig, 2012). From this vantage point, which strongly contrasts the medical model's conceptualisation of disability as a personal tragedy (Retief & Letšosa, 2018), the study's findings instead recognise the significant interplay of the various systems processes, and present disability among those who live with the aforementioned impairments as a social situation created by their congregation, where their experience of disability is produced by social forces (Swinton, 2011), and not by their impairments.

Despite the problematic aspects in the ICF concerning constructs related to personal factors, the applicability of the classification of the environmental codes and categories were demonstrably advantages, as it made it possible to document all the relevant environmental factors represented in the participants' perceptions in a structured manner. While the results of this case study cannot be generalised (Qi, 2009), the numerous compelling connections between the participants' responses and the ICF's environmental codes, validate the comprehensiveness and universality of the ICF, and its suitability as a theoretical framework for understanding the causes and consequences of disability on the functioning of persons with disabilities, not only in

the faith-based setting of the current study, but also across any given context and discipline (Welch Saleeby, 2016a).

The focus on the nature of the environmental factors in this study also highlights the importance for the occurrence of disability and societal attitudes toward persons with disabilities to be addressed as human rights issues (Erasmus et al., 2016; Hurst, 2003), and can help to initiate the development of interventions to create facilitators, alleviate or eradicate barriers to functioning and participation, and ultimately produce social change. Notwithstanding the need for revision of the ICF's inclusion and application of personal factors (Simeonsson et al., 2014), it is this extensive applicatory potential of the ICF that has earned its endorsement by the World Health Organisation and the World Bank in the World Report on Disability (Welch Saleeby, 2016b; WHO & World Bank, 2011), making it a reliable tool for understanding the outcome of functioning and disability on the health of persons with disabilities in the congregation of this study (McDougall et al., 2010).

## 5.4 Social deconstruction of disability

Considering the lessons learned from discussing the results and its implications specifically in relation to the ICF, the subsequent segment of the discussion focuses more generally on the findings concerning the emergent themes in comparison to the relevant literature and includes observations and considerations pertinent to the congregation of the study from a broader systems perspective. Since the results suggest that the main barriers are positioned within the social and attitudinal spheres of the environment of this congregation, and that disability transverses other contexts as a social construct, Wendell (1996) recommends that, given the appropriate means, social constructions should be socially deconstructed.

One such means is by employing the principles of *systems thinking* (Cabrera et al., 2008), which is described in more detail in section 5.5. In essence, systems thinking is the application of systems theory discussed in Chapter 2. Firstly though, in review of the emergent themes, a thematic map is presented in Figure 5.2, which shows the relationship among the themes and indicate how certain abstract conceptual models of thought have found concretisation in the congregation.

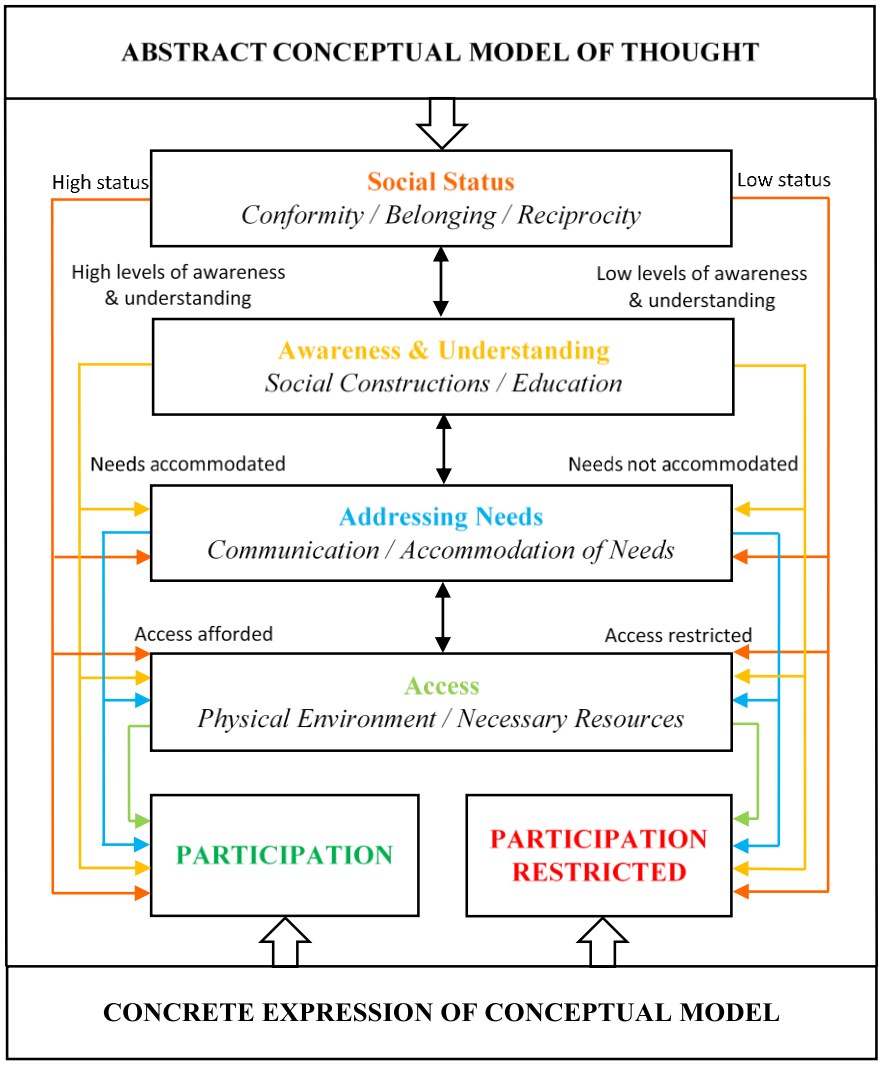



Figure 5.2 *Thematic map of emergent themes*

Figure 5.2 shows how the extent to which needs are perceived and addressed, and accessibility and participation enabled, are tangible expressions of the conceptual thought models espoused within this faith-based system, where, in essence, it is distorted worldviews that have led to the exclusion of persons with disabilities. The results further revealed that persons with disabilities have basic needs that must be met before their participation in their congregation's various activities can be possible. To achieve this, increased awareness and accurate understanding of disability is required so as to fully appreciate and fulfil these needs, some of which involve practical, observable affordances, such as creating access to the physical environment and necessary resources, while, on a more complex and covert level, exists the most

pressing need for a sense of belonging to a faith community, where persons with disabilities are recognised as equal to non-disabled members in respect of their value and the contributions they have to share. However, unless some drastic change in awareness occurs at a heart and mind level, it appears that the manner in which these needs will continue to be addressed, relates to the status bestowed upon persons with disabilities, which is influenced by negative attitudes and ideologies concerning social norms for appearance and behaviours upheld by the congregation.

Drawing attention to the underlying systems processes at work in this congregation, the diagram in Figure 5.2 does not illustrate the themes in the order in which they were presented in the results chapter, but rather in relation to the levels of thinking evident in the perceptions of the three participant groups of this study. If the changes they deem necessary are to occur within their congregation, there is a need to change the way they think. While changing the way everyone involved thinks will not spontaneously resolve the issues they face, changed thoughts will nevertheless reframe how they think about the identified barriers and what the best solutions may be (Cabrera et al., 2008).

To simplify the interpretation of the results, it might be helpful to engage with a generic framework for understanding problems at a deeper level by looking at a method informed by a *systems thinking* approach consisting of four levels of thought (Maani & Cavana, 2007), which is presented in Figure 5.3.

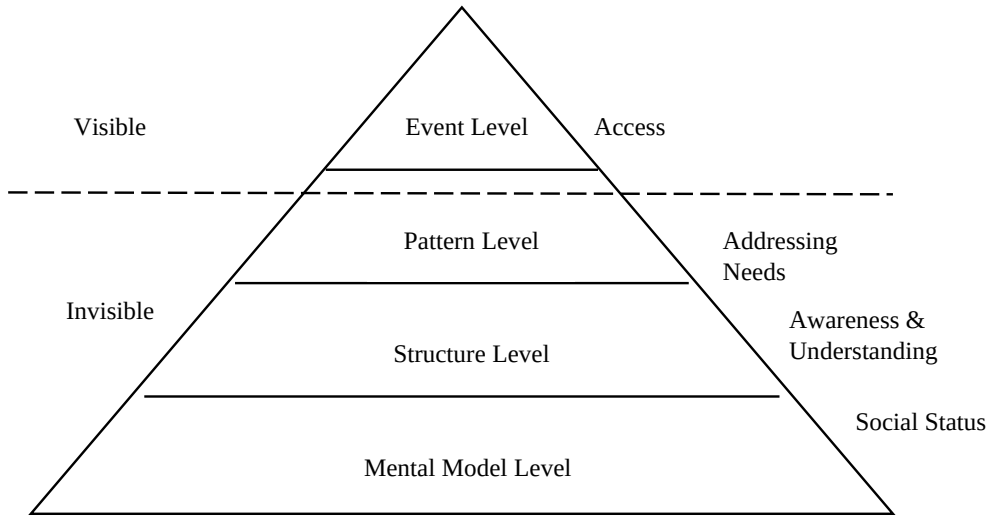



Figure 5.3 *Levels of thought revealed in themes*

Figure 5.3 depicts the four-level nature of the thought patterns present in the participants' themed perceptions and is easily understood by the analogy of an iceberg. Using Sheffield, Sankaran and Haslett's (2012) conceptualisation, the first level of thought encompasses the recognition of *events*, the visible tip of the iceberg, which is captured in the participants' suggestions for practical problems to be solved. These observable, everyday issues that routinely prevent the participation of persons with disabilities in the activities at their congregation, such as barriers concerning the accessibility of the physical environment and resources to enable such involvement, are demonstrated by the participants' responses organised in the theme, Access. When 'problems' are viewed at this level, solutions tend to be reactive and rash, rather than considered responses that adequately address the issues at hand, since the concealed thought processes that influence and sustain the events are not identified, understood and changed (Maani & Cavana, 2007).

Further down, partly visible and partly hidden from view, lies the *pattern* level, which involves the history of the enduring recurrence of the aforementioned events. Given that the affordances that facilitate the participation of persons with disabilities remain inadequate owing to the sustained gaps in the communication and accommodation of their needs, the barriers experienced tend to continue repeatedly over time, as depicted in the theme, Addressing Needs.

At the submerged *structure* level are the non-linear feedback loops (Laszlo et al., 1974), or causal relationships between the patterns, concealing the systemic structures that create and uphold the observed patterns and events. Since relationships are unseen, people seldom engage with thoughts at this level, which was evident in the theme, Awareness and Understanding, where stereotypes and ignorance were uncovered as barriers. Most hidden, underneath the events, patterns and structures that produce and perpetuate the tangible barriers, rest the embedded mental models that keep the existing social structures in place. These are the worldviews, feelings and motivations that affect actions and decisions (Maani & Cavana, 2007; Sheffield et al., 2012), as captured in the theme, Social Status.

In the same way that new wine cannot be poured into old wineskins without ruining the wine and the skins (Luke 5: 37-38), new events and patterns cannot rise from the substance of the same old rigid typecasts and worldviews that created the barriers in the first place, without corrupting persons with disabilities and their caregivers. Vital for the health of this congregation, is that, through faith in God and holding fast to the teachings of Jesus, these buried

glaciers are resolutely moved, keeled over and brought to the light, so that the truth is known and everyone involved set free (Mark 11:22-24; John 8: 31-32) from the differences in mind and heart that divide the body of Christ.

**5.5 Disability: A systems thinking perspective**

It is thus preeminently the unwavering flawed conceptual models regarding disability in this congregation that need to change before persons with disabilities' needs are addressed and their participation enabled. Informed by the theoretical underpinnings of systems theory, the themed results of the study have been subjected to the principles of systems thinking, seeing that the congregation of the study is enmeshed in many systems, and therefore needs to be understood according to its interrelated system processes (Gregory, 2012). This approach provides a practical means for analysing, understanding, and ultimately, changing complex systems (Cabrera et al., 2008).

Accordingly, beneath the concept of systems thinking lie four rules or principles universal to human thought, representing four cognitive functions as a problem-solving algorithm to form fresh ideas and renewed understandings. These principles, which go by the initialism, DSRP, involve distinctions, systems, relationships and perspectives, where *distinctions* can be made between and among people and concepts, people and concepts can be organised into *systems* (where both parts and wholes can be distinguished), *relationships* are formed between people and concepts, and people and concepts can be viewed from the *perspectives* of other people and concepts (Cabrera et al., 2015). Making distinctions involves boundaries that differentiate between who is *in* and who is *outside* the set boundary, and given the distinction between the two parties, there must be some relationship between them, even if it is only the relation of being distinct from one another. Any group of interrelated people or concepts are naturally viewed as a system, since a system is defined as a whole made up of two or more related parts. In addition, people and concepts carry with them a perspective, or frame of reference, which distinguishes between the point from which something is viewed and that which is viewed (Cabrera et al., 2008).

Since making distinctions and gaining awareness of systems, relationships and perspectives are interconnected and co-occur simultaneously, these principles are not reviewed individually or consecutively in separate sections in this chapter, but instead interweaved with

the discussion to demonstrate its application. While it is important to remember that ideas (thoughts and concepts) constantly develop in cognitive systems like the human mind, concurrently changing in response to other concepts by linking, conflicting, or coexisting with them, human minds are not only responsible for cognitions (Cabrera et al., 2015). They also process feelings, and motives along with thoughts, with a definitive link between affect, cognition and motivations for behaviours (Decety & Yoder, 2016), each of these systematically influencing and reinforcing the other. It is not surprising then that the three participant groups' perceptions were emotionally charged and loaded with affective nuances that revealed how their feelings toward their circumstances impact and maintain their respective perspectives. Awareness of one's own thinking, or metacognition, including one's own feelings, encourages the balance between the needs of the self and the other, and increases empathy and understanding, as well as interpersonal awareness, which promotes introspection and prosocial behaviours (Bogdan, 2017; Cabrera et al., 2015).

The results suggest that these levels of awareness have not occurred for all the participants of this study. While such introspection toward a prosocial approach was to some extent noted in the perceptions of the caregiver participant group, this was not the case for the groups for persons with disabilities and church leaders, who each seemed to view the reasons for unmet needs only in respect of their own frames of reference. One-sided perspectives like these blind side people and are not helpful, as it only observes the situation at hand from a single vantage point (Bogdan, 2017). A systems perspective, however, allows for all other viewpoints to be considered and greater levels of understanding to be achieved (Cabrera et al., 2015), but this can happen only *"when first you see the world through the eyes of another"* (Churchman, 1968, p. 231). Accordingly, granted an awareness of the interrelating factors (relationships) that created the existing barriers in this congregation, any potential blaming of each other is soon replaced with understanding of why or how each stakeholder has interacted as part of their wider systems, giving meaning to reason they acted (or not) in the way they did (Cabrera et al., 2015).

Having a bird's eye view of the situation (perspectives), it is clear to see the church leader participants' genuine lack of knowledge about the needs of persons with disabilities and their caregivers in their congregation, and likewise, the participants with disabilities' and caregivers' lack of awareness of the church leaders' predicament. One of the reasons offered in the literature as to why neither persons with disabilities nor their caregivers voluntarily

communicate their needs, is that they are prone to use avoidance behaviours (Krypotos, Effting, Kindt, & Beckers, 2015) as a coping strategy. This is as a result of their past experiences of strained relationships with family and friends after the announcement of the disability, and therefore they find it difficult to reach out for support to people even further removed (Vernhet et al., 2019), such as the church leadership and other congregants. While it is important for persons with disabilities and caregivers to develop agency and speak out about their needs, desires and preferences (Gurbai, 2014), it is also important that the church leaders are aware of possible avoidant behaviours to enable them to reach out to persons with disabilities and caregivers, instead of waiting on them to come forward by themselves. In order for this awareness to occur, it will be necessary for persons with disabilities, caregivers of persons with disabilities, and church leaders to develop face-to-face relationships characterised by empathy and interdependence (Armistead, 2006) where fruitful dialogues can be had to jointly identify the areas where action is needed most in their congregation (Carter, Bumble, Griffin, & Curcio, 2017).

### *5.5.1 Many parts but one Body*

Revealed by the results of the current study, an area needing urgent attention relates to the subconscious polarised thought processes existing in the perceptions of the participants with disabilities and church leaders, which suggests the presence of division, in that these two groups seem to lack a sense of solidarity between them. Accordingly, both the participants with disabilities and the church leader participants appear to have divided themselves into *us-them* identities (White, 2014), with persons with disabilities in one camp, and the church leaders in the other, juxtaposing *them*, who are different, against *us*, who are not different (Meininger, 2008), and vice versa, where persons with disabilities seemed to view the congregation's leadership as the opposing 'other' (distinctions) (Cabrera et al., 2015).

While there is a tendency in many Christian congregations for persons with disabilities to become the 'other' through discriminating acts against them and their families (Gaventa, 2012), much is recorded in Scripture concerning additional reasons for such divisions in the Body, as well as the solutions toward oneness. For example, 1 Corinthians 1:10-17, 1 Corinthians 3:1-23 and 1 Cor 12:12-31 (New International Version) show that union among Christians require joint efforts by everyone involved in the congregation, where the obligation for ensuring unity rests on

all its members, including persons with disabilities as a part thereof, whether or not they view themselves as such. This also applies to the caregiver participants, who need to learn well-adjusted ways to face uncomfortable encounters, instead of developing a tendency to avoid challenges (Vernhet et al., 2019).

The results also suggest that the participants in the groups for persons with disabilities and caregivers may at times possibly consider themselves helpless, and as a result become passive in the face of their challenges, turning into *"victims of their impairment"* (Retief & Letšosa, 2018, p. 6) as it were. However, unless they become aware of this mindset, they will be complicit in perpetuating the conceptualisations of individual models, such as the pre-modern charity model, and subsequent medical model of disability, conceiving disability as victimhood (Creamer, 2012; Retief & Letšosa, 2018). For true inclusion, belonging and participation to occur, it is crucial that this us-them mentality changes, where everyone, including persons with disabilities, primary caregivers and church leaders, shift their perspectives from viewing persons with disabilities as 'apart from', to 'a part of' their faith community (Gaventa, 2012), in which they recognise one another as equal members of their part-whole faith system, the body of Christ (Brock, 2011). With such an understanding, each member will know their worth and value based on what God says about them – not people, which will empower them to each fulfill their own unique function in their Body.

It is thus people in the church who have divided themselves along these separating lines, not God. Applying systems thinking principles to this dilemma in the congregation of the current study demonstrates how such categorisations of people are in fact part-whole groupings from a particular perspective, rather than real-world distinctions (Cabrera et al., 2015). However, concerning the body of Christ in society, there are indeed distinctions among people. Nevertheless, these are between the church and the rest of the world, and not between believers (with or without disabilities) *inside* the church, as there is no theological discrepancy between persons with and persons without disability, who both belong to one and the same body of Christ (White, 2014).

If Christians had any doubts about who is *in* and who is *out*, scripture is clear about the fact that *"…all have sinned and fall short of the glory of God, and are justified freely by his grace through the redemption that came by Christ Jesus"* (Romans 3:23). All people are thus in the same position, as God's focus on distinctions is between believers and non-believers, and *not*

on inconsequential, irrelevant dissimilarities between persons with disabilities and those without. God's emphasis on otherness is on those who belong to His Body and those who do not. In other words, those who have been grafted into the Vine (John 15:4; Romans 11:11-32) and became part of Christ's body and has life, and those who turn away from Christ, having no part of the body, and therefore no life (1 John 5:12). Although it has always been God's plan for the church to transform society, the world's distorted views of humanity have woefully infiltrated the church, negating its sanctifying purpose (Pillay, 2017).

Evident in the findings of this study, there seems to be perceptions revealing that all the participants have in some way or another closed their eyes to viewpoints (perspectives) other than their own, holding onto convictions to the point where no other alternatives, including God's worldview of His corporate people are contemplated. While people use disability to create distinctions among one another to divide, God's original plan intended for His people is to live and function as one, unified body, where all the different parts love and care for each other (1 Corinthians 12: 24-27) to fulfil His original cosmic purpose for believers to be an example to the rest of the unbelieving world so as to draw them into His love and fellowship, so that, as His Body is meant to be whole (many parts but one Body), they too could be part of His Body and become whole (Brock, 2011). As sin has damaged God's image in all human beings bearing His likeness, the image of God will thus be distorted when the church is perceived consisting of splinter parts, not belonging to the one another. Only when *all* people, including persons with disabilities, are viewed as part of one Body (systems), will God's image be redefined and restored in His church, where each Body part is affirmed for what they uniquely have to offer to the total image of God (Swinton, 2001). Such is the image of the church as an interconnected and interdependent Body (systems/relationships) that will indeed be a transformative agent (Pillay, 2017) in its distinction from wider society (White, 2014).

### *5.5.2 From inclusion to belonging and participation*

Another critical area for change pertains to the church leaders' understanding regarding the meaning of participation. Participants from this group expressed their awareness of many persons with disabilities in the surrounding community, who do not have any means to get to church. The church leaders subsequently planned solutions to the transportation difficulties faced by individuals with disabilities. In these instances, the focus was solely on lifting persons

with disabilities to and from church. During their discussion, the church leader participants' dialog seemed to be predominated by ideas of disability and inclusion in terms of severe physical and intellectual impairment, evidenced by the numerous references made to the residents of a nearby disability care centre, none of whom participated in the study. Except for two participants in the group for persons with disabilities, the church leaders did not indicate any awareness of the other persons with disabilities who participated in the study, nor of any other members of the congregation. This might explain why the participants with disabilities expressed that their needs are overlooked in this congregation. Going unnoticed seems to relate to visible versus invisible disabilities, where the severity of disabilities that remain unseen, appear to be underplayed and ultimately neglected. It is often this invisibility that leads to exclusion (Baraza, 2017).

There seems to be the presumption (perspectives) by the church leader participants, that, if individuals are able to *attend* church services – as is the case for all the study's participants with disabilities – their participation is not restricted after all. However, the participants with disabilities all shared many ways in which their participation is indeed hindered. At this structure level of thought in the church leaders' perceptions, there appeared to be an assumption that inclusion, belonging and participation are synonymous, and that participation is single-handedly achieved through church attendance. Echoing Swinton's (2012) supplication that *"inclusion is not enough"* (p. 182), there is a need for the church leaderships' thinking to move *"away from the idea of inclusion and towards the experience of belonging"* (Swinton, 2012, p. 182), where true belonging means that persons with disabilities are known and missed when they are not at church. If persons with disabilities are seen as the 'other' or placed in the 'out-group' (distinctions), the church leaders will not recognise their need for belonging as they experience it, nor will they understand what true participation means as the ICF defines it. If participation is envisioned purely from an inclusion angle (perspectives), it can be expected that the church leaders may fail to consider the indispensable deeper relational aspects of cultivating authentic friendships (relationships) through acceptance, mutual social exchanges and interdependence, which constitutes participation through fellowship at the heart of belonging (Leshota, 2015).

The participants with disabilities, as well as the caregivers appeared to wrestle with their apparent attributed value as signified by their forgotten status. They expressed that, if they were indeed deemed part of this Body (systems), they would not have to campaign for their needs all

the time, as they would be regarded as important and accordingly accommodated in the first place. As recorded in the participant descriptions in Chapter 3, considering the length of time most of these participants have been attending this congregation, as well as their reported efforts to communicate their needs, it is no surprise that they would expect certain basic support structures to be in place by now. Consistent with Hauerwas' (2000) sentiments, this study confirms that the deepest suffering that persons with disabilities and their families endure is typically caused by feelings of being excluded, unloved and worthless – a misery that can only be healed through loving relationships in close communion, where persons with disabilities can experience that they are loved and thus lovable, that they have inestimable value, and that their contributions are indeed needed and welcomed by the rest of the Body. It is important, however, to remember that the value of persons with disabilities is inherently bestowed upon them by the One whose image they bear and is thus not contingent on the contributions they make. Therefore, this worth is unalterable, even if they cannot, or choose not to, contribute something to the benefit of others (Anderson, 2015).

Without any mention of adults with disability, both the caregiver and church leader participants included their opinions on the necessity of accommodating children with disabilities through the provision of a specialised assistant, skilled in the recognition and service of special needs. Previous attempts at disability accommodation in this congregation barred inclusion and participation during family services, since persons with disabilities and their caregivers were removed from the rest of the congregation. The presumption of discomfort and personal choice for isolation on the part of the caregiver or the person with a disability frequently resurfaced during the church leaders' discussion and may in fact be projections of their and the congregants' own true feelings about the presence and behaviours of persons with disabilities in their midst. However, in their respective further discussions on this topic, the perceived impact that this type of situation may have on the parents, both during children's and family services, were viewed very differently. Where the caregiver participants perceived parents and caregivers in these circumstances to feel misunderstood, judged and unsupported, the church leader participants perceived the likely feeling to be one of being a nuisance to the congregation. Contrastingly, informed by their own experiences as parents or caregivers, the caregiver participants did not perceive themselves or the persons in their care as a burden to the congregation, but rather burdened by the congregation, who appears to lack awareness and understanding of their

situations and their need for consideration and unconditional acceptance.

This study highlights how views with misconstrued assumptions (perspectives) about persons with disabilities, their caregivers and families, have regrettably led to the non-participation of families in church-related activities. This is sad, since research underscores the positive care structures that religious supports can and should be the lives of families with children with disabilities (Prendeville & Kinsella, 2019). Since caregivers and parents of children with disabilities do not receive adequate support from society, it is imperative for the church to intervene (White, 2014). As important as this is, such intervention should not be limited to children and their families only. Confirmed in the caregiver and church leaders participants' focus on supporting children, recent research on the participation of persons with disabilities in their faith communities shows that congregations generally give more attention to younger children, than to adolescents and adults concerning their accommodation and inclusion (Carter et al., 2017). In order to honour their equal right to inclusion and participation, it is important that the same level of support is extended to *all* persons with disabilities, children, youth and adults alike. However, none of the participants in the current study framed the inclusion and participation of persons with disabilities as a human right, or their exclusion as a breach thereof. South African mainline protestant churches, such as Methodist denominations, often hold more conservative belief systems compared to the liberal values and progressive acknowledgement and protection of human rights established in the country's constitution (Kotzé & Loubser, 2017). It is therefore possible that the current study's participants are not well-versed on the subject of human rights. In this regard, church leaders need to learn ways to become models of inclusion for persons with disabilities, and thereby also speak to issues concerning human rights and social justice for all (Creamer, 2012). However, if the church leaders in this case study do not recognise inclusion as a basic human right, moving toward belonging and participation might be a big ask.

### *5.5.3 'With' persons with disabilities, not 'for' or 'to'*

Frequently referring to their sense of duty toward persons with disabilities, the church leader participants implicitly unveiled the view of themselves and the wider congregation as charitable benefactors, coming to the aid of needy, dependent beneficiaries, in this instance, persons with disabilities and their caregivers. This view is consistent with that of the charity and

medical models of disability (Retief & Letšosa, 2018), where persons with disabilities are seen as reliant on the help of 'normal' people. While the participants from the focus groups for persons with disabilities and caregivers openly expressed their need for more meaningful connections, support and assistance, they did not seem to consider themselves as mere recipients, but instead as worthy contributors with the potential to make valuable impacts on their congregation, which is in contrast to the church leaders' viewpoint of persons with disabilities and caregivers being dependent on their and the congregation's goodwill. It is evident that the participant groups for persons with disabilities and caregivers viewed being part of the Body in a very different way from the church leaders, who seemed to think that they and the congregation should serve persons with disabilities, but did not consider it necessary being served *by* them. This is another reason why it is so important for persons with disabilities and caregivers to contribute actively toward their own visibility and inclusion, and claim their belonging to their own Body.

With ample references to a moral responsibility toward persons with disabilities that they and the rest of the congregants ought to share, the church leader participants conveyed their rendition of inclusion through encouraging among the congregants more acts of goodwill by doing things for persons with disabilities and their caregivers. Insinuating that persons with disabilities' purpose is solely linked with being helped is problematic, as such thinking does not recognise the need for, nor anticipate any reciprocity in relationships from persons with disabilities. It is also known that people typically act prosocially only toward those from whom they expect to receive some benefit in return. If it is in fact so that the church leaders and congregants do not expect anything in return from persons with disabilities, they may perhaps not be likely to act in ways that seek the benefit of persons with disabilities in the first place (Bogdan, 2017). This is a mindset that devalues persons with disabilities (White, 2014), which needs to change to an understanding of the importance of *being with* (relationships) persons with disabilities, instead of estimating whether or not to *do something for* them (Hauerwas, 2000). Ultimately, this implies the development of mutual relationships where all parties are equal, with no supposed benefit for one but not the other (Brock, 2011). As it is intended in the body of Christ, it is not about only one receiving from the other but instead both giving to and accepting gifts from each other, where every part offers different yet essential contributions to the whole (systems). The acts of giving and receiving are thus not mutually exclusive, given that the members of the Body all have different functions and different gifts that belong to all the others

(Romans 12:4-6). Participating in the functions of the Body is meant to be the collective ministry of each body part in turn to all the others (systems/relationships). Without this interchange among the different interconnected members of the Body, there is no cooperation among the body parts, which means that the Body cannot function effectively (1 Corinthians 12: 15-21). It is only through the willingness of the church leaders to look beyond (perspectives) the sociological and demographic assumptions (distinctions) attached to individual congregants, that they will be able to discern the necessity of receiving gifts from *all* the members of the congregation, including persons with disabilities (Brock, 2011). This involves more than the mere acceptance of their presence in the congregation; it means ministering *with* persons with disabilities, instead of *to* them (Yong, 2010).

Ironically, it was within the church leader group where the suggestion for disability representation in their leadership structure was hailed and supported. While leadership affiliation with disability appeared to be sincerely proposed as a participation facilitator with the well-being of persons with disabilities in mind, the motivation behind the way in which such a conceptualisation materialises may very well be one of tokenism. However, disability cannot be deconstructed by drawing on persons with disabilities as nominal representatives (Wendell, 1996). Unless the true meaning of communion, fellowship, belonging and participation (Leshota, 2015) is discovered and put into practice from the top down, presenting persons with disabilities to the congregation in this manner may depreciate them in a sheer symbolic act of inclusion. Awareness of this risk is important, especially since the transpiring beliefs beneath the church leaders' discourse throughout their discussion seemed to be shaped by a mentality that conceive of persons with disabilities as helpless, revealing the one-way benefit they anticipate to give in their interactions with persons with disabilities – acting benevolently on their behalf, but impervious to receiving in return anything deeper than the momentary satisfaction of doing a conscience-clearing good deed, or checking off duties on a to-do list.

### *5.5.4 Planning 'with', not 'for' persons with disabilities*

Regarding misconceptions about disability, the participants in all three focus groups recognised the need for raising disability awareness. Urging church leaders to be more active and outspoken against negative attitudes toward disability, and showing openness themselves by encouraging persons with disabilities' active involvement in all activities and ministries in the

church, White (2014) places the duty fully on church leaders to educate their congregations on accurate disability theology, since it is usually persons with disabilities and their families who are burdened by this task when they are often already overloaded with responsibilities.

Unified in their suggestions, complementing ideas to address the congregation on these matters were made by all three participant groups, not only as an avenue to increase disability awareness and understanding among the congregants, but also as a practical tool to communicate the needs of persons with disabilities. In this instance, the participants in each group adopted an approach of shared responsibility amongst them, with suggestions for disability awareness services led by the leadership, and testimonies volunteered by persons with disabilities and caregivers. This was the only time when an opportunity for collaboration among all the participants was recognised by them. Such opportunities for collaborative problem-solving should be sought and utilised to its fullest potential in order to develop a spirit of communion among all the stakeholders in the congregation to increase fellowship and open sharing among them (Leshota, 2015; Walsh, 2012).

However, in this congregation particularly, such a process may need to be mediated, since, throughout their discussion, the church leader participants had a tendency to immediately enter into solution modes of thought, making active plans for improvement in the areas they identified as barriers, without considering it necessary to first consult with the persons with disabilities and caregivers in their congregation to hear from them what their needs or preferences are, and how they wished it to be addressed. These reflex actions can thus be viewed as reactive, impulse-driven ‘problem-solving’ attempts occurring at the events level of thought, where persons with disabilities’ needs are viewed as problems to be solved. This outlook is ill-fated, since it was the persons with disabilities of this study themselves who expressed their wishes that the church leaders would simply ask them about their specific needs and wishes. Similar findings from other research (White, 2014) echo the experiences of persons with disabilities in their faith communities, which suggests that this level of thinking and resultant actions by church leaders is not an isolated incidence limited only to the congregation of the current study. It is thus vital that church leaders gain the insight to plan *with*, instead of plan *for* persons with disabilities and their families (Treloar, 2002), whether it involves something as small as arranging a lift to church, or as big as organising disability awareness campaigns. However, such collaborative problem-solving can only be achieved through open

communication where thoughts, feelings and needs can be shared safely by means of conversations (Carter et al., 2017; McDaniel & Pisani, 2012; Walsh, 2012) established in relationships that are free from differentiations (distinctions) between people based on their power and position within the church (Treloar, 2002).

Without hearing directly from those affected, that is, by making assumptions about their needs without truly understanding, the church leaders in the congregation of the study will perpetuate the longstanding identified barrier of a lack of awareness and understanding. Perhaps the best example of an area that received much one-sided problem-solving at this concrete level, is represented by the theme, Access.

### *5.5.5 Breaking down walls instead of building ramps*

As the starting point in each of the discussions, the participants from all three focus groups cited tangible features of their congregation that impede the participation of persons with disabilities, and urged the need for improvement of the accessibility of the physical surroundings, and necessary resources. While the participants from all three focus groups voiced the need for the improvement of the physical surroundings of their congregation, only the church leader participants included practical suggestions regarding going about these improvements, possibly because the persons with disabilities and caregivers did not really expect that anything could in fact be done about their situation. It is also possible that the participants in the groups for persons with disabilities and caregivers did not view these concrete obstacles as the most important changes to be made, as their main grievance was with the attitudes and lack of relational support they perceived from the church leadership and the rest of the congregation. While it remains crucial to address these practical barriers, without which many will continue to be excluded, the heartfelt plea that inspired a recent study, is resounded in the results of the current research: *"It is not about putting up ramps. It is about breaking down walls…"* (Fischer, 2018, p. 15) that are at times erected between persons with disabilities, their caregivers and families, and the congregation and its leadership.

The environmental spaces and the buildings within this congregation mirror and strengthen the nature of the societal views that shaped them (Karusseit & Gibberd, 2009). Given that the church campus has many buildings and rooms that can only be accessed by stairs, the participants concurred that the built structures and surrounding environment of their

congregation were not designed with disability in mind, nor modified and maintained to ensure accessibility. All the participant groups focused particularly on issues such as the poor quality (i.e. steep gradients) of the few existing ramps, which in fact turn their presence into barriers to access and even safety hazards. In line with suggestions for improvement made by the participants from all three focus groups, literature supports that providing better access to persons with disabilities will hold a number of benefits to the congregation of the study, as well as to other congregations, who face similar challenges, given that there are universal design principles that can be applied to create designed environments that work well for everyone, even in the widest range of situations, conditions and environments (Imrie, 2012). Under Article 2 of the CRPD (United Nations, 2006), universal design is described as the creation of environments, devices, services and programmes that are usable by all people, extending the greatest range of ability and impairment, without needing to specially adapt its design.

Accordingly, three important reflections, which go beyond disability accommodation itself, can be considered by this congregation. Firstly, several other people, apart from those with disabilities, will be able to benefit from the improvements in accessibility, such as older people and parents using the ramps for prams and strollers carrying their young children. Ultimately, as inferred by all the participants, such improvements will be a welcome invitation to persons with disabilities, as well as to other non-disabled individuals in the congregation's surrounding community who were previously unaccommodated. Secondly, since the prevalence of disability increases with age (WHO & World Bank, 2011), those who work toward improving accessibility now may themselves benefit from it later in life, thus focusing on long-term, future-oriented investments and not only on the immediate benefit for a perceived select few. Thirdly, with provisions made to the physical environment, the increased presence of persons with disabilities in the public sphere, such as the church, has benefits for those with and without disabilities (Gurbai, 2014; Leshota, 2015; LoBianco & Sheppard-Jones, 2007), as it promotes accurate knowledge of disability and an understanding of the reality of human limitations. It also reduces fears related to disability and becoming disabled, which is often aggravated by expectations and beliefs that impairment equals exclusion from major life areas (Wendell, 1996), such as attending and participating in church-related activities.

In summary, it is evident from the results that the participant groups for persons with disabilities and caregivers on the one hand, and the church leader participants on the other, have

noticeably different ideas about inclusion, participation and belonging, as well as the contributions persons with disabilities have to offer to their congregation. The results capture the sense that the participation of persons with disabilities in this congregation is restricted by their social ranking conferred on them based on their difference *(distinctions)*, governed by misguided beliefs *(perspectives)* that lead to relational transactions (*relationships)* that disable their opportunities for participation to varying degrees, thus excluding and severing them from their Body (*systems*) of which they are in reality an essential part (Cabrera et al., 2015). Rather than staring blindly into all the barriers they face, this congregation is in a particularly favourable position to enact exemplary social change, not only in its evangelical outreach to the unsaved but literally starting on its own doorstep in catering to the needs of all its members. Even so, this is only achievable if the church leadership (and everyone else involved), granted their willingness and openness to the truth, recognise persons with disabilities as indispensable members, and become sensitised to the high priority disability inclusion and participation ought to have in their congregation (White, 2014).

By uncovering the four levels of thought present in the perceptions of the three participant groups, and by applying Cabrera et al.'s (2015) DSRP principles to the emergent themes, it revealed the extent to which personal views are often amiss and in fact skewed mental models of reality, while it promoted awareness of:

a) the distinctions between who really *is* and who *is not* included in the body of Christ,
b) a different way to combine and recombine people (parts) into groups (wholes),
c) the true interrelatedness of human beings (the unity of the body of Christ), which facilitates belonging and increases awareness of the effect one person can have on another when ministering *with* and not just *to* persons with disabilities,
d) perspective taking and how it shapes understanding of evens and patterns, and the internal cognitive and affective processes underneath that uphold them, and
e) important matters that persons with disabilities and caregivers can address themselves to facilitate their own inclusion and participation, such as harnessing their God-endowed worth to fulfil their core functions within the Body, speaking out about their needs, and overcoming avoidant tendencies that deter their own prominence in their congregation.

## 5.6 Conclusion

In this chapter, a discussion of the findings of the study were presented, first in relation to the theoretical framework of the study, giving attention to the meaning of the connections between the results and the ICF environmental codes, and subsequently with regard to the emergent themes in comparison with the existing body of literature, applying a broad systems thinking approach. The next and final chapter of the dissertation contains the conclusions and recommendations, including a critical reflection on the strengths and limitations of the research, as well as practical implications of the study.

# CHAPTER 6
# CONCLUSIONS

## 6.1 Introduction

Marking the completion of the study, this chapter provides an overview and conclusion of the research, and contains practical implications of the findings, preceded by a critical evaluation of the contributions and strengths of the study, as well as its limitations. Finally, recommendations are offered regarding aspects that could be explored in future research.

## 6.2 Summary of the study

In reaching the main and sub-aims of the study in response to the research question, the results of this study offered a detailed description of the perceptions of persons with disabilities, primary caregivers of persons with disabilities, and church leaders regarding the barriers and facilitators to the participation of persons with disabilities in their Methodist congregation. Participants' perceptions were obtained from three focus groups, where each of the three participant groups was handled as a separate data source. Analyses of the data occurred through both inductive and deductive processes, where four emergent themes, with nine sub-themes, were developed from the verbatim transcriptions of the participants' responses. The themes are discussed in connection to each other and linked to the relevant theoretical framework, namely the ICF. Subsequently, 27 links between the data and the corresponding ICF component Environmental Factors were shown, representing environmental codes from all five chapters.

Participants identified barriers and facilitators related to the participation of persons with disabilities in their congregation's various ceremonies, activities and events. The emergent themes included perceptions concerning the low social status of persons with disabilities, based on their conformity to the normative identity of the congregation, as well as their perceived belonging and benefit to it. Related, is the extent to which their needs are addressed and accommodated, based on the levels of awareness and understanding of disability resulting from ignorance and stereotypes. Additionally, perceptions surfaced around access to the physical environment and the resources necessary to enable the involvement and participation of persons with disabilities in their congregation.

Numerous connections were made between the participants' responses and the ICF environmental codes, with the most data links within the category, *Attitudes* (Chapter 4). Since a facilitator that is absent or insufficient (despite its existence) comprises a barrier (WHO, 2001), the participants identified no facilitating factors in the environment of their congregation. Participant responses linked with Chapter 1 related mostly to the absence, or inadequacy of facilitators. Contrastingly, data links with Chapters 2-5 were mainly associated with imposed barriers. It is thus evident from the results that the participants generally considered the environmental factors at work in their congregation to hinder, rather than enable, the functioning and participation of persons with disabilities. These compelling links between the health conditions of persons with disabilities and the external influences on their functioning, confirm the occurrence of disability as a social construct, implying that disability is not caused by bodily impairments but instead by debilitating features within the physical, social and attitudinal environment of their congregation.

## 6.3 Evaluation of the study

The following section critically considers both the strengths and limitations of the study, where its positive qualities and contributions, as well as its shortcomings are discussed respectively.

### *6.3.1 Strengths*

- On the whole, the intersection of religion and disability has received limited attention in the literature (Carter et al., 2017). Likewise, considering the extensive literature available on the application of the ICF related to Body Functions, there is a paucity in the body of research around Religion and spirituality (d 930) in Chapter 9 (Community, social and civic life), as part of the Activities and Participation component. This study has contributed to the comparatively small number of studies addressing the component Environmental Factors and its interplay on the health and functioning of persons with disabilities within this domain (Simeonsson et al., 2014).
- The framing of the study within a qualitative, descriptive case study design allowed the researcher to amass and document a particularly comprehensive account of the study's

three diverse participant groups, as well as the interchange between the relational dynamics among them and the real-life setting of their congregation (Qi, 2009).

- Using focus groups as the data collection instrument, information was obtained from three data sources. Given that the research inquiry expressly sought detailed accounts from this relatively small sample in their specific context, the focus groups provided an avenue for the participants' perceptions to be explored and described in an in-depth manner. This also made it possible to include the subtle affective nuances underneath the participants' responses, which may not have been captured as thoroughly through other measures, such as experimental or survey research (Zaidah, 2007).
- This case study provided an intensive analysis and description of a single social system, providing both emic (from within the case) and holistic (the whole system's context) perspectives (Qi, 2009) concerning the Methodist congregation of the study. In this system, the persons within it could be simultaneously viewed as a part and a whole, as they function both as individual members of their congregation but also as a united entity as one faith-based system. While this case study does not claim to represent the interrelational dynamics and outcomes among persons with disabilities, caregivers and church leaders in other Christian congregations, it is nonetheless important to consider this congregation as a microcosm of its wider system – that is, the Church in its broadest sense – the body of Christ. Although the findings from this case study may not be generalisable to wider populations, the results can, however, be transferable to other settings (Anderson, 2010), where other researchers and readers with similar experiences may potentially see their application (Qi, 2009).
- During data collection, a script with pre-prepared questions was meticulously followed in triplicate, using the same questions and format for the focus groups with all three participant groups. This ensured procedural integrity and consistency in the data (Naudé & Bornman, 2018).
- The rigorous and systematic manner in which both the inductive thematic analysis of the data and the subsequent deductive linking of the ICF environmental codes occurred, ensured the credibility, dependability and ultimately the trustworthiness of the results (Cieza et al., 2019; Maguire & Delahunt, 2017).

### *6.3.2 Limitations*

- Despite its advantages, the case study method of the current research holds little basis for scientific generalisation, given its single case in-depth exploration and the small number of participants involved (Zaidah, 2007), especially pertaining to the focus group for primary caregivers. However, as this study was a first attempt at understanding and describing the participants' perceptions, this method was appropriate.
- The research question directed the use of a qualitative method to gather, analyse and interpret the data in an elaborate, meaningful manner, which would not have been achieved through pure quantitative measures that reduced the data to statistics (Anderson, 2010). However, using a mixed-method approach by integrating both qualitative and quantitative data may have produced a study that *"hangs together"* more compellingly, and may have provided a more comprehensive answer to the research question than the results obtained through this qualitative methodology only (Leedy & Ormrod, 2015, p. 330). Although focus groups are conventionally only used qualitatively, quantitative data through feedback forms, handouts, or electronic surveys completed by the participants before or after the focus groups may have been useful to improve the trustworthiness of the study's single-method instrument of focus groups (Naudé & Bornman, 2018).
- In addition, no statistical analysis was carried out on the data links between the participants' responses and the ICF environmental codes. As a result, the frequencies at which these codes occurred as barriers or facilitators were not measured.
- Moreover, since no qualifier codes were applied to the pertinent environmental factors, the degree to which the codes were considered as barriers or facilitators was not established. However, the aim of the study was to identify the participants' perceptions on the presence of barriers and facilitators to participation, and not the extent to which they were perceived as such.
- The study's focus was limited to the perceptions of three main participant groups, that is, persons with disabilities, primary caregivers, and church leaders within their congregation. In their respective discussions, these three participant groups made ample references to the congregants of their Methodist community, who accordingly,

featured significantly in the results and discussion of this research. However, no representation from this prominent group was included in the study's sample to corroborate the participants' inferred perceptions of them. While the study was concerned only with exploring the participants' lived experiences, and not with authenticating the actuality of their perceptions, it is important to be cognisant that there are other viewpoints from this important part of the congregation that are amiss, and that they may have added a different perspective to the current view the study provides. Whether or not it would have altered the results by including a sample of the congregants is immaterial at the present time. What is important though, is the recognition that the current study does not present the full picture. To quote Margaret Wheatley (2002): *"Everyone in a complex system has a slightly different interpretation. The more interpretations we gather, the easier it becomes to gain a sense of the whole"*.

## 6.4 Practical implications

With the intention to support the participation of persons with disabilities and become a more welcoming, inclusive congregation, the first plan should not necessarily be to represent persons with disabilities in the church's leadership, as was advised by the church leader participants. Barring one participant with a disability who expressly stated this desire, others may not feel called to this level of involvement in the church. Participating in leadership roles is a personal choice that they must be given. It is also not vital that a disability ministry is established. In the spirit of ministering *with* and not *to* persons with disabilities, it is, however, essential that persons with disabilities are given opportunities and encouraged to discover and employ their spiritual gifts (Yong, 2010), so that they can be connected and integrated with the existing ministries in their congregation.

The results also implied the need for some practical suggestions to create an open communication system between persons with disabilities, caregivers and church leaders, who did not seem to have much awareness of each other's perspectives. This can be facilitated by fostering routine conversations, where groups of all the different stakeholders (including the other members from the congregation who were not included in the study) can interact in a meaningful way, learn from each other, and deliberate potential solutions to pressing issues collaboratively (Carter et al., 2017; Kretzschmar, 2018). In her book, *"The church and disability*

*in Southern Africa: Inclusion and participation"*, Kretzschmar (2018) assists local church leaders and laity with a helpful resource to cultivate such dialogues, where she emphasises the co-responsibility of persons with disabilities to employ a recommended list of practical suggestions and principles for creating opportunities for these dialogues. Having regular conversations according to these guidelines will not only include persons with disabilities but also earnestly encourage their participation, since they are supported in taking an active, central role.

Sensitivity and conscientisation around disability can be facilitated among the congregants and church leadership, potentially utilising the above resource as course material. Alternatively, or additionally, the dialogue outcomes may guide the development of other educational interventions to increase disability awareness and understanding, promote pro-social behaviour and reciprocity, and elicit empathic concern (Decety & Yoder, 2016) among everyone within the congregation and beyond to other persons with disabilities, their caregivers and families in their surrounding community.

To successfully end the exclusion of persons with disabilities, the matter that needs to be addressed most principally is the state of the congregation's heart, and ultimately, its welfare and overall societal functioning. A thorough examination is thus needed to tend to the wounds of the congregation's alleged self-harming afflictions to its members, and its resultant failures to model self-care and love, and offer hospitality to the wider community it is meant to serve. With an apparent veil of ignorance and apathy that distorts and disguises the truth about persons with disabilities as vital parts of the body of Christ, it is critical to accurately diagnose the ailing health condition of this congregation. Since the Christian faith is a supernatural one, injustice against persons with disabilities is not entirely a human rights contest, nor a battle of wills between persons with disabilities and caregivers in one corner, and the congregation and its leadership in the other. The real warfare here is against the spiritual forces that bring division among believers (Ephesians 6:12; 1 Corinthians 1:10; 1 Corinthians 11:18, New International Version), as Christians are commanded to demolish any worldviews that arrogantly oppose the truth about God (and about persons with disabilities who bear His image), empowering them to forcibly seize and overthrow the strongholds (2 Corinthians 10:4-5) that uphold the models of oppressive thoughts and ideas that maim and sever persons with disabilities from their Body. Without a sincere conversion (Yong, 2009b), characterised by a *"constant change of heart"*

(Leshota, 2015, p. 8) and a transformation through a renewal of mind (Ephesians 4:23), this congregation cannot become truly inclusive. Unless, with unveiled faces they behold, contemplate and reflect God's glory through compassion and graciousness (2 Corinthians 3:18; Exodus 34:6), all efforts to comply with human rights standards (necessary as it is) will simply amount to a conformation to the patterns of this world, a way of life from which God has explicitly called His disciples away (Romans 12:2). Becoming an inclusive faith community requires a leader-led, theologically sound perspective on the differences between, yet unity among all believers – a view that will support the development of living out the symbiotic relationships of interdependence that God envisages for His Church (Leshota, 2015; White, 2014).

### 6.5 Recommendations for further research

Given the Methodist context of this study, no Christian theologies, apart from Wesleyan doctrines were explored, and only a few other theologies on disability were briefly mentioned in the literature review chapter. It is known that the diverse theologies on disability and healing in different church denominations directly impact the treatment of persons with disabilities, and that a congregation's adopted theological approach and attitude toward disability will accordingly shape the experiences of persons with disabilities within their faith community (Swinton, 2011). This was also found in the current study; however, no direct inquiry regarding theology of disability and healing was made, and therefore, no links could be made between the participants' experiences and any specific theological aspects concerning disability and health. Since it is church leaders' responsibility to provide their congregations with accurate theology on disability and to take the necessary stance against negative attitudes and practices (White, 2014), it will be necessary to understand what their disability theology is at present. Building extensively on the current study whilst still maintaining the interests of its present stakeholders, future research can be conducted on a comparison between the experiences of participants from a variety of Christian denominations, with a particular focus on investigating contextual factors such as preachers' espoused theologies on disability, health and healing, and how this impacts their attendance, sense of belonging and participation in their congregations. Such a study should substantially further develop the research design and sampling of the current research, ensuring that persons with disabilities, primary caregivers of persons with disabilities, church

leaders and congregants from each denomination are suitably represented in a sample large enough to additionally perform statistical analyses of the data obtained from a mixed-method approach, where multiple instruments are employed through both qualitative and quantitative measures. In this way, the findings can be generalised beyond the study's parameters and make considerable contributions to the existing literature.

The confession of faith, along with the recitation of religious liturgy are prerequisites for the involvement in ceremonies in many church denominations. As a result, persons with intellectual disabilities are prohibited from participating in sacraments such as Baptism and Holy Communion if they cannot demonstrate their understanding of the doctrinal concepts fundamental to their faith (Peters, 2009). The theology that is enacted in religious practices can be explored in a study that investigates the level of involvement of persons with intellectual disabilities, particularly in the sacraments.

Notwithstanding valuable resources from Christian organisations abroad (Dicken et al., 2008), there is a need for the development of individual, personalised programmes to facilitate the inclusion and participation of persons with disabilities in South African churches. This is because there are currently no adequate practical guidelines applicable to South Africa's contextually and culturally diverse milieus (Möller, 2012). It would therefore be important to gauge the readiness of local church leaders for ministering to persons with disabilities in their congregations. This might include exploring the skills required to enable such a ministry, and the implementation of a 'curriculum', or a custom programme, if any, to enable the accommodation, inclusion and participation of persons with disabilities.

Further to the above, research and intervention toward disability inclusion and participation in the church is required especially in South Africa's vast rural areas. Since the prevalence of disability is correlated with socioeconomic circumstances (WHO & World Bank, 2011), there is a considerable number of persons with disabilities in under-resourced communities who remain excluded from their faith communities owing to transportation challenges and insufficient means to make church buildings accessible (Möller, 2012).

## 6.6 Conclusion

This final chapter provided some closing reflections on the current study, which sought to explore, understand and describe the perceptions of three participant groups, and revealed the

extensive barriers to participation that persons with disabilities, their caregivers and families face within their Methodist congregation. In a critical appraisal of the study, its strengths and limitations were discussed, followed by practical implications and concluding suggestions for future research.

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# APPENDIX A1

## Formal Letter of Approval – Ethics

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

8 May 2018

Dear Ms McMahon-Panther

| | |
|---|---|
| **Project:** | **The perceptions of persons with disabilities, primary caregivers and church leaders regarding barriers and facilitators to inclusion in a Methodist congregation** |
| **Researcher:** | **G McMahon-Panther** |
| **Supervisor:** | **Prof J Bornman** |
| **Department:** | **Speech-Language Pathology and Audiology** |
| **Reference number:** | **17373752 (GW20171039HS)** |

Thank you for your response to the Committee's correspondence of 21 November 2017.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study at an *ad hoc* meeting held on 8 May 2018. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project.

Sincerely

**Prof Maxi Schoeman**
**Deputy Dean: Postgraduate and Research Ethics**
**Faculty of Humanities**
**UNIVERSITY OF PRETORIA**
**e-mail: PGHumanities@up.ac.za**

cc: Prof J Bornman (Supervisor and HoD)

Fakulteit Geesteswetenskappe
Lefapha la Bomotho

**Research Ethics Committee Members: Prof MME Schoeman (Deputy Dean);** Prof KL Harris; Mr A Bizos; Dr L Blokland; Dr K Booyens; Dr A-M de Beer; Ms A dos Santos; Dr R Fasselt; Ms KT Govinder Andrew; Dr E Johnson; Dr W Kelleher; Mr A Mohamed; Dr C Puttergill; Dr D Reyburn; Dr M Soer; Prof E Taljard; Prof V Thebe; Ms B Tsebe; Ms D Mokalapa

# APPENDIX A2

## Participant Informed Consent Form

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

**Date:** _____

Dear Participant

My name is Gail McMahon-Panther and I am currently enrolled for a Master's degree in Augmentative and Alternative Communication (AAC) at the University of Pretoria. As part of the requirements for this degree, I have to complete a research study.

**The title of the study**

*The perceptions of persons with disabilities, primary caregivers and church leaders regarding barriers and facilitators to inclusion in a Methodist congregation*

**What is the aim of the study?**

The study aims to describe the perceptions of persons with disabilities, primary caregivers of persons with disabilities, as well as church leaders, in order to determine what they consider to be barriers and facilitators to participation in ceremonies, activities and events in the church.

**What will be expected of you if you choose to take part in the study?**

Participation in the study would require you to share your views in a group discussion about aspects that hinder or promote the inclusion and participation of persons with disabilities in the life of the church. The group discussion should take approximately 90 minutes and will be conducted at a time and place that is most convenient for all participants.

With your informed consent, the discussion will be audio recorded. Given that the group is made up of individuals, the researcher alone does not have complete control of the confidentiality of the content of the discussion. However, in transcribing and reporting the data, confidentiality will be guaranteed. In addition, your name will be removed and no names of other people or places will be revealed in the transcriptions or research report. Should direct quotes be used, participant codes will be used to protect your identity.

Participation in this study is entirely voluntary and you will not be disadvantaged in any way should you choose not to participate. You also have the right to withdraw from the study at any point in time, without any negative consequences and without the need to supply a reason.

Fakulteit Geesteswetenskappe
Lefapha la Bomotho

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**What are the risks and the benefits to participating in the study?**

At no time during the study will you be at risk of any harm. Potential benefits of this study may include an improved understanding of the participation needs and preferences of persons with disabilities, as well as learning about possible mutual benefits for all involved when persons with disabilities are effectively included in all aspects of the life of the church. In addition, the results of the study may be used to extend further research to help develop practical guidelines for disability inclusion in religious congregations that promote full participation for all.

**Who will have access to the results of the study?**

All information will be kept confidential from those external to the study. The data will thus only be accessed by me (the researcher), my research supervisor and a research assistant. The data will be stored in both hard copy and electronic format at the University of Pretoria in the Centre for Augmentative and Alternative Communication for 15 years. The data obtained from the research will be used for writing a Master's dissertation, writing scientific papers and for presentation at professional conferences and seminars. A summary of the results will be made available to you, if you so request. Audio recordings and transcriptions may be used for secondary data analysis. If you choose to participate in the study, please complete the reply slip attached. Please feel free to contact me or my supervisor on the contact details below if you have any questions about this study.

Kind regards

**Gail McMahon-Panther (Researcher)** **Prof. Juan Bornman (Supervisor)**

# APPENDIX B

## Biographical Questionnaire – Pilot Study

**Name of study:**

*The perceptions of persons with disabilities, primary caregivers and church leaders regarding barriers and facilitators to inclusion in a Methodist congregation*

| **Participant Code** *(For official use only)* | |
|---|---|

**Biographical Information:**

Please answer the following questions by placing a tick in the appropriate box / column, or by writing in the space provided.

1. Gender:

| | |
|---|---|
| Male | |
| Female | |

2. Age: _____

3. Race:

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Black | | Coloured | | Indian | | White | | Other | |

4. Nationality: _____

5. Home language: _____

6. In which geographical area do you reside? _____

7. Education: What is the highest degree or level of schooling you have completed?
   *(If currently enrolled – highest degree received)*

| | |
|---|---|
| Grade 1 to Grade 8 | |
| Some high school | |
| Matric certificate | |
| Some college credit, no degree | |

| | |
|---|---|
| Trade / technical / vocational training | |
| Bachelor's degree | |
| Honour's degree | |
| Master's degree | |
| Doctoral degree | |
| Other | |

If 'Other', please specify.

_____

_____

8. Do you have any experience with persons with disabilities? | Y | N |
   If yes, please specify.

_____

_____

_____

_____

_____

_____

_____

9. Do you have any family member(s) with a disability? | Y | N |
   If yes, please specify.

_____

_____

_____

_____

10. What, if any, is your religious affiliation? *(e.g. Christianity, Hinduism, Islam, Judaism, etc.)*

_____

_____

11. Are you aware of any persons with disabilities who participate in Christian ceremonies, activities and events?

| | |
|---|---|
| Y | N |

If yes, please specify.

_____

_____

_____

_____

12. Do you know of any existing disability inclusion policy, or specific disability training programme endorsed by any Christian church?

| | |
|---|---|
| Y | N |

If yes, please describe.

_____

_____

_____

_____

**Thank you for completing the form.**

# APPENDIX C

## Preliminary Focus Group Script

| | |
|---|---|
| **Welcome** | (Explain that some parts will be read out to ensure that all focus groups follow the same procedure.)<br><br>**Introduction of Myself and Purpose of Focus Group**<br><br>*Welcome to everyone, and thank you for taking the time to be part of this focus group discussion.*<br><br>*My name is Gail McMahon-Panther and I am currently enrolled as a student at the Centre for Augmentative and Alternative Communication at the University of Pretoria.*<br><br>*I have an interest in persons with disabilities and how they participate in everyday life – more specifically – church-life.*<br><br>*The purpose of this focus group is to determine your perceptions about the issues you think may potentially aid or hinder the participation of persons with disabilities in church.*<br><br>*Remember that there are no correct or incorrect answers – I am simply interested in what you think and what your perceptions are.*<br><br>**Introduction of Participants**<br><br>*I will now ask you to please introduce yourself by giving your first name.* |
| **Purpose** | **What I wish to achieve in the focus group** (Give a brief introduction to the aims of the study.)<br><br>*The purpose of my study is to describe the perceptions of persons with disabilities, primary caregivers of persons with disabilities, as well as church leaders, in order to determine what they consider to be barriers and facilitators to participation in the church.*<br><br>*I will thus also conduct separate focus groups with the two other groups of people.*<br><br>*The results of these three focus groups will make it possible to describe, compare and understand how each group thinks and feels about this topic.*<br><br>*Your help and knowledge is very valuable because you can share your wealth of experience from your own perspective.* |

| | |
|---|---|
| **Administrative Matters** | **Details about Participation in the Focus Group, Confidentiality and Ground Rules**<br><br>• *Thank you for completing the consent form.*<br>• *Please ensure that you complete the biographical information form before you leave today.*<br>• *Note that the discussions of this focus group will be audio recorded, so please speak clearly.*<br>• *The purpose of this audio recording is to act as a reminder for me so that I do not accidently miss valuable information.*<br>• *I will also write out some of your comments and display them so that everyone can see.*<br>• *The focus group will not take longer than 90 minutes.* (Additional time is allowed for the focus group for persons with disabilities.)<br>• *Remember that you have the right to withdraw from the study at any time.*<br>• *You can be assured that your identity will not be disclosed to anyone when I process the data, so you are safe to express your opinions without any consequence.*<br><br>(Introduce ground rules for participation and invite participants to add their own)<br><br>• *Please ensure that your cell phones are on silent for the duration of the focus group.*<br>• *Let us agree that whatever is shared in this group remains confidential.*<br>• *Only one person may speak at a time, so as to be respectful to one another, and to allow for the clarity of the audio recording.*<br>• *Please share your true views, regardless if they are similar or very different from the views of the other people in this group.*<br>• *You have the right to disagree but please do so openly, in a respectful manner, with constructive dialogue and feedback.*<br>• *There is no such thing as a bad idea, so you are asked to table any new ideas so they can develop the discussion.* |
| | Next, the pre-prepared questions are addressed to the group and the discussion is facilitated around the answers to the questions.<br><br>In order to ensure even participation and avoid the dominance of one or two participants, I will thoughtfully call on the other group members, using tactful phrases such as *"Let's have some other comments"*, or *"Thank you; what do other people think." I am now going to ask you some questions about disability inclusion in the church. I am not here to contribute my* |

| | |
|---|---|
| **Discussion** | *views but only to guide your discussion. You may ask me to repeat or clarify any question at any time.*<br><br>**Introductory Question**<br><br>*What comes to mind when you think about the participation of persons with disabilities in church ceremonies, activities and events?*<br><br>Participants are given sticky notes on which to record their responses, after which I will duplicate them on a flip chart. Considering the physical and intellectual challenges some participants in the focus group for persons with disabilities may experience, I will write down all their responses on the flip chart from the outset.<br><br>Once I have visually displayed and verbally reiterated the comments, I will make a neutral response with a probing question: *"Is there anything else you would like to add?"*<br><br>**Key Questions**<br><br>*i. Name areas or issues that you think might be a hindrance to the participation of persons with disabilities in church ceremonies, activities and events?*<br>*ii. What do you think might facilitate the participation of persons with disabilities in church ceremonies, activities and events?*<br><br>Follow-up questions, such as *"Can you elaborate on that?", and "Do you have an example?"* will be asked throughout to assist with the flow of the discussion and to obtain further information. I will also ask questions, such as *"What you are saying is…"*, and *"Can I confirm that I understood you correctly?"*<br><br>To establish trustworthiness and credibility, member checks will be used during and at the end of the discussion. A summary of the emerging points will be given, followed by two further questions, *"Do these statements accurately represent what you said?",* and *"Is there anything we have missed that you feel we should have included?"*<br><br>Time is given to ask specific questions about statements that may need further clarification. |
| **Closing Statement** | *Thank you for your valuable contributions and the time you have taken to be a part of this focus group. Because this is a group made up of individuals, I cannot completely control that everything that was discussed here remains confidential. I would therefore like to remind you of your* |

| | |
|---|---|
| | *agreement of confidentiality during the establishing of ground rules earlier.*<br>*Thank you once again for your participation.* |

# APPENDIX D

## Focus Group Script – Main Study

| | |
|---|---|
| **Welcome** | (Explain that some parts will be read out to ensure that all focus groups follow the same procedure.)<br><br>**Introduction of Myself and Purpose of Focus Group**<br><br>*Welcome to everyone, and thank you for taking the time to be part of this focus group discussion.*<br><br>*My name is Gail McMahon-Panther and this is my assistant …* (introduce assistant). *I am currently enrolled as a student at the Centre for Augmentative and Alternative Communication at the University of Pretoria.*<br><br>*I have an interest in persons with disabilities and how they participate in everyday life – more specifically – church-life.*<br><br>*The purpose of this focus group is to determine your perceptions about the issues you think may potentially aid or hinder the participation of persons with disabilities in church.*<br><br>*There are no correct or incorrect answers – I am simply interested in what you think and what your perceptions are.*<br><br>**Introduction of Participants**<br><br>*I will now ask you to please introduce yourself by giving your first name.* |
| **Purpose** | **What I wish to achieve in the focus group** (Give a brief introduction to the aims of the study.)<br><br>*The purpose of my study is to describe the perceptions of persons with disabilities, primary caregivers of persons with disabilities, as well as church leaders, in order to determine what they consider to be barriers and facilitators to participation in the church.*<br><br>*I will thus also conduct separate focus groups with the two other groups of people.*<br><br>*The results of these three focus groups will make it possible to describe, compare and understand how each group thinks and feels about this topic.*<br><br>*Your help and knowledge is very valuable because you can share your wealth of experience from your own perspective.* |

| | |
|---|---|
| **Administrative Matters** | **Details about Participation in the Focus Group, Confidentiality and Ground Rules**<br><br>• *Thank you for completing the consent form.*<br>• *Please ensure that you complete the biographical information form before you leave today.*<br>• *Note that the discussions of this focus group will be audio-recorded, so please speak clearly.*<br>• *The purpose of this audio-recording is to act as a reminder for me so that I do not accidently miss valuable information.*<br>• *I will also write out some of your comments and display them so that everyone can see.*<br>• *The focus group will not take longer than 90 minutes.* (Additional time is allowed for the focus group for persons with disabilities.)<br>• *Remember that you have the right to withdraw from the study at any time.*<br>• *You can be assured that your identity will not be disclosed to anyone when I process the data, so you are safe to express your opinions without any consequence.*<br><br>(Introduce ground rules for participation and invite participants to add their own)<br><br>• *Please ensure that your cell phones are on silent for the duration of the focus group.*<br>• *Let us agree that whatever is shared in this group remains confidential.*<br>• *Only one person may speak at a time, so as to be respectful to one another, and to allow for the clarity of the audio-recording.*<br>• *Please share your true views, regardless if they are similar or very different from the views of the other people in this group.*<br>• *You have the right to disagree but please do so openly, in a respectful manner, with constructive dialogue and feedback.*<br>• *There is no such thing as a bad idea, so you are asked to table any new ideas so they can develop the discussion.* |
| **Ice Breaker** | (A quick ice breaker game is played by the participants before the first question is asked) |
| | Next, the pre-prepared questions are addressed to the group and the discussion is facilitated around the answers to the questions.<br><br>In order to ensure even participation and avoid the dominance of one or two participants, I will thoughtfully call on the other group members, using |

| | |
|---|---|
| **Discussion** | tactful phrases such as *"Let's have some other comments"*, or *"Thank you; what do other people think?"*<br><br>*I am now going to ask you some questions about disability inclusion in the church. I am not here to contribute my views but only to guide your discussion. You may ask me to repeat or clarify any question at any time.*<br><br>**Introductory Question**<br><br>*What are the different ceremonies, activities and events that people attend at church?*<br><br>Participants are given sticky notes on which to record their responses, after which I will duplicate them on a flip chart. Considering the physical and intellectual challenges some participants in the focus group for persons with disabilities may experience, I will write down all their responses on the flip chart from the outset.<br><br>Once I have visually displayed and verbally reiterated the comments, I will make a neutral response with a probing question: *"Is there anything else you would like to add?"*<br><br>**Key Questions**<br><br>*iii. Name areas or issues that you think might be a hindrance to the participation of persons with disabilities in church ceremonies, activities and events?*<br>*iv. What do you think might facilitate the participation of persons with disabilities in church ceremonies, activities and events?*<br><br>Follow-up questions, such as *"Can you elaborate on that?", and "Do you have an example?"* will be asked throughout to assist with the flow of the discussion and to obtain further information. I will also ask questions, such as *"What you are saying is…"*, and *"Can I confirm that I understood you correctly?"*<br><br>To establish trustworthiness and credibility, member checks will be used during and at the end of the discussion. A summary of the emerging points will be given, followed by two further questions, *"Do these statements accurately represent what you said?",* and *"Is there anything we have missed that you feel we should have included?"*<br><br>Time is given to ask specific questions about statements that may need further clarification. |

| | |
|---|---|
| **Closing Statement** | *Thank you for your valuable contributions and the time you have taken to be a part of this focus group. Because this is a group made up of individuals, I cannot completely control that everything that was discussed here remains confidential. I would therefore like to remind you of your agreement of confidentiality during the establishing of ground rules earlier.*<br>*Thank you once again for your participation.* |

# APPENDIX E

## Biographical Questionnaire – Persons with Disabilities

**Name of study:**

*The perceptions of persons with disabilities, primary caregivers and church leaders regarding barriers and facilitators to inclusion in a Methodist congregation*

| **Participant Code** *(For official use only)* | |
|---|---|

**Biographical Information:**

Please answer the questions by placing a tick in the correct box, or by writing in the space provided.

1. Gender:

| | |
|---|---|
| Male | |
| Female | |

2. Age: _____

3. Race:

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Black | | Coloured | | Indian | | White | | Other | |

4. Nationality: _____

5. Home Language: _____

6. In which residential area do you reside? _____

7. Education: What is the highest degree or level of schooling you have completed?
   *(If currently enrolled – highest degree received)*

| | | |
|---|---|---|
| Attended Regular Mainstream School | Grade? --------- | |
| Attended Special Needs School | | |

| | |
|---|---|
| Some High School | |
| Matric Certificate | |
| Some College Credit; No Degree | |
| Trade / Technical / Vocational Training | |
| Bachelor's Degree | |
| Honour's Degree | |
| Master's Degree | |
| Doctoral Degree | |
| Other | |

If 'Other', please specify.

_____

_____

8. What type of disability do you have? Please explain.

_____

_____

9. What is the severity of your disability? *(e.g. mild, moderate, severe)*

_____

10. What type of difficulties do you experience? Select all applicable areas.

| Vision | Hearing | Speech | Moving and walking independently | Understanding | Learning | Seizures | Other |
|---|---|---|---|---|---|---|---|

If 'Other', please specify.

_____

_____

11. How long have you been living with this disability? Please specify.

_____

_____

12. What is your church denomination? *(e.g. Anglican, Catholic, Methodist, Presbyterian, etc.)*

_____

_____

13. What is your connection to this church? *(e.g. visitor, member, etc.)*

_____

14. How long have you been attending this church? _____

15. Who goes with you to church? _____

_____

16. How do you get to church? _____

_____

17. Can you attend church on your own?

| | |
|---|---|
| Y | N |

18. How regularly do you attend this church? *(e.g. once a week, more than once a week, once a month, only on special occasions, e.g. Christmas, etc.)*

_____

_____

19. Apart from Sunday services, what other events and activities do you attend at this church? Please specify.

_____

_____

_____

20. Do you know of any other persons with disabilities who attend this church?

| | |
|---|---|
| Y | N |

21. Do you know about any existing disability inclusion policy, or specific disability training programme endorsed by this church?

| | |
|---|---|
| Y | N |

If yes, please explain.

_____

_____

_____

22. Would you support having such a policy or training programme in place in this church?

| Y | N |
|---|---|

Please motivate your answer.

_____

_____

_____

_____

23. Do you also attend any other church?

| Y | N |
|---|---|

If yes, please elaborate.

_____

_____

_____

_____

**Thank you for completing the form.**

# APPENDIX F

## Biographical Questionnaire – Caregivers

**Name of study:**

*The perceptions of persons with disabilities, primary caregivers and church leaders regarding barriers and facilitators to inclusion in a Methodist congregation*

| **Participant Code** *(For official use only)* | |
|---|---|

**Biographical Information:**

Please answer the following questions by placing a tick in the appropriate box, or by writing in the space provided.

1. Gender:

| | |
|---|---|
| Male | |
| Female | |

2. Age: _____

3. Race:

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Black | | Coloured | | Indian | | White | | Other | |

4. Nationality: _____

5. Home Language: _____

6. In which residential area do you reside? _____

7. Education: What is the highest degree or level of schooling you have completed?
   *(If currently enrolled – highest degree received)*

| | |
|---|---|
| Grade 1 to Grade 8 | |
| Some High School | |
| Matric Certificate | |
| Some College Credit; No Degree | |

| | |
|---|---|
| Trade / Technical / Vocational Training | |
| Bachelor's Degree | |
| Honour's Degree | |
| Master's Degree | |
| Doctoral Degree | |
| Other | |

If 'Other', please specify.

_____

_____

8. What type of disability does the person in your care have? Please explain.

_____

_____

9. What is the severity of the disability of the person in your care? *(e.g. mild, moderate, severe)*

_____

10. What type of difficulties does the person in your care experience? Select all applicable areas.

| Vision | Hearing | Speech | Moving and walking independently | Understanding | Learning | Seizures | Other |
|---|---|---|---|---|---|---|---|

If 'Other', please specify.

_____

_____

11. What is the age of the person with the disability in your care? _____

12. How long has the person in your care been living with the disability? Please specify.

_____

_____

13. How long have you been the primary caregiver of this person?

_____

_____

14. What is your church denomination? *(e.g. Anglican, Catholic, Methodist, Presbyterian, etc.)*

_____

_____

15. What is your connection to this church? *(e.g. visitor, member, etc.)*

_____

_____

16. How long have you been attending this church?

_____

_____

17. How regularly do you attend this church? *(e.g. once a week, once a month, only on special occasions, .e.g. Christmas, etc.)*

_____

_____

18. How regularly does the person with the disability in your care join you in attendance at this church? *(e.g. once a week, once a month, only on special occasions, .e.g. Christmas, etc.)*

_____

_____

19. Apart from Sunday services, what other events and activities do you attend at this church? Please specify.

_____

_____

_____

20. Apart from Sunday services, what other events and activities does the person in your care attend at this church? Please specify.

_____

_____

_____

21. Are you aware of any other persons with disabilities, or their caregivers, who attend this church?

| | |
|---|---|
| Y | N |

22. Do you know about any existing disability inclusion policy, or specific disability training programme endorsed by this church?

| | |
|---|---|
| Y | N |

If yes, please explain.

_____

_____

_____

23. Would you support having such a policy or training programme in place in this church?

| | |
|---|---|
| Y | N |

Please motivate your answer.

_____

_____

_____

_____

24. Do you and the person in your care also attend any other church?

| | |
|---|---|
| Y | N |

If yes, please elaborate.

_____

_____

_____

_____

**Thank you for completing the form.**

# APPENDIX G

## Biographical Questionnaire – Church Leaders

**Name of study:**

*The perceptions of persons with disabilities, primary caregivers and church leaders regarding barriers and facilitators to inclusion in a Methodist congregation*

| **Participant Code** *(For official use only)* | |
|---|---|

**Biographical Information:**

Please answer the following questions by placing a tick in the appropriate box / column, or by writing in the space provided.

1. Gender:

| | |
|---|---|
| Male | |
| Female | |

2. Age: _____

3. Race:

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Black | | Coloured | | Indian | | White | | Other | |

4. Nationality: _____

5. Home Language: _____

6. In which residential area do you reside? _____

7. Education: What is the highest degree or level of schooling you have completed?
   *(If currently enrolled – highest degree received)*

| | |
|---|---|
| Grade 1 to Grade 8 | |
| Some High School | |
| Matric Certificate | |
| Some College Credit; No Degree | |

| | |
|---|---|
| Trade / Technical / Vocational Training | |
| Bachelor's Degree | |
| Honour's Degree | |
| Master's Degree | |
| Doctoral Degree | |
| Other | |

If 'Other', please specify.

_____

_____

8. What additional training did you receive that is specific to your church ministry?

_____

_____

_____

9. What specific role do you currently perform in this church?

_____

_____

_____

10. How long have you served in this specific role at this church?

_____

_____

_____

11. Altogether, how long have you served at this specific church, in any role?

_____

_____

_____

12. Altogether, how long have you served at any congregation, in any role?

_____

_____

_____

13. Do you have any experience with persons with disabilities? | Y | N |
    If yes, please specify.

    _____
    _____
    _____
    _____
    _____
    _____

14. Do you have any family member(s) with a disability? | Y | N |
    If yes, please specify.

    _____
    _____
    _____
    _____

15. Are you aware of any persons with disabilities in the community surrounding this church? | Y | N |

    If yes, please specify who and if they attend this church.

    _____
    _____
    _____
    _____

16. Do you know of any existing disability inclusion policy, or specific disability training programme endorsed by this church? | Y | N |

    If yes, please describe.

    _____
    _____
    _____
    _____

17. Would you support having such a policy or training programme in place in this church?

| | |
|---|---|
| Y | N |

Please motivate your answer.

_____

_____

_____

_____

**Thank you for completing the form**