

THE EXPERIENCES OF PEOPLE WITH DISABILITIES
IN FAITH COMMUNITIES: A SOCIAL WORK PERSPECTIVE

By

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I declare that **THE EXPERIENCES OF PEOPLE WITH DISABILITIES IN FAITH COMMUNITIES: A SOCIAL WORK PERSPECTIVE** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

Signature

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ABSTRACT

This report portrays the findings of research on the experiences of inclusion/exclusion of people with disabilities in faith communities, from a social work perspective. It was a journey undertaken with a group of people with disabilities in Pietermaritzburg, South Africa during 2009 and 2010. In narrations on the journey, participants expressed their experiences of exclusion, not being considered and their personhood not always being respected in faith communities. However, the journey also revealed suggestions of how their inclusion could be enhanced by changing practices, developing understanding of the needs of people with disabilities, and raising awareness of these. The report concludes with recommendations for ways that people with disabilities and others in faith communities can journey together in faith communities to the benefit of all.

KEYWORDS: exclusion, inclusion, people with disabilities, faith communities, qualitative research.

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LIST OF ABBREVIATIONS

PWD : People with disabilities or Persons with disabilities

FGI : Focus group interviews

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1 CHAPTER 1: INTRODUCTION AND METHODOLOGY

MAPPING THE JOURNEY

People with disabilities in faith communities, as in society at large, experience exclusion and express their frustration by saying “*Why must we fight in the church for something that is our constitutional right?*” This study explores their experiences of exclusion and makes suggestions to enhance their inclusion.

1.1 INTRODUCTION

The worldwide increased focus on the rights of people with disabilities has also gained impetus in South Africa with several policy and legislative documents that address health, social development, education, justice and labour issues of people with disabilities (Disability Action Research Team – DART, 2006). Examples of such policy documents are the South African Constitution and the Integrated National Disability Strategy. Three of the rights listed in the Constitution have specific relevance to people with disabilities. The first is the right to equality, which means that *everyone* is equal before the law and has equal protection and benefit of the law. Secondly, the Constitution gives rights to *all* children, which implies the rights of children with disabilities to basic nutrition, shelter, health and social services and protection from maltreatment, neglect, abuse and degradation. Thirdly, the South African Constitution also states that everyone has the right to basic education (DART, 2006:3).

South Africa has also ratified the United Nations Convention of the Rights of People with Disabilities that encourages people with disabilities to increasingly claim their right to equal citizenship. This document consists of 50 articles that spell out specific rights of people with disabilities in the different spheres of society. While all the articles obviously apply to faith communities as well, some can be highlighted as having specific relevance to the church and people with disabilities. One example is the article (article 8) on awareness raising in fighting the stereotypes and prejudices which were found in this study. Another article in the UN Convention is the one on accessibility indicating that all buildings as well

as *all* forms of communication and information, should be accessible to people with disabilities,. Since the church environment is, in a sense all about communication, this is an important point for the church, to develop inclusive communities in compliance with the above-mentioned documents of human rights (United Nations, 2006).

Regarding the actual implementation of all these legislative measures, Howell, Chalklen and Alberts (2006:79) point out the ongoing challenge to translate these policies to the practical situation of the lives of people with disabilities.

In terms of disability awareness in churches, a conference on the topic 'Doing theology from a disability perspective' was held in Manila in the Philippines in 2007. In the conference publications (Longchar and Cowans, 2007: iii) Longchar writes about the wide-spread bad treatment by society of people with disabilities, specifically in Christian circles. He notes that within church contexts, there are those who regard disability as a result of sin, the work of demons or as a punishment from God. Some Christians also believe that disabled people who are not healed do not have enough faith, or that a lack of faith leads to or maintains a disability.

Longchar and Cowans (2007:iv) continue that fostering the aforementioned beliefs and further complicating the issue is the misconception relating to perfection and beauty of the human body which is ingrained in the human psyche and which tends to exclude any form of disability. It appears that this belief leads to a perception that any disability makes a person less human. Longchar states that because the person with a disability is regarded as not being created in the image of God, he is excluded from society and religious life. This belief is demonstrated by some parents being embarrassed to appear with their disabled children and preferring to hide them at home. Referring to the above-mentioned Christian circles, Longchar sees the church as a disabled community if it cannot accommodate the diversity that is an integral part of creation, including people with disabilities.

In my work as a social worker of the Leprosy Mission, working in the field of health and disability, I became aware of a similar situation in South Africa, and that no

previous research on the topic had been conducted from a social work perspective.

1.2 BACKGROUND OF THE RESEARCH STUDY

In its work with people affected by leprosy in South Africa since 1982, the Leprosy Mission has been largely involved with people affected and disabled by leprosy and excluded from society. In recent years, as a result of effective medication and good availability of services, the incidence of leprosy in South Africa is now low (The Leprosy Mission, 2005:10). This resulted in a decline in services needed by people affected by leprosy, and the organisation realised that its expertise in the field of leprosy-disability and fighting the stigma of leprosy could possibly be applied to the wider field of general physical disabilities. In 2005 and 2006, the organisation conducted a survey in four provinces, under my leadership, to explore the life situation of marginalized¹ people with physical impairments and possible gaps in services available and rendered to them. Recommendations from the survey pointed to a need (especially in rural areas) for culturally specific disability awareness and advocacy programmes with people with disabilities playing an integral role in the process (The Leprosy Mission, 2007:35).

During the above-mentioned survey, the Leprosy Mission came across an organisation in Pietermaritzburg, *disAbility ConneXion*, which had started an advocacy programme in churches about five years ago. The organisation operates under the auspices of a Christian organisation, African Enterprise, which consists of a group of about fifteen people with disabilities with Mrs Barbara Watt as their leader. The group includes people with different kinds of disability and different age and cultural groups. Membership is open to all people with disabilities who

¹ The term "marginalized" was used at the time of the survey in 2005 -2006 with the understanding that it is a position where people are on the periphery of society. The term exclusion (as used in this study, 2009) can be seen as the experience of people who do not share optimally in normal participation of society.

share their vision. Since the inception of this study another branch of *disAbility ConneXion* has been established in Durban.

The aims of *disAbility ConneXion* are to connect people with disabilities:

- To themselves
- To others
- To the church

Groups such as *disAbility ConneXion* are described by Swanepoel (2002:35) as an action or interest group. *disAbility ConneXion* is a group of concerned individuals with the common need to do something about the inclusion of people with disabilities in faith communities. They have taken action to address this problem and they operate with the advantage of their common understanding, living in the same communities and sharing a concern for other people with disabilities.

The Leprosy Mission saw the above initiative as an opportunity to support awareness and advocacy programmes for disability (as recommended in the above-mentioned report) and started discussions with *disAbility ConneXion*. This led to a mini-consultation on 17 and 18 November 2008 in Pietermaritzburg with representatives from *disAbility ConneXion*, the Leprosy Mission and a few local Christian faith communities. From this consultation the following insights arose: the need for written, visual and interactive material to promote the inclusion of people with disabilities in churches and the promotion of an annual Disability Awareness Sunday in churches. There was also a suggestion to explore the viewpoints of church leaders and people with disabilities in the wider Pietermaritzburg area by way of an exploratory meeting (The Leprosy Mission SA, 2008).

American authors like Webb-Mitchell (1996:55) and Carter (2007:53) have written useful materials to train and sensitise church members about disability. Another good example of a disability advocacy programme, focussed on faith communities, is that of *Joni and Friends*, which was started by Joni Eareckson-Tada, a person with quadriplegia herself. The *Joni and Friends* organisation have become influential, not only in the USA but also with outreach programmes in African

countries (Joni and friends, n.d). While there are valuable lessons to be learnt from this material, *disAbility ConneXion* members felt it was not applicable and comprehensive enough for the South African context and culture. They pointed out the problems of people with disabilities in under-resourced communities, for example, not being able to get to church because of a lack of transport and churches not having the means to make buildings accessible. A further point mentioned was the problematic exclusionary perceptions of disability in the African culture (The Leprosy Mission SA, 2008).

It became clear that further exploration into the experiences of local people with disabilities in faith communities was necessary. As the social worker of the Leprosy Mission, I offered to undertake research of this phenomenon. It was agreed that the research needed to explore the positive *and* negative experiences and perceptions of people with disability and of church leaders regarding disability, as well as asking their suggestions for improving the inclusion in faith communities.

The Leprosy Mission subsequently formed a partnership with *disAbility ConneXion* to begin exploring the situation in the Pietermaritzburg area as this is where *disAbility ConneXion* operates. It was hoped that the lessons learned from this process could be replicated in a wider context. Henceforth deliberations were to be with the four or five prominent members of *disAbility ConneXion*, who, in this report, will be referred to as the core group.



Photo 1: Some of the core group members Barbara Watt, Bonggi Zuma, Patricia Naidoo, with the researcher, Erna Moller

As from mid 2008, to orientate myself, I involved myself in a process of listening to the stories and experiences of members of *disAbility* ConneXion, and the problems they experienced regarding inclusion/exclusion in faith communities. They also introduced me to some of their friends who had similar experiences.

As suggested in the consultation of November 2008, an exploratory meeting with church leaders and people with disabilities took place in February 2009 to obtain a wider perspective.

From these two processes, namely the stories told by *disAbility* ConneXion members and the exploratory meeting with church leaders, the following five themes emerged:

- The inaccessibility of church buildings and activities in the faith community
- Experiences of exclusion from the church community
- Psycho-social issues of people with disabilities
- Faith practices that hamper the inclusion of people with disabilities
- The lack of etiquette in relating to people with disabilities

In the following section, these five themes will be discussed.

1.3 INITIAL DISCUSSION OF THEMES OF EXCLUSION IN FAITH COMMUNITIES

The following paragraphs describe the above-mentioned themes as experienced by *disAbility* ConneXion members, portrayed by church leaders who participated in the consultation and documented in existing literature.

1.3.1 The inaccessibility of church buildings and activities in the faith community

In the context of disability, accessibility can be defined as physical access, communication access, and social access to facilities, services, training and jobs. This implies that accessibility exists where people with disabilities can, without

assistance and undue difficulty, participate in society. Section 1.9.1 gives a full description of accessibility and inaccessibility.

Many stories and experiences uppermost in the minds of members of disAbility ConneXion testify to the fact that church buildings are generally not physically accessible for people with mobility impairment who use wheelchairs or walking aids. Ramps are either non-existent or not user-friendly, toilets at churches are inaccessible, and the fixed position of pews in church buildings causes further problems. People with mobility impairments also experience the inaccessibility of other facilities around the church such as halls where, for example, tea is served after the worship service, or Sunday school rooms where children with disabilities would like to participate. One wheelchair user told the story of being pushed by a door steward to a spot at the side of the church auditorium “*where you will not be a disturbance for others*”. Another person remarked that in a certain church the only accessible place for him to sit with his wheelchair is in the storeroom where the church’s brooms and cleaning materials are kept.

disAbility ConneXion members also mentioned several practices in church services that are inaccessible for people with disabilities. This could be described as communication inaccessibility. Blind and partially sighted people, Deaf² people and people with hearing impairments all found it difficult to participate in the liturgy of services because no provision or adaptation is made to accommodate their inclusion. In many churches, the words of hymns are projected onto an electronic board or hymns are announced without allowing enough time for blind people to find them in a Braille hymnbook. Some people with hearing impairments felt the need for a summary of the sermon in writing and / or the opportunity to have the sermon interpreted for them.

² People who are deaf since birth (pre-lingual) regard themselves as a cultural group and prefer to identify themselves as **D**eaf people.

Other frustrations experienced by *disAbility* ConneXion members and their friends are inappropriate adaptations made to church buildings without their being consulted. Their hope is that churches will be made accessible in a standardised way.

On the other hand, church leaders at the exploratory meeting felt that some provision is made to accommodate the limitations of people with disabilities. Examples of these provisions are ramps, provision for people with hearing impairment to sit in front at the worship service or making home visits to those who cannot attend church, the latter being an example of social accessibility. However, some provisions seemed to emphasise the difference of people with disabilities rather strongly, treating them as “separate”. Examples are having a special place for them at the back of the church or a special service for people with disabilities, “where they can participate in the whole service”.

Literature on the accessibility of church buildings in South Africa for people with disabilities is limited to a study undertaken by Razaka (2005) regarding the inaccessibility of churches in the Pietermaritzburg area and confirms the above-mentioned experiences. Razaka (2005:36) points out that there is a lack of ramps, doors are too narrow and pathways are not free of loose stones or are uneven. Many churches do not budget for altering the buildings because of the perception that these alterations will be quite costly. Furthermore, the National Building Regulations which describe all the needs of people with physical disabilities are not adhered to (South African Bureau of Standards 2011).

In summary, it appears, from the above-mentioned examples, that the inaccessibility of church buildings and some practices in the church make it difficult for people with disabilities to feel welcome and included in the life of the church. They experience feelings of exclusion and not really being a part of the Christian community. This is confirmed in the news column of the *Journal for Religion, Disability and Health* (Churches asked to examine attitudes as well as structure in confronting barriers to those with disability, 2001:96) that many people with disabilities escape the inaccessibility of churches and condescending attitudes by simply withdrawing from the church. On the other hand, some church leaders felt that some provision is made, even if it means people with disabilities are

separated from others in worship such as being seated in the aisle. This may point out that while some adaptations have been made at some churches, the experiences of people with disabilities have not yet changed.

1.3.2 Experiences of exclusion from the church community

In the context of this study, exclusion refers to those experiences of people with disabilities of being deprived or denied the benefits and participation in faith communities that non-disabled people have.

Exclusion in the faith communities is experienced by disAbility ConneXion members in various ways. They mentioned that some people with disabilities do not go to church because of the negative reactions of church members. Their experience is that of prejudice and that people assume that those with disabilities have low levels of *abilities*. People with mobility impairment are often treated as if they have a mental disability. The following comment made by a middle-aged man attests to this:

“People talk to my wife as if I cannot speak for myself; they see my wheelchair, instead of seeing me as a person”.

disAbility ConneXion members felt that church members are ignorant about the practical implications of a disability and therefore excluded them from participation. One member of disAbility ConneXion remarked:

“They think when I take a little longer to finish a task that I’m not capable of doing it and they pity me. So, for a long time I was not invited to participate in the choir”.

Another member from disAbility ConneXion mentioned that persons with disabilities are not considered for leadership positions, nor invited to make their contribution in the life of the church, for example, serving as a Sunday school teacher. She felt that with some adaptations, opportunities for leadership are quite possible but that the church is unwilling to make these adaptations. For example, making the place of the Sunday school classes physically accessible would allow her to be a Sunday school teacher.

The above experiences of disAbility ConneXion members coincide with Hubach's (2007) descriptions of similar situations. Barriers to inclusion of people with disabilities in church communities include anxiety, negative attitudes of members, and leadership not giving priority to the inclusion of people with disabilities. Church members are often afraid of engaging with disabled people in their church community. This is mostly based on a fear of the unknown (Hubach, 2007:4).

Negative attitudes of church members can appear in many different guises, including "ignorance," "indifference" and "arrogance". Ignorance is usually the result of lack of exposure to people with disabilities and their specific needs, as well as a lack of accurate information about their conditions. Sometimes people seem indifferent and thus do not really care. Some non-disabled people have an attitude of superiority or arrogance when approaching people with disabilities and talk down to them (Hubach, 2007:5). A member of disAbility ConneXion attested to this: *"The pastor thinks his perception of our inclusion is correct and he doesn't really have an open mind to our views"*.

Church agendas often exclude or do not give priority to the needs of people with disabilities (Hubach, 2007:5). For example, big outreach projects may take priority over making provision for children with developmental disabilities in the Sunday school. In church leadership, there is often resistance to change. For a minority group of disabled people in the church this can be a very difficult situation with which to be confronted.

Despite these experiences of people with disabilities there are church leaders who do make efforts to include people with disabilities. In the exploratory meeting of February 2009, church leaders related their efforts to include people with disabilities in church activities. Examples were mentioned such as *"We are trying to come alongside them and welcome them; "We see them as equal, and try to include them in the leadership of the church"*. However, there was also acknowledgement of the fact that the needs of people with disabilities are often overlooked by the church. *"We do not always know how to deal with them"; "Some other members in the church are unaware that people with disabilities are just the same human beings as us"*. This acknowledgement of the problem is also reported in an article of the Journal of Religion, Disability and Health (Churches asked to

examine attitudes as well as structures in confronting barriers to those with disability, 2001:93). A group of churches in America wanted to address the lack of participation of people with disabilities. The leadership asked themselves how this situation had developed, and how to develop the change that will ensure that all may be included in worship. They called on their congregations to “re-examine our ideas of disability”. A statement of their commitment to this change was written and churches were asked to adhere to the changes.

While it appears that there is a willingness from churches to accommodate people with disabilities, it is possible that it is not wide-spread and not enough to change the overwhelming experiences of people with disabilities. It is possible that people with disabilities feel that they are not really heard when trying to be included in the life of the church. Webb-Mitchell (1996) compares the relationship between the church and people with disabilities with the communication difficulties between a person with hearing impairment and a person with normal hearing. If the messages between the two do not get through and the receiver does not perceive the message, the sender remains ignored and may even feel unseen. Webb-Mitchell (1996:28) says a wall of silence is then built and often maintained. However, the act of being heard, of having one’s message received and recognised validates a person as relevant to the discussion of life.

In summary, it appears that the minority position of people with disabilities in faith communities can result in their feelings of being different and odd. They feel wrongly perceived in terms of their abilities and ignored by not being heard in terms of, for example, their physical needs. On the other hand, some churches do make efforts but, as Webb-Mitchell suggests (1996:29), it takes practised listening to hear anew what people with disabilities are trying to communicate.

1.3.3 Psychological issues having a social impact on persons with disabilities

Psychological traits relevant to people with disabilities include issues of identity and self-concept, lack of self-esteem, confidence, assertiveness and sensitivity.

1.3.3.1 Identity and self-concept

It is possible that a disabling condition can pose a threat to the person's identity and self-concept. This may affect the person's ability to deal with his/her environment, including relationships, be it with persons who are close or in wider contexts. Ross and Deverell (2007:15) state that people with a chronic condition have a constant struggle to lead valued lives and maintain definitions of self that are positive and worthwhile.

One young mother with mobility impairment (a friend of *disAbility* ConneXion members) shared that she still feels sensitive about her personhood and her disability, to such an extent that she mostly does not want to talk about it. In her childhood, her family would not take her to church, pretending that she was ill. She always felt that they were not proud of her.

1.3.3.2 Low self-esteem

In spontaneous discussions and sharing several members from *disAbility* ConneXion spoke of the lack of self-confidence and sense of helplessness that people with disabilities sometimes feel. Examples of these are their difficulty in asking for help because of the fear that they might inconvenience other people. Specifically, in the African culture, it is difficult for women with disabilities to openly speak about the complexities of their own lives. Many of them do not see any better possibilities for themselves, such as, leaving an abusive relationship.

A few church leaders who participated in the exploratory meeting of February 2009 shared their observations that while they tried to show confidence in people with disabilities, there may be a need for counselling to develop their confidence. On the positive side, a church leader whose wife is a wheelchair user mentioned the role of a sense of humour in keeping psychologically healthy while living with a disability.

Razaka (2005:37) emphasises that low self-esteem of people with disabilities must be seen in the context of the general inaccessibility of society to them. When society is inaccessible, the voice of people with disabilities is not heard, and in many cases, such oppression becomes internalised, which aggravates their

experience of a low self-esteem. Eventually, many do not have the confidence to speak up for themselves.

However, amidst issues of low self-esteem, it is not pity that people with disabilities are asking for, as illustrated by the following remarks:

“Pity de-humanizes me; it says I will not get anything right, while I know I can achieve things. I may do them a bit differently and a bit slower, but the end result is the same”.

“The able-bodied community needs to discern the difference between pity and appropriate concern”.

In summary, living with a disabling condition can pose a threat to a person’s self-concept and finding a meaningful life. Being dependent on others for help and struggling against an inaccessible society may result in a person with disability, internalising the oppression that he experiences. Thus the voices of persons with disability are not heard.

1.3.4 Oppressive faith practices that hamper inclusion of persons with disabilities

Some faith practices and beliefs about disability in faith communities are experienced very negatively by people with disabilities.

According to the stories of disAbility ConneXion members, they are sometimes offended by church leaders who impose themselves and their prayers and healing practices on people with disabilities. Experiences shared were: *“We are perceived only as in need of prayer for healing from our disability, while all other aspects of our lives are simply ignored”.*

Other hurtful experiences included being accused by church leaders of having demons that cause their disability. A pastor shared her own experience with a family member who is deaf and was told by church leaders that he has demons. *“Today he is a successful person with a lovely family, so where are those demons now?”* A young lady was coerced into prayer practices and shouted at to start

walking. When she fled from the church the leader shouted at her, “*Look what Satan does*”.

With regard to these negative (almost abusive) experiences of people with disabilities, Lane (1992:22) refers to a ‘victim theology’. She echoes the reality of people pronouncing that those who are not healed of their disabilities lack faith. She describes it as “spiritual abuse”, which is the act of denying disabled people their full humanity. Such abuse produces spiritual wounds, a sense of meaninglessness and despair.

The church’s lack of attention to the specific questions people with disabilities have of their faith hampers their inclusion in the church. *disAbility ConneXion* members admitted that some people with disabilities do indeed have difficult questions of faith, such as: “Why does God allow me to be like this?” Some people with disabilities may go through seasons of blaming God. However, they felt the role of the church should be to help them grow to spiritual maturity and find spiritual meaning in their life with disability, rather than being accused of a lack of faith. Treolar (2002:594) confirms that people with disabilities can use their spiritual beliefs to establish meaning for their disability and its challenges.

The lack of recognition by the faith community that people with disabilities can contribute to the spirituality of the church also hampers their inclusion. *disAbility ConneXion* members felt that they could make a meaningful contribution to the spirituality of the church and even fulfil leadership roles. A middle-aged man with paraplegia shared his insight that non-disabled people can actually learn from the faith of disabled people. He illustrated this by relating how he had to hold on to God in difficult times and how his faith encouraged others who were close enough to him to understand the process. However, he observed that this rarely happens. Treolar (2002:599) confirms this, stating that people with disabilities are confronted with the limited readiness of the church to welcome them. So often, the point of departure in perceiving people with disabilities is that they are viewed as a burden or a drain on the limited resources of the church (Treolar, 2002:599).

In the exploratory meeting of February 2009, church leaders did not comment substantially on the aspect of faith practices related to disability. In general the

voice of the church leaders at this meeting was that they are trying to show unconditional love to people with disabilities. However, in a subgroup of the meeting which I observed one person with disability in the group who expressed her frustration about being regarded as demonised and being coerced into prayer for healing, was met with apathy (silence to be precise) from the church leaders in the group.

In summary, people with disabilities experience oppressive practices in faith communities. For example, they are coerced into prayers for healing and being blamed for not being healed. Some are regarded as demonised and their questions of faith are not addressed. These experiences are confirmed by the writings of Treolar (2002:559).

1.3.5 The lack of sensitivity and etiquette in relating to people with disability

In my interaction with people with disabilities in this research project, I learnt that etiquette and sensitisation in the context of disability refer to ways of interacting with people with disabilities that respects the person as a human being and that is sensitive to his/her limitations.

disAbility ConneXion members reported regular experiences of non-disabled people who do not know how to interact appropriately and with respect to wheelchair users and may address their caregivers instead of themselves. This lack of appropriate interaction is aggravated by a general gap between able-bodied and disabled people in church, as the latter are often allocated specific “separate” places in church in which to sit.

disAbility ConneXion members and their friends mentioned that able-bodied church members lack the basic etiquette of how to approach disabled people, for instance, how to interact with a blind person or how to help families who may hide their disabled members at home. In general, church members may feel pity for people with disabilities but are not sensitive about treating them with respect and dignity.

In the exploratory meeting of February 2009 church leaders revealed their need to teach their members about the needs and experiences of people with disabilities. “How do church members perceive people with disabilities?” was a question posed in this regard. One church leader shared the fact that she is specifically aware of the needs of Deaf people, but also feels that the church is not ready to receive Deaf people in their midst.

The above experiences of the awkward interaction between disabled and non-disabled people are also described by United Spinal Association (2008:10,12,18). Examples are a non-disabled person asking a wheelchair user if he could hold things for him/her, grabbing the arm of a blind person in order to guide him, pretending to understand what a person with a speech impairment is saying or obscuring one’s face when communicating with a person with hearing impairment.

Based on the experiences of the *disAbility* ConneXion members, their friends and church leaders in the exploratory meeting (February 2009), the five themes discussed above, emerged as critical for their inclusion and exclusion in faith communities. The inaccessibility of church buildings and procedures; experiences of exclusion from the church community; psychological issues of people with disabilities such as feelings of inferiority; oppressive faith practices that hamper inclusion of people with disabilities and the lack of sensitivity and etiquette of relating to people with disabilities, all seem to contribute to a problem of exclusion of people with disabilities in faith communities.

1.4 PROBLEM STATEMENT

A problem statement in research is about the focus of the research endeavour. It is the beginning of a research process, of identifying an area of interest, then clarifying and refining the idea and producing a clearly posed statement. This is critical for the rest of the research process because it will determine the focus of all that will be relevant or not for the purpose of the research. (Fouché and De Vos, 2005:100).

From the social problem of exclusion of people with disabilities in faith communities as described in the previous section, the following **research problem** emerged:

- *disAbility* ConneXion members who are people with disabilities feel excluded from their churches and want to take action to change the situation in South Africa, but lack knowledge on which to base the action.
- Although guidelines for the inclusion of people with disabilities in faith communities are available in other countries, for example the USA, this knowledge is not contextually and culturally appropriate to the South African situation which *disAbility* ConneXion wants to address.
- *disAbility* ConneXion members felt their knowledge and experience is a valuable, but incomplete, starting point for development of such guidelines for South Africa. Although they have suggestions on how faith communities need to be sensitised, they also realise that these suggestions are limited and there is a need to explore the experiences of a larger group of people with disabilities and more church leaders.

The need for more comprehensive knowledge and understanding of experiences and suggestions of people with disabilities and the church from which they feel excluded, on which to base guidelines for promoting inclusion, was therefore the motivation for this study.

1.5 THE RESEARCH QUESTION, PRIMARY GOAL AND OBJECTIVES OF THE STUDY

Based on the above-mentioned problem statement, the ensuing **question** for this study was as follows:

What are the experiences, perceptions and suggestions of people with disabilities and church leaders regarding the inclusion of people with disabilities in faith communities on which practice guidelines for inclusion can be based and developed?

In order to answer this question, the **primary goal** of this study was to gain an in-depth understanding of the experiences, perceptions and suggestions of people with disabilities and church leaders regarding the inclusion of the former in faith communities on which to base the development of guidelines for inclusion.

This research goal was broken down into **objectives** which form the steps to be taken in order to achieve the goal. The stated research goal therefore consisted of the following research objectives:

- To explore and describe the experiences and suggestions of people with disabilities relating to their inclusion in faith communities.
- To explore and describe the experiences and suggestions of church leaders with regards to disability and the inclusion of people with disabilities in faith communities
- To explore and describe the suggestions of people with disabilities and church leaders for practice guidelines for the inclusion of people with disabilities in faith communities, in order to develop culture and context specific guidelines for their inclusion in South African churches. The latter will be an application of the knowledge gained and not part of the actual research.

1.6 THE RESEARCH APPROACH

A research approach is the basic framework, which provides guidance about all facets of a research study. For Creswell (2003:3) such a framework consists of three elements, namely, the philosophical assumptions about what constitutes knowledge claims, the strategies of inquiry and the specific research methods that will be used. Different research approaches such as quantitative, qualitative and mixed methods of quantitative and qualitative approaches all have these three elements.

In the section below, a description of the qualitative research approach is given with the reasons why it was chosen for this research project.

1.6.1 Description of the qualitative research approach

A qualitative research approach is a broad umbrella term for research methodologies that explore, describe and explain persons' experiences, behaviours interaction and social contexts, without the use of statistical procedures or quantifications (Fossey, Harvey, McDermott and Davidson 2002:717). It uses a process where participants in the research give account of their meanings, experiences and perceptions of a phenomenon. It includes their own written or spoken words that portray their beliefs, insights and values (Fouché and Delport, 2005:74). Corbin and Strauss (2008:12) expand on this by saying the qualitative research approach allows the researcher to discover how participants form their meanings in the different contexts where they live. In this way the research approach has a fluid, evolving and dynamic nature, in contrast to rigid structures of quantitative research.

Qualitative research ensures the "thick descriptions" of participants' opinions and meanings. Babbie and Mouton (2006:272) refer to this phrase as a rich, lengthy, detailed description that captures the sense of actions as they occur. These expressions of the participants may also help them to understand their own context better.

Qualitative research also gives the opportunity for new knowledge, not previously researched, to be produced and can be based on the multiple meanings of individual experiences with the intent of developing a new theory (Creswell, 2003:181). This is done through collecting open-ended emerging data and developing themes from this data. The study on the experiences of inclusion and exclusion of persons with disabilities in faith communities could contribute to new knowledge not previously researched from a social work perspective. This can assist churches and people with disabilities to develop guidelines to promote their inclusion in faith communities.

1.6.2 Characteristics of qualitative research

Some **characteristics** of qualitative research, outlined by Creswell (2003:181), that are applicable in this research are discussed below.

- Qualitative research takes place in the natural setting and actual context of the participants' living experience. This provides an enabling environment for the participants to be comfortable with the researcher. Therefore interviews were planned to be conducted in the communities where the participants live and worship, at their homes for the individual interviews and at churches for the groups. This would allow the researcher to observe the community and their experiences.
- Qualitative research uses multiple methods that are interactive with participants (Creswell, 2003:181). These methods provide the opportunity for the researcher to connect with the participants on a personal level and to learn from them. The researcher brings his whole self into the process, sees himself as a research instrument and has the ability to see value in the work that is produced (Corbin and Strauss, 2008:12). Therefore multiple methods of data collection such as interviews, focus groups and observation providing the opportunity for collection of in-depth data were planned. From the responses to open-ended questions and discussions of experiences, themes for understanding the meanings, perceptions and suggestions could emerge.
- Qualitative research is emergent rather than tightly prefigured (Creswell, 2003:181). Several aspects can change during a qualitative research project. These changes can be the questions in the interview guide, or the type of participants that are invited for interviews, or opportunities to do focus groups. Qualitative research asks the researcher to use such instances of change as an opportunity to enrich the process.
- Qualitative research is fundamentally interpretive with the researcher making an interpretation of the data (Creswell, 2003:182). This means developing a description of what was found in a particular setting, analysing it for themes and sub-themes and finally making an interpretation about its meaning.
- The qualitative researcher views social phenomena holistically (Creswell, 2003:182). Rogers, as referred to by Grobler, Schenck and Du Toit,

(2005:3) expands on what “holistic” implies, namely the various perceptions, feelings and values of the participants. In this study, these perceptions, feelings and values of both interest groups were to be explored to ensure that a rich and comprehensive understanding could be developed. Space needs to be allowed for complex and interactive narrative which could enhance the quality of the study, for example having translators and enough time available in interviews and group discussions.

- Qualitative research uses complex reasoning which is inductive, which Speziale and Carpenter (2007:459) describe as the process of moving from specific observations to generalizations. From the observations of specific experiences of many individuals on inclusion and exclusion of people with disabilities in faith communities, themes could emerge that could provide generalizations on which to build guidelines for use by other faith communities.

From the above descriptions of qualitative research it seemed that it is applicable for this study. The goal of the study was to explore and describe the experiences, perceptions and suggestions of people with disabilities and church leaders regarding the inclusion of people with disabilities in faith communities. Therefore, a qualitative approach was applicable as exploration is the essence of qualitative research.

1.7 RESEARCH DESIGN

Within the wider context of the qualitative research approach, the next step was to set out the research design of the study. The following is a description of the concept ‘research design’ and how it was planned to be applied in this study.

1.7.1 Description of research design

A research design is the practical plan for a scientific inquiry. Babbie and Mouton (2006:72) introduce the topic of **research design** by describing it as the planning of the scientific process with two major aspects. These aspects are firstly the need to specify what is to be found out as clearly as possible, and secondly the best way to do it. The bottom line of scientific inquiry is observations to be made and

interpreting these observations. One has to determine *what* will be observed and analysed, *why* and *how* it will be done. The choice of design has to be related to the evidence or data that will be needed to answer the research question.

Research design also refers to groups of small worked-out formulae from which qualitative researchers can select one or more that may be suitable for their specific research goals (Fouché, 2005:268). However, it is accepted that qualitative researchers also develop their own designs as they go along using one or more of the available strategies or tools as a guideline. Research design is about the options available to a researcher to study certain phenomena according to certain 'formulae'.

According to Babbie (2007:87) the most common designs for research are explorative, descriptive and contextual research designs. These three were found to be the most applicable to this study and will be described below.

1.7.2 Exploratory research design

An exploratory research design is about an attempt to obtain a basic familiarity with a topic (Babbie and Mouton, 2006:79). It is used when a researcher examines a new interest and usually answers a "what" question. In this research the objective was to explore the "what" experiences of inclusion/exclusion of people with disabilities in their faith communities and the experiences of church leaders regarding the inclusion of people with disabilities in their faith communities. It also sought to explore "what" are the suggestions from these two interest groups which could be used as guidelines in a process of social change in faith communities. To this end, I planned to use the data collection methods of in-depth individual interviews, focus group interviews and observations (Babbie and Mouton, 2006:80). These methods will be described in section 1.8.2.

An exploratory design is also used in cases where little is known about the topic. This was particularly applicable to this study since literature searches did not reveal any studies done on the topic in South Africa from a social work perspective.

1.7.3 Descriptive research design

A descriptive research design is usually used to give a more comprehensive picture of a group of people. According to Fouché and De Vos (2005:106), descriptive research presents a picture of the specific details in a situation, social setting or relationship and also focuses on “how” and “why” questions. It also means a more intensive, richer and thicker examination of phenomena and their deeper meanings.

One of the objectives of this study was to get a more comprehensive picture of experiences of people with disabilities in their churches, as perceived by themselves, but also by church leaders. Alston and Bowles (2003:116) indicate that semi-structured interviews could be a useful method to collect data for a descriptive research design. Questions and probes were therefore used to explore the richer meaning of the experiences of participants and in this way get thicker descriptions of why there are barriers to their inclusion and what would remove these barriers. The use of semi-structured interviews will be further discussed in section 1.8.2.2.

1.7.4 Contextual research design

Contextual research design, which also had relevance for this study, is focussed on the specific context and culture of the people in the research study. Babbie and Mouton (2006:272) describe contextual design as the qualitative researcher’s preference for understanding events, actions and processes of participants in the specific context of their daily lives. It is only if one understands events against the background of the whole context and how such context confers meaning on the events concerned, that one can truly claim to “understand” the events. The method for this qualitative contextual research design will be focus group interviews (Babbie and Mouton, 2006:292), which will be further explained in section 1.8.2.1.

The study included people from a range of cultural and faith contexts. Part of the motivation for this study lay in the fact that although guidelines for inclusion of people with disabilities in faith communities exist, these have been developed in

America and were not found to be contextually applicable in the South African context.

The perceptions of the church leaders from different contexts were also explored in terms of their cultural and church perspectives of disability, as well as their actions that lead to either inclusion or exclusion.

1.8 RESEARCH METHOD

The following paragraphs cover the different aspects of the research method, namely, the population and sampling of participants, the methods of data collection, data analysis, data verification and ethical considerations, which are applicable for exploratory, descriptive and contextual research designs.

1.8.1 Population and sampling for the data collection process

I will first explain the relevant concepts of population and sampling and then give the criteria of inclusion in the sample for this study.

Although the terms population and universe are often used interchangeably, Strydom (2005b:193) explains the distinction between the two. Universe means “..all potential subjects who possess the attributes in which the researcher is interested”, while population “ . . refers to the individuals in the universe who possess the specific characteristics” needed for the study. Therefore a population is drawn from the universe as it is a narrower connotation of the specific and realistic characteristics that the researcher is interested in studying to answer the research questions for the study (Yegidis and Weinbach, 2002:180)

The **population** for this study included people with disabilities and church leaders in the Pietermaritzburg / Msunduzi local municipality. This area was chosen because it is the geographical area where *disAbility ConneXion* operates.

However, this entity would have been too big and no research project could include studying all cases. Therefore, from the above-mentioned population a **sample** of people to participate was drawn according to specific criteria. The concept sampling refers to the process used to accumulate a portion of the

population for study (Nieuwenhuis, 2007a:79). In this way, the researcher is enabled to obtain better information from a sample of specific people than from an entire population.

Two types of sampling were applicable to this study, namely snowball and purposive sampling. Firstly, **snowball** sampling is a non-probability sampling method (Babbie and Mouton, 2006:167). It refers to the process of accumulation as each located subject suggests other subjects. In this study, I planned to start by interviewing participants as suggested by *disAbility* ConneXion core group members. (Details of these core group members will be given in chapter two, section 2.3.4). These participants were then to be asked to suggest more participants from their community.

Secondly, in **purposive** sampling, participants are selected purposefully because of their knowledge of and ability to describe the phenomenon, enabling the qualitative researcher to achieve an in-depth understanding thereof (Donalek and Soldwisch, 2004:356). This purposive sampling was planned to be applied as set out below.

The following criteria for inclusion in the sample were applicable:

Concerning **people with disabilities**, participants would be representative of the following groups:

- Adult persons representative of the different disability types, namely physical, sensory or intellectual impairment since these different disabilities may have a specific bearing on their experiences in churches.
- Males and females, equally represented as far as possible
- People living in the wider Msunduzi / Pietermaritzburg area, including the suburbs as well as the townships, Imbali and Sobantu.
- People with disabilities from the Zulu speaking (or other African language speakers), English and Afrikaans language groups to represent different cultures.

- Members from different church groups namely main line churches, charismatic churches and African independent churches in order to hear the possible difference in experiences.
- Fathers and/or mothers of children with disabilities.
- People who were willing and available for the interviews.

Purposive sampling techniques were also to be employed to procure a sample of **leaders of faith communities**: Participants belonging to this interest group would be included in the sample according to the following criteria:

- Church leaders from the wider Msunduzi / Pietermaritzburg area, including the town as well as the townships, Imbali and Sobantu.
- Church leaders from a variety of main line, charismatic and African independent churches, in order to compare the possible difference in experiences.
- Church leaders from the Zulu speaking (or other African language speakers), English and Afrikaans language groups
- Leaders from churches who do include people with disabilities, as well as churches who do *not* have any people with disabilities. This would allow exploration of the possible difference in experiences.
- Church leaders who are willing and available for the interviews.

In qualitative research it is customary not to determine the **size of the sample** at the outset of the study since **saturation** should determine the sample size. This means that multiple participants are to be interviewed until the same data appears repeatedly. The repetitive nature of the data is an indication for the researcher that saturation of data is reached and the process of data collection can be concluded (Speziale and Carpenter, 2007:31).

1.8.2 Method of data collection

The four main methods of qualitative data collection are observations, individual interviews and focus groups, documents and audio/visual materials (Creswell, 2003:186).

As referred to in section 1.6.2, the methods of qualitative research designs selected for the purpose of this study, were focus group discussions, individual interviews and observations because of their value in a qualitative study. The three methods are described in further detail below.

It was planned to discuss the data collection procedures with the core group members of *disAbility ConneXion*, with the suggestion of the three methods. The input of the core group members was asked regarding the sample (see sections 1.2 and 1.8.1) and how to implement the data collection. (Details of these core group members will appear in chapter two, section 2.3.4).

1.8.2.1 Focus group interviews

Focus groups interviews (FGI) are particularly useful in qualitative research. FGI can be described as a space where people get together and create meaning among themselves around a specific topic (Babbie and Mouton, 2007:292). The shaping and reshaping of opinions can provide a richness of data for the topic of the study.

Yegidis, Weinbach and Morrison-Rodriguez (1999:128) state the following advantages of FGI:

- It encourages people to talk about sensitive issues because there is emotional support.
- Members are stimulated to talk about experiences that they otherwise may not have remembered.
- For the researcher there is also the benefit of collecting data from many participants in a short period. (Yegidis, et al. 1999:128).

In terms of organising the focus groups, I planned to implement the suggestions of Holloway and Wheeler (1996:148) by ensuring a convenient venue, putting members at ease about the topic, setting ground rules that would enable everybody to participate equally and balancing extreme views of members with that of the majority. Techniques to cultivate in-depth discussion as listed by the United Nations University (1993:6) would be applied to enhance the depth of the discussion. These were making use of pauses and prompts to encourage a member to continue to talk; a probe that can help a person to give more information, for example “Could you explain further..?”; and rephrasing if a group member finds it difficult to understand a question.

I planned to record the focus group interviews with a digital voice recorder (Nieuwenhuis, 2007a:89). This would allow me to give my full attention to the discussion. Furthermore I planned to transcribe the recordings in order to do the data analysis.

For this study I planned the following focus group interviews:

- Two groups with people with disabilities, from each of the townships around Pietermaritzburg, Imbali and Sobantu. Each group would consist of eight to ten people invited according to the criteria as mentioned above. Each group would meet once. These group interviews would be conducted in isiZulu with the help of a translator Mrs Bongzi Zuma.
- Two groups of church leaders from the above-mentioned townships, also with eight to ten people invited according to the criteria for church leaders as set out above. Each group would meet once, since it would be difficult to get the commitment of people to attend on more than one occasion. The groups would be conducted mainly in English but with the help of the same isiZulu translator where necessary.

1.8.2.2 Individual interviews

An individual interview is “a two-way conversation in which the interviewer asks the participant questions to collect data and to learn about the ideas, beliefs, perceptions, opinions and behaviours of the participant” (Nieuwenhuis, 2007a:87).

The purpose of qualitative interviews is to obtain rich descriptive data that will help the researcher to understand the participant's construction of knowledge and social reality. The type of interview appropriate to this study is a **semi-structured interview** aided by a short **interview schedule** with **open-ended questions** to guide the interview.

Semi-structured interviews consist of a set of predetermined questions for a participant which allows for further probing and clarification of answers. The interview schedule defines the list of questions which are appropriate for obtaining the data that is needed. However, these questions are open-ended allowing participants to respond freely from their own perspectives. Therefore this type of inquiry needs the close attention of the researcher, because it is easy to get sidetracked by trivial aspects not related to the study (Nieuwenhuis, 2007a:87).

Probing techniques are helpful, namely detail-orientated probes, 'who', 'where', 'what'; elaboration probes such as 'Will you tell me more?'; and clarification probes to check understanding such as 'Did I hear you correctly?' Empathetic responses to evoke further exploration may be appropriate at times as participants may share painful feelings (Nieuwenhuis, 2007a:88).

Recordings of the individual interviews were planned in the same way as for the FGI's.

For the purpose of this study the following individual interviews were to be conducted until data saturation is reached:

- People with disabilities from the Afrikaans and English speaking communities.
- Church leaders from the Afrikaans and English speaking communities.

1.8.2.3 Observation

Observation as a third method of data collection is described by Nieuwenhuis (Nieuwenhuis, 2007a:84) as follows: "It is the systematic process of recording what the researcher observes regarding the behavioural patterns of participants and occurrences without necessarily questioning or communicating with them". In

qualitative research, this technique enables the researcher to gain a deeper insight and understanding of the phenomena being observed. Babbie and Mouton (2006:295) point out the following advantages of such observation. It forces the observer to familiarise himself/herself with the subject; it allows previously unnoticed aspects to be seen; people's action are probably more telling than their verbal accounts and observing these are valuable; and it is unobtrusive, but when obtrusive, the effect wears off in reasonable time.

In applying this technique, I prepared myself with a clear idea of what it is I wanted to observe, namely anything that may relate to the experiences of exclusion and inclusion of people with disabilities in faith communities, such as non-verbal behaviour because of negative experiences with the church. The type of observation would be that of "participant as observer" (Nieuwenhuis, 2007a:85), getting myself immersed in the setting of the *disAbility ConneXion* group and the church leaders in order to gain an insider perspective of the situation. To this end, I planned to spend as much time as possible with the participants, by socialising with them before and after interviews and group discussions.

Recording my observations was planned to be done by means of anecdotal notes in my journal, of what I heard, saw and experienced while with the participants.

1.8.2.4 Preparation for the data collection and preparation of the participants

Preparation for data collection is about convening all the necessary aspects for the process of data collection. Tutty, Rothery and Grinell (1996:60) set out these aspects as preparing oneself as the researcher, preparing the way to the interviewees, and preparing the interviewees themselves.

In **preparing myself**, I planned to re-visit the literature on interview skills and techniques (Greeff, 2005:288) as well as consider my position as an outsider to the Pietermaritzburg area and the community of people with disabilities who live there. I needed to take stock of my possible biases and prepare myself to be as open as possible towards the context of the people with disabilities and church leaders whom I hoped to interview.

To **prepare the way to the interviewees** (Tutty, et al. 1996:62), in other words to gain access to them, I planned to liaise with the core group members of *disAbility ConneXion*. These members were well connected to the disability community around Pietermaritzburg and would be able to prepare the way to interviewees. I also prepared to discuss with them ethical issues such as confidentiality, informed consent and avoidance of harm to the interviewees.

In **preparing the individual interviewees** for the interviews I drafted a letter of invitation which explained what the study is about, where all the interviews would take place, the questions to be asked and that all information would be kept confidential. The person is then invited to participate on a voluntary basis (see appendices 1, 2 and 3 for English, Afrikaans and isiZulu invitation letters). In discussions with the core group members we were to compile a list of suggested names of people with disabilities and church leaders. Getting the invitations to these potential participants was to be done in two ways. In some cases the core group members were to contact the people and ask for their involvement. In other cases the telephone numbers were to be given to me to contact the people myself. As far as possible the letters of invitation were to be given to the participants beforehand.

Preparation for the focus groups (people with disabilities and church leaders) to be conducted in isiZulu, was planned to be done with the help of the translator, Mrs Bongzi Zuma, who was also a core group member. This preparation would include suggestions of possible participants from Sobantu and Imbali to be invited. I, as the researcher, would prepare written invitations with an explanation of the study, the criteria for selection as a participant, the questions and a consent form. This would allow participants to take an independent decision to participate on a voluntary basis. We planned for Mrs Bongzi Zuma to deliver these documents and explain them to the participants in their own language. Upon signing the consent forms, the date, time and venues of the focus group meetings would be set for the participants' convenience.

Preparing the interview guides was also done in collaboration with the core group members from *disAbility ConneXion*. Possible questions were formulated for people with disabilities and church leaders:

Questions for people with disabilities (see appendices 4, 5 and 6):

- I'm interested to know more about your life, living with a disability. Would you like to tell me more?
- How do you participate in activities of the church? Tell me more of your involvement.
- What good or positive experiences have you encountered at church?
- What makes it easy to be part of the church?
- What makes it difficult to be part of the church?
- Can you suggest how the church can include people with disabilities in all their activities? What can the church do to make it easier for people with disabilities? (to indicate criteria for inclusion in the church).

Questions for church leaders (see appendices 10, 11 and 12 for English, Afrikaans and isiZulu interview guides):

- How do you understand the inclusion of people with disabilities in churches? What does it entail?
- What kind of disabled people do you have in your church?
- From your perspective, how integrated do you think they feel in the church?
- What do you think helps the inclusion of people with disabilities in your church?
- What do you think hinders the inclusion of people with disabilities in your church?
- What do you think could be done in the church to make life easier for people with disabilities?
- How would you accompany ("walk the road with") a person with disability who wrestles with the question: Why am I like this?

Preparation was made to **capture** the data with a digital voice recorder (Greeff, 2005:298). All focus group discussions and individual interviews would be recorded, transcribed and, where necessary, translated and prepared for analysis. Where possible the Zulu translation would be verified by an independent translator. All these recordings would be kept in a safe place to which only I, as the researcher, would have access (see section 1.8.5 on ethics and confidentiality).

1.8.2.5 The role of the researcher

The role of the researcher in the data collection process needs to be clarified. Creswell (2003:184) sets out several points on the position of the researcher in qualitative research. Because the inquirer is involved in a sustained and intense experience with the participants, a range of strategic, ethical and personal issues is introduced to the process. The inquirer therefore has to explicitly identify his/her biases and values. In addition, gaining entry through the community's gatekeepers is essential.

The study was planned to take place in a trans-cultural situation, where I as a white Afrikaans-speaking female had to relate to English-speaking and black Zulu-speaking participants. However, the *disAbility* *ConneXion* group had established themselves as a culturally and racially mixed group who complemented each other. In my sharing with them I planned to build on these relationships which contributed to mutual understanding and trust (Creswell, 2003:185).

Furthermore, I was aware that for some participants their disability could be a sensitive issue. I therefore planned to be empathetic to such persons who might need to be supported throughout the process and assured that if they wanted to they could opt out (Creswell, 2003:184).

1.8.2.6 The pilot study

In preparation for this study, a pilot study was planned. Bless and Higson-Smith, (2000:155) give the following definition of a pilot study: "A small study conducted prior to a larger piece of research to determine whether the methodology, sampling, instruments and analysis are adequate and appropriate". A pilot study could have several benefits, for example, gaining an overview of the field of

investigation, ensuring that the appropriate questions are asked and THAT specific participants are included because of their ability to provide rich information about the topic (Strydom, 2005c:206).

In this research project the pilot study was planned to consist of:

- Two interviews with people with disabilities
- Two interviews with leaders of churches
- One focus group with people with disabilities in order to verify the appropriate questions

The intention was to test the appropriateness of the questions of the interview guide and the criteria for inclusion in the sample.

1.8.3 Data analysis

Data collected in a research endeavour have to be analysed in order to see how it answers the research question, goal and objective. Data analysis can be described as the process of trying to establish how participants make meaning of a specific phenomenon by analysing their perceptions, attitudes, understanding, knowledge, values and experiences in an attempt to approximate their construction of the phenomenon (Nieuwenhuis, 2007b:99).

The practical process of analysis and coding as suggested by Creswell (2003:191) was to be applied in this study. The coding steps are originally from Tesch (1990:142):

The researcher works with the data in the following way:

- Gets a sense of the whole by reading all the transcripts carefully and making notes in the margin of ideas that come to mind on each topic.
- Chooses a transcript either the on top of the pile, or one with rich meaning, and reads through it while asking, "What is this about?" in terms of underlying meaning. Makes notes of these impressions.

- Repeats the process until a list of topics or themes is acquired. These themes are then grouped according to major topics, unique topics and “left-overs”.
- With the list at hand, the data is re-visited. Each theme is given a code and the codes are written next to the appropriate segments of the text. It is possible that new themes can emerge, which are then added to the scheme of themes.
- Finds the most descriptive wording for the themes, which can possibly have sub-themes, categories and sub-categories. This will indicate the relationships between the different parts of the data.
- Makes a final decision on the abbreviations or codes for each theme, sub-theme, category and sub-category.
- The data belonging to each theme is assembled in one place and the analysis process can then be completed.

In presenting the research findings, this data analysis is then subjected to a literature control, i.e. comparing and contrasting the research findings with available literature in order to portray the rich meaning of responses from participants.

1.8.4 Data verification

Data verification is about ensuring the trustworthiness of a research project, in other words, establishing validity and reliability of qualitative research. Qualitative research is trustworthy when it accurately represents the experience of the study’s participants (Speziale and Carpenter, 2007:460). Guba’s model of trustworthiness (in Krefting, 1991:214-222) has four characteristics namely truth value, applicability, consistency and neutrality. Each of these is discussed below:

- Truth value
Truth value refers to the confidence of the researcher regarding the truth of the findings in relation to the research design, the participants and the context. A qualitative study is credible when it presents such an accurate

description of human experience that people who share the same experience will immediately recognise the descriptions. Such truth value will be obtained from and is subject to what participants share about their experiences. Lincoln and Guba as referred to by Krefting, (1991:217) call this “credibility” which can be ensured by a number of strategies.

- Reflexivity: the qualitative researcher needs to prevent a too close relationship with for example the participants, in order not to lose his ability to interpret the findings. A process of reflexivity will assess the influence of the researcher’s own background, perceptions and interests on the process. To this end, Good and Cooper (in Krefting, 1991:218) suggest the use of a journal with three types of information. A daily schedule and logistics, a list of methods used, and a write up of all thoughts, feelings, ideas, frustrations and problems that give an opportunity to become aware of the researcher’s biases. Once aware of these biases and possible preconceived assumptions, researchers may alter the way that they collect the data or approach the analysis, to enhance the credibility of the research.
- Interview techniques such as reframing, repeating and expanding of questions can also provide the opportunity to cross check the meaning of responses from participants.
- Triangulation, which is the convergence of multiple perspectives for mutual confirmation of data, enhancing its credibility powerfully, was planned to be applied in various ways (Krefting, 1991:219). Triangulation of data collection methods was possible by planning individual interviews, focus group discussions and observation. Triangulation of data sources was possible by including people with disabilities, with different disabilities, from different cultures and different churches as well as church leaders from different cultures and denominations.
- Applicability
Applicability refers to the degree to which the findings can be applied to

other contexts or generalised to other larger populations. According to Guba (in Krefting, 1991:216) this can be established through transferability. A key factor in transferability is the representativeness of informants of the particular group. For this purpose, two strategies were planned to be applied in this study. These were a nominated sample and providing a detailed background of the informants and their context.

- For a nominated sample, a panel of judges can help in the selection of informants to be as representative as possible of the phenomenon under study, the experiences of people with disabilities in their faith communities. One or two persons, typical and long-time members of the group, are identified as ideal representatives (Guba in Krefting, 1991:216). In this study the core group members of *disAbility ConneXion* were in a position to be the panel of judges who could suggest the nominated sample.
- Providing a detailed description about the informants and their context allows others to assess how transferable the findings are. This is, in the first place, the responsibility of the researcher while others can then make the judgments for transferability. Krefting (1991:216) states that the adequacy of such data is of particular importance in studies regarding people with disabilities, because people with the same conditions may be very different in their functionality.
- Consistency
Consistency refers to the question whether the findings would be consistent if the study was to be replicated with the same subjects or in a similar context. In order to achieve consistency, the research methodology should be according to dependent strategies. For this study, I planned to apply the three strategies of Guba as referred to by Krefting (1991:216).
 - The dense description of research methods as they were applied in data collection, analysis and interpretation. This would provide the information as to how repeatable the study might be or how unique the situation is.

- The code-recode procedure in analyzing the data by coding it twice with an extended time space in between.
- The enhancement of dependability by the involvement of an independent coder. The researcher and the independent coder would independently code the data and through discussions reach consensus with the study leader on themes, sub-themes and categories.
- **Neutrality**
Neutrality is the extent to which the findings are free from the influence of bias. However, since no researcher can be completely free from biases, one can at the most, be transparent and acknowledge these. To achieve conformability several strategies such as a conformability audit, triangulation and reflexive analysis will be used. I planned to apply the latter as described above in this section 1.8.4, regarding truth value (Lincoln and Guba in Krefting, 1991:217).

Through employing these strategies of credibility, applicability, consistency and neutrality, the researcher planned to verify the trustworthiness of the study.

1.8.5 Ethics

Ethical principles need to be followed to ensure that no aspect of a research project is to the detriment of its participants.

The concept “ethics” can be defined as a set of moral principles which is widely accepted, and which offers rules and behavioural expectations about the most correct conduct towards experimental subjects such as participants, employers, sponsors, other researchers, assistants and students (Strydom, 2005a:57). Strydom further states that ethical principles should be internalised in the personality of the researcher to the extent that ethically guided decisions are taken throughout the process. For the purpose of this study the following four principles were found appropriate and planned to be upheld:

- **Avoidance of harm**
This principle implies that participants should not experience any negative

effects, physically or emotionally, as a result of their involvement in the study (Strydom, 2005a:58). Therefore it was planned to explain the content of the interviews to participants to ensure that they understood that it was about *their* experiences and finding ways to benefit *them*. Specifically vulnerable people would have to be protected, for example, women with disability who are sometimes not well accepted in their families and who may have felt too vulnerable to participate in the study. Such persons would be given enough space to decide if they really wanted to be involved.

- Informed consent

Informed consent is about the endeavours to inform participants in a research project as appropriately as possible. This includes all possible and adequate information on the investigation, all procedures that will be followed, and the possible advantages, disadvantages and dangers. The emphasis is on accurate and complete information. This implies that participants should be legally and psychologically competent to comprehend what is asked of them and thus be able to make a voluntary and informed decision (Strydom, 2005a:59).

Application of this principle was followed by planning to discuss a written letter of invitation (see appendix 1, with Afrikaans and isiZulu translations in appendices 2 and 3) with all possible participants informing them of the purpose and content of the study, assuring them that they may withdraw at any stage and that they will not be coerced into participating. Participants would be asked to sign a consent form (see appendix 13) translated into Afrikaans and isiZulu (see appendices 14 and 15). In the case of participants who are illiterate, the preamble and consent form would be translated verbally.

It was important for the researcher to acknowledge that research might be associated with power and therefore participants might feel obliged to take part, simply because they were not familiar with research processes and would not feel free to refuse participation. Therefore preparation was made to present the consent form in such a way, that prospective participants had

the freedom to take an independent decision about whether to participate or not.

- Prevention of the deception of participants

It is possible that researchers can withhold information or give incorrect information to prospective participants in order to ensure that they do participate (Strydom, 2005a:60). It was possible that the questions might give rise to either fear or unrealistic expectations by the people with disabilities. Therefore the purpose and use of the research and how the findings might be implemented should be explained.

- Anonymity and confidentiality

It is important to distinguish between confidentiality and anonymity (Strydom, 2005a:61). Confidentiality implies that only the researcher and possibly a few members in the research team will be aware of the identity of participants. Anonymity on the other hand means that no one, including the researcher, is able to identify any participant in the data collection documents. The principle of anonymity was not applicable in this study since the interviewees were asked to sign their names when giving consent to participate.

The researcher of this study had to commit herself to ensuring that the privacy of participants would not be encroached upon, by respectfully negotiating their cooperation. It was planned to keep any identifiable information for the access of the researcher only. Names of participants were not to be disclosed on any documents such as transcriptions and the research report that would be read by anyone else. Audio recordings were to be locked away where only the researcher could have access to them.

In this study the researcher endeavoured to adhere to ethical principles in order to ensure that as far as possible participants did not experience any negative effects. These principles are: avoidance of harm, informed consent, prevention of deception and confidentiality of all participants.

1.9 CLARIFICATION OF KEY CONCEPTS

In the following paragraphs I will give definitions from literature of the key concepts used in this research report including my working definitions as applied in the study.

1.9.1 Accessibility and inaccessibility

The accessibility of built environments concerns how easily, safely and equally people with specific needs or impairments can use buildings, facilities and constructed spaces. Physical and other barriers discriminate against people with specific needs like mobility impairment, by preventing them from moving freely and independently within their built surroundings. (South African Human Rights Commission 2002:6).

However, in its fullest sense access refers to physical access, communication access and social access to facilities and services. It implies that people with disabilities can without assistance, approach, enter, pass to and from, and make use of, an area and its facilities without undue difficulties (Christian Blind Mission - CBM, 2007:33). Inaccessibility therefore implies that people with disabilities experience barriers that exclude them from participating fully in society because of their impairments. In the context of this study, it is furthermore understood that physical barriers are often accompanied by attitudinal barriers, where the way that people think about disability determines whether they include or exclude people with disabilities.

In the context of faith communities, accessibility for people with disabilities refers to access to all the buildings of the church complex, access to information like announcements about church activities, and access to participation in liturgy, activities and leadership. This would imply that some adaptations may be needed to ensure that people with disabilities can participate in the life of the church.

1.9.2 Attitudes towards disability

Attitudes towards disability can be described as the core manner in which individuals think about disability and persons with disabilities. It is this way of

thinking that leads to practices that either exclude or include persons with disabilities (Christian Blind Mission, 2007:33).

1.9.3 Church or Faith communities

Church and faith communities refer to any of the following as identified in discussions with *disAbility* ConneXion members:

- Main line churches, for example, the Anglican Church, Roman Catholic Church, Reformed churches which are nationally represented.
- Charismatic churches, for example, City Harvest, Pentecostal church.
- African independent churches which have no specific network with other churches and operate as individual groups.

1.9.4 Church leaders

References in this report to church leaders as participants, usually mean the official pastors of churches. However, when recommending the roles of church leaders in chapter five, any person who takes leadership and initiative, who has concern for and is knowledgeable about disability, can be regarded as a church leader.

1.9.5 Deaf people

People who are deaf since birth (pre-lingual) regard themselves as a cultural group and prefer to identify themselves as **Deaf** people (with capital letter D). They use South African Sign language for communication (Smit, 2010).

1.9.6 Disability and impairment

It is important to distinguish between these two concepts as described below. In discerning between disability and impairment, it is understood that disability is the way(s) in which people with impairments are discriminated against through physical and attitudinal barriers in society. These barriers cause their disability.

Disability:

Disability can be described as the interaction between a person with impairment or a health condition and the negative barriers of the physical environment, including attitudes and beliefs (Christian Blind Mission, 2007:35).

For the purpose of this study, disability is understood as the physical barriers that people with impairments experience in being unable to access the physical environment, as well as the attitudinal barriers to their full participation in society.

Impairment:

An impairment can be described as a characteristic and condition of an individual's body or mind which unsupported, has limited, does limit or will limit that individual's personal or social functioning in comparison with someone who has not got that characteristic or condition. Impairment relates to a physical, intellectual, mental or sensory condition (Christian Blind Mission, 2007:36).

For the purpose of this study, impairment is seen as the loss of body function or structure that necessitates an adaptation in activities of daily living.

1.9.7 Etiquette

A general definition of etiquette reads as follows: the formal rules of correct or polite behaviour in society or among members of a particular profession (Oxford Advanced Learner's Dictionary, 2010: s.v. "etiquette").

The meaning of etiquette adopted in this study is interaction with people with disabilities that respects the person as a human being and that is sensitive to his/her limitations.

1.9.8 Faith practices

Faith practices are the way things are done in relation to one's faith. This could include prayer, worship, singing, preaching and healing practices.

1.9.9 Non-disabled and/or able-bodied people

Terms for people **without** disabilities are not standardised. In this study non-disabled is the term of preference, although in a few cases “able-bodied” is used.

1.9.10 Persons with disabilities

Persons with disability can be described as follows: A person (or people) with an impairment or health condition who encounters disability or is perceived to be disabled (Christian Blind Mission, 2007:44).

Terminology for people with disabilities is not standardised. In some countries the preferred term is “disabled people”. In this study the preferred term is “person(s)/people with disability”. In cases where this is cumbersome or linguistically limiting, the term disabled people is used.

In a few places in this report, e.g. in tables, the term people with disabilities is abbreviated as PWD for the purpose of convenience, although the researcher wants to avoid creating another label for people with disabilities.

1.9.11 Social inclusion and exclusion

Christian Blind Mission (2007:41) defines **inclusion** as ensuring the ideal of equal opportunities and the exercise of rights – civil, political, economic, social and cultural – for every person, regardless of his/her social status, gender, physical or mental condition and ethnic affiliation.

For the purpose of this study, social **inclusion** will be understood as people with disabilities being fully part of society in all its dimensions and not discriminated against because of their impairments.

Therefore, for the purpose of this study social **exclusion** means to be deprived or denied of any benefits and participation in society that people without disabilities can access.

Another aspect of inclusion is gender inclusivity. In this report I generally refer to a person as he or him. This is done for brevity sake, although including she and her

is implied. Quotes from participants, which are not gender inclusive, were left as such.

1.10 STRUCTURE AND FORMAT OF THE RESEARCH REPORT

The report comprises five chapters:

Chapter 1 provides a general introduction, problem formulation and motivation for the study, the research approach, the research design and method, ethical considerations, clarification of key concepts, and the provisional outline of the research report.

Chapter 2 focuses on the researcher's application of the qualitative research approach and the exploratory, descriptive and contextual design. The chapter will describe how it was implemented and how challenges were experienced.

In chapters 3 and 4 the research findings are presented, discussed and compared with existing literature on the topic, i.e. a literature control is performed.

Chapter 5 provides a summary of the research report and outlines the overall conclusions and recommendations.

1.11 CONCLUSION

This chapter has provided an introduction and background to the study on the inclusion of people with disabilities in faith communities. An account was given of the initial exploration of the topic with the two interest groups, namely people with disabilities and church leaders. The research approach, research design and research method as planned for the study were then set out. Clarification of the key concepts was made.

The following chapter will explain how the research methodology was applied in the given practical circumstances of the research context

2 CHAPTER 2: APPLICATION OF THE METHODOLOGY

TRAVELLING ACCORDING TO THE MAP

2.1 INTRODUCTION

Chapter one of this report, provided a background to the research on the inclusion of people with disabilities in faith communities, including the methodology that was planned for collecting and analysing the data to answer the following research question:

What are the experiences, perceptions and suggestions of people with disabilities and church leaders regarding the inclusion of people with disabilities in faith communities on which practice guidelines for inclusion can be based and developed?

Based on this research question, the **primary goal** of the study was to gain an in-depth understanding of the experiences, perceptions and suggestions of people with disabilities and church leaders regarding the inclusion of the former in faith communities on which to base the development of guidelines for inclusion.

Furthermore, the research goal was broken down in to the following **objectives**:

- To explore and describe the experiences and suggestions of people with disabilities relating to their inclusion in faith communities.
- To explore and describe the experiences and suggestions of church leaders with regards to disability and the inclusion of people with disabilities in faith communities
- To explore and describe the suggestions of people with disabilities and church leaders for practice guidelines for the inclusion of people with disabilities in faith communities, in order to develop culture and context specific guidelines for their inclusion in South African churches. The latter will be an application of the knowledge gained and not part of the actual research.

In this chapter, I will describe how the methodology was actually applied in the different phases of the research procedure. I pick up from the description in chapter one, section 1.6 of the qualitative research approach and then spell out how the methodology panned out in the practical circumstances of the research context.

2.2 APPLICATION OF THE QUALITATIVE RESEARCH APPROACH

The qualitative research approach as described by Fossey et al. (2002:717) was applied in this study by exploring, describing and explaining persons with disabilities' experiences and contexts in their faith communities. Participants had the opportunity to give account of their meaning, experiences and perceptions through focus group interviews (FGI) and individual interviews through their own spoken words that portrayed their beliefs, insights and values (Fouché and Delport, 2005:74) as was planned and described in chapter one, section 1.7. The two interest groups were people with disabilities and church leaders.

The following **characteristics** of qualitative research proved to be alive in this research project (Creswell, 2003:181; see section 1.6.2).

2.2.1 The natural setting of participants

The research took place right in the natural settings of the participants including their homes, church buildings and community halls where they often have their meetings. I could observe how they have worked out practical ways of doing things that make life easier for them, for example building good relationships with people that can give practical support.

Observations were also made that community halls were mostly available for the regular meetings of the people with disabilities, although some were not easily accessible for those with mobility impairment. Some churches made some efforts to build ramps at the entrances, but did not think to make toilets accessible for wheelchair users. Some of the roads in townships are completely inaccessible for wheelchair users, with the consequence that they often cannot go where they would like. In rainy weather, this is even a bigger problem.

2.2.2 Multiple research methods that are interactive

Multiple interactive methods were employed to collect the data (Creswell, 2003:181). These were individual interviews as well as focus group discussions with people with disabilities and church leaders, where participants had the opportunity to talk at length about their experiences. Open-ended questions lead to in-depth discussions. Observation was the other method that I applied in the natural setting of the participants as referred to in section 2.2.1 above.

2.2.3 Emergent rather than prefigured

The research approach required a **flexible** approach, specifically in the data collection process. Availability of participants, transport, and translators often determined what could be done. For some people with disabilities, their energy levels had to be considered when planning activities such as meetings with the core group members. Flexibility in arrangements for venues for meetings was also necessary when we could not do meetings in the townships during political upheavals.

My liaison with the core group members played a helpful role in keeping an open mind in the research process. Their enthusiasm for the ultimate vision of a resource pack (giving guidelines) for the inclusion of people with disabilities in faith communities often led to creative ways for the data collection. An example was their suggestion for me to do a focus group with both people with disabilities and church leaders together.

2.2.4 Interpretive process

Qualitative research is about interpreting, analysing and drawing themes from the collected data (Creswell, 2003:182). From the specific experiences of many people with disabilities and church leaders, the data was interpreted and analysed into themes, sub-themes and categories which now portray the voice of people with disabilities and church leaders in a comprehensive way. These themes are presented as the findings of the study in chapters three and four of this report.

2.2.5 Holistic perspective

A holistic perspective was followed in considering as far as possible the whole person of participants' in their experience of disability. In the case of people with disabilities, this included their feelings, values and perceptions about their disability and being excluded from faith communities. Through my probing in the individual and group interviews, they shared their values to be respected as people, the pain of not being respected, their longing to be heard and understood, and their commitment to speak their minds on their inclusion in the church.

Characteristics of qualitative research not mentioned in chapter one, but that emerged in the implementation of the research project, were the humanistic characteristic and the giving of thick descriptions.

2.2.6 Humanistic methods

The humanistic character of the qualitative research process is the way in which qualitative researchers look for the involvement of participants in data collection and seek to build rapport and credibility with these individuals (Creswell, 2003:181).

This process of direct involvement manifested largely in the connection between myself as the researcher, the core group members and some of the participants that I got to know quite well. I did several home visits to core group members and a few other participants, even after interviewing them for the research. In this way rapport developed amongst us, which gave the process an underlying strength. Because trust was established among us, we could take risks with one another, often asking for extra responsibilities and time when the research process demanded that. In a conversation with a core group member, we discussed in confidence a sensitive situation where somebody (outside of our own sphere) behaved inappropriately. The core group member said to me: "*Please correct me if ever I do something similar that is out of line*", demonstrating her trust in working together in the research process and with me as the researcher. This trust opened the space for the core group members to make more suggestions and discuss complexities of their lives in the church.

2.2.7 Thick descriptions of opinions

Among the characteristics of qualitative research that Babbie and Mouton (2006:271,272) present, are the following: process, and insider perspective, and description and understanding. The characteristic regarding description refers to “thick descriptions” of participants which is rich, detailed, lengthy and in contexts that are understandable to the participants themselves.

In this study, examples of the thick descriptions were the responses of people with disabilities regarding certain aspects of their life journeys. These were the onset of their disability, especially in cases of traumatic experiences like car accidents. Participants shared how difficult it was, how long it took them to make meaning, but also how they eventually came to acceptance and were able to face life again. Some of the thick descriptions of church leaders were from those who had experience of people with disabilities in their churches. They illustrated their efforts to be an inclusive community by showing unconditional acceptance.

In summary, this research project used a qualitative approach because its objectives were to **explore and describe** the meanings, perceptions and suggestions concerning the inclusion of people with disabilities in faith communities. The researcher therefore focussed on the very people who are affected in the phenomenon, namely people with disabilities themselves and leaders of faith communities. The evolving and dynamic nature of the approach yielded many thick descriptions of the voices of the participants.

2.3 APPLICATION OF THE RESEARCH DESIGN

As outlined in chapter one (section 1.7) a combination of three research designs, the exploratory, descriptive and contextual research designs, were appropriate for this study in order to specify *what* is to be found out in the research and secondly, the *best way to do it*.

The following sections 2.3.1 – 2.3.3 describe how these designs were applied in the study.

2.3.1 Application of exploratory research design

As set out in chapter one, (section 1.7.2) the exploratory design was suited to gaining an initial basic understanding of the phenomenon of inclusion/exclusion of people with disabilities in churches (Babbie and Mouton, 2006:79). This was achieved through the explorative “what” questions asked in individual interviews and focus groups to people with disabilities. Some of these exploratory questions, to a person with disability were: “What makes it easy/difficult for you to participate in the activities of the church?” and to a church leader: “What do you think helps/hinders the inclusion of people with disabilities in your church?” Participants had the opportunity to give their views and were often asked to expand in order for me to develop an understanding of “what” their experiences are about.

In response to these questions people with disabilities talked about inaccessibility of church buildings, oppressing theological ideas and practices that hamper their inclusion.

Church leaders revealed their perceptions that the church is trying to include all people, that they are not aware of people with disabilities in their churches and that they don’t see the necessity to make special provision for people with disabilities.

The findings of these explorations will be reported in full in chapter three.

2.3.2 Application of descriptive research design

The descriptive research design (section 1.7.3) is focussed on a more comprehensive picture of the phenomenon. After the initial explorative “what” questions, the researcher was looking to find answers to questions of “why” and “how”. For example, “Why do you think are the church buildings not made accessible?” Or “Why do you find these theological ideas so unacceptable?”

Examples of “how” questions to church leaders were about how they would accompany a person with disability with difficult questions and how they would enhance the inclusion of people with disabilities.

With both these interest groups, participants described their feelings, insights, perceptions and also frustrations in some cases. These findings will be reported in chapters three and four.

2.3.3 Application of contextual research design

The contexts of the participants was borne in mind by including people with disabilities and church leaders from a range of church backgrounds and cultural groups. As Babbie and Mouton (2006:272) explain, the context has to do with events, actions and processes in which the participants of the research are involved. The participants gave their different meanings of a phenomenon like disability, how they perceive inclusion and exclusion given the context of their different social worlds. Participants representative of different contexts presented different realities and different suggestions for inclusion.

The findings of these suggestions will be reported in full in chapter four of this report.

2.3.4 The participatory action research design

Originally the participatory action research design was considered for this study because of the origin of the problem in the community of disabled people, and their goal of doing something about it. Participatory research is a tool for bringing about social change through increased knowledge; thus improving the quality of life of participating communities (Bless and Higson-Smith, 1995:55). It also empowers the people to be involved in all aspects of a project, from planning to implementation.

However, as the design evolved, it was clear that the study was more characteristic of the exploratory, descriptive and contextual designs as described above. The ultimate goal of social change (as in participatory research) which would include developing guidelines for inclusion, would happen later and outside the study, based on its exploration and descriptions.

The participatory aspects that did emerge were limited to a few elements, namely valuing the opinions and thoughts of all participants through in-depth interviews, focus groups and participant observations (Bless and Higson-Smith, 1995:56).

With regards to this participatory aspect, specific mention needs to be made on the input of the core group members of *disAbility ConneXion* who helped to steer the data collection process. For the background of this group see section 1.2.

This core group consisted of the following people

- Mrs Barbara Watt, the coordinator of *disAbility ConneXion*, a person with paraplegia and a wheelchair user. She is an accountant by profession.
- Mrs Bongzi Zuma, a person with mobility impairment, with many years of experience as an advocacy officer at CREATE, a disability organisation in Pietermaritzburg.
- The Reverend Micheline Kamba, a person with mobility impairment, pastor of the Presbyterian Church in the Democratic Republic of Congo and presently a PhD student at the University of KwaZulu-Natal.
- Two other members of *disAbility ConneXion* sometimes attended the meetings as transport was available: Mrs Patricia Naidoo and Ms Zonke Cele, both with mobility impairment.

The participatory role of this group manifested in the following ways:

- Deciding on questions to be asked in individual interviews and focus group interviews.
- Selecting the participants representing the different variables, for example, different disabilities, cultural groups and churches. They provided the first names for the snowballing process.
- Helping to organise the focus groups. One member, Mrs Bongzi Zuma co-facilitated the groups with people with disabilities in the Zulu-speaking community and assisted with translation. The core group members also helped to find a co-facilitator for the groups with Zulu speaking church

leaders to ensure that the focus groups would be conducted in a culturally appropriate manner.

- Participating in bi-monthly reflection meetings with me as the researcher. It was in these meetings that they helped to keep focus on the research problem that asks for social change. For them the research findings would lead to a resource pack which could help churches to become disability-friendly.

The four research designs, namely exploratory, descriptive, contextual and participatory applied in the research project, helped to ensure a smooth process, which now describes the phenomenon of people with disabilities' experiences in faith communities.

2.4 APPLICATION OF THE DATA COLLECTION METHOD: THE POPULATION AND SAMPLING OF PARTICIPANTS

The following paragraphs will describe how I applied the sampling process to accumulate participants for the study.

2.4.1 The population

The study was done in the Pietermaritzburg/Msunduzi municipality, which is the capital of KwaZulu-Natal province in South Africa. The municipal area has a population of 616,730 (South Africa, 2007), spread over the city with its suburbs and surrounding areas like the Sobantu township to the east of the city and the Imbali township towards the southwest of the city.

Figure 2-1: Map of KwaZulu-Natal



The above map is based on Google maps. The city and suburbs are urban developed areas. In both the townships there is a range of different types of housing from small brick houses to informal shacks, but most have water and electricity access.

Concerning numbers of people with disabilities, the Department of Statistics (South Africa 2005:12) reported the disability situation of the KwaZulu-Natal province as follows:

Of the 2.25 million people with disabilities in the whole of South Africa, 470 588 disabled live in the KwaZulu-Natal province. The actual number of people with disabilities in the research area, namely Msunduzi Municipal district, is unknown. This figure may not be correct, as it is generally accepted that statistics for disability is very much under-reported. The other part of the population of the study, were church leaders of the various denominations and independent churches in Pietermaritzburg/Msunduzi municipality. The number of these church leaders is unknown.

2.4.2 Sampling

Two types of sampling were used, namely snowball and purposive sampling.

The process of snowball sampling was discussed with the *disAbility ConneXion* core group. The core group members knew the Pietermaritzburg area well and had many connections among people with disabilities and church leaders from the area. They suggested people with whom I could start the interviews. In some cases the core group members phoned the proposed participants, explained the research project and delivered the letter of invitation to them to make a decision to participate or not. In other cases, the core group members felt that I could contact the proposed names directly and ask their participation with the invitation letter. In two cases, people who were invited, phoned me before the interviews to say they rather would not participate. I assured them that that is understood.

After interviewing the first round of interviewees, these interviewees were asked to suggest others from the population of people with disabilities and church leaders. Purposive sampling was also applied and in discussion with the core group members, we agreed on representatives from the following groups of people for the two participant groups:

The people with disabilities were to include:

- Adult persons, representative of one of the different disability types, namely physical, sensory or intellectual impairment since these different disabilities may have a specific bearing on their experiences in churches.
- Males and females, equally represented as far as possible
- People living in the Msunduzi / Pietermaritzburg municipal area, including the suburbs as well as the townships, Imbali and Sobantu.
- People with disabilities from the Zulu speaking (or other African language speakers), English and Afrikaans language groups
- Members from different church groups namely main line churches, charismatic churches and African independent churches in order to hear the possible difference in experiences.

- Parents of children with disabilities, male or female.

The church leaders were to include:

- Church leaders from the Msunduzi / Pietermaritzburg municipal area, including the town as well as the townships, Imbali and Sobantu.
- Church leaders from a variety of main line, charismatic and African independent churches, in order to hear the possible difference in experiences.
- Church leaders from the Zulu speaking (or other African language speakers), English and Afrikaans language groups
- Leaders from churches who include people with disabilities as well as churches who do *not* have any people with disabilities. This would allow exploring the possible difference in experiences.
- Church leaders who were willing and available for the interviews.

Participants representative of the above criteria were included. In the case of participants with disabilities I had to work with those who were available and actually could not control the numbers of representatives of different disabilities, nor from different church groups.

Regarding church leaders, availability was largely the determining factor. I could not control the number of representatives from church groups. It was also not always possible to find church leaders who had people with disabilities in their churches. However, in the focus group interviews in Imbali, there were a few church leaders with disabilities.

The table below gives the overall picture of the sample: people with disabilities (PWD) who participated as individuals and in focus groups, and church leaders who participated as individuals and in focus groups.

Table 2-1: Overview of the sample

Participants	Total number of individuals interviewed	Total number of focus groups conducted	Total number of participants in the focus groups	Total number of all participants
PWD	14	5	25	39
Church leaders	8	1	8	16
Mixed group of PWD and church leaders	PWD	Church leaders	Church leaders with disabilities	Total no. of participants in mixed group
	4	3	3	10
Total number of all participants				65

In summary, the participants consisted of:

- People with disabilities: fourteen individuals and 25 in groups.
- Church leaders: eight individuals and 16 in groups.
- A mixed group of these two interest groups consisted of ten people. Four were people with disabilities, three were church leaders and three were church leaders with disabilities.
- A total of 65 participants.

2.5 COLLECTING THE DATA FROM PARTICIPANTS

This section sets out the process of data collection:

- Preparing for the data collection process.
- The pilot study.

- Data collection.
- Observations as part of the data collection.

2.5.1 Preparing for data collection process

Preparation for data collection was done in conjunction with the core group members. We had eight meetings where we discussed the following aspects of the data collection:

- Finding the participants: the core group members suggested names as was explained in section 2.4.2 above.
- Preparing the participants

A letter of invitation was written to the potential participants which explained the background to the research project and the invitee's own choice to participate or not - see appendices 1 and 7. This invitation letter was faxed, e-mailed or delivered by hand, before the interviews, either by myself or by some of the core group members. For the isiZulu-speaking participants the invitation letter was also translated into isiZulu and delivered by Mrs Bongzi Zuma in the course of her work in the townships where participants live.

- Preparing for the focus groups meetings

All the FGI's were to take place in the Zulu speaking community with the help of Mrs Bongzi Zuma and pastor Mbulelo Hina. This included delivering invitations, explaining to potential participants what the research is about, arranging venues, coordinating times and dates for meetings, and discussing how we will facilitate the focus group interviews.

I coordinated with Bongzi Zuma as a co-facilitator and translator in the two groups for people with disabilities. One group was to take place in Imbali at the community hall. The other group was to take place in Sobantu at the disability centre.

For the groups with church leaders, it was discussed with the core group members that it would be culturally appropriate to ask an African church

leader to help arrange these groups. Pastor Hina was suggested since we all knew him and he expressed his interest in the inclusion of people with disabilities in his church. I therefore coordinated with pastor Hina as a co-facilitator and translator in the two groups for church leaders. One group was to take place in Imbali at the community hall. The other group was to take place in Sobantu at a church.

- Preparing the data collection instruments

Preparing the data collection instruments was done as planned and set out in chapter one, section 1.8.2.4. Initially several questions were suggested around the many theological issues of healing for people with paralysis. Eventually it was decided that the questions should focus on what promotes or hinders the inclusion of people with disabilities in faith communities and not on healing per se - see the questions in appendices 4 and 10. For the Zulu speaking participants, the questions were translated by and discussed beforehand with the translators Mrs Bongzi Zuma and pastor Mbu Hina (see appendices 6 and 12).

- Preparing myself as the researcher

As I became involved in the research, I was aware of my position as an outsider to both the community of disabled people as well as the Pietermaritzburg area (cf. Creswell, 2003:184). I therefore made efforts to get to know the community. On two occasions, I accompanied the *disAbility* *ConneXion* group on a weekend retreat, which gave me the opportunity to build relationships with the wider group and to establish a common ground of understanding. I also used opportunities to visit several of them at home.

2.5.2 The pilot study

The pilot study (see chapter one, section 1.8.2.6) took place during February to May 2009 and consisted of the following:

- Two interviews with individual people with disabilities
- An interview with one individual church leader

- One focus group with people with disabilities

Through this process, I would determine whether the methodology would be appropriate and adequate. I therefore describe in the following paragraphs how it was done and the lessons learnt from the pilot process.

2.5.2.1 Pilot individual interviews

Two pilot individual interviews with **people with disabilities** were done as planned. Both the persons were English speaking, wheelchair users and the pilot interviews took place during a retreat weekend of *disAbility ConneXion* in March 2009. The questions were confirmed as appropriate. Concerning testing the interview guide (Strydom, 2005c:209), I noticed that the participants were eager to talk and I realised that some interviews would probably take longer than the one and a half hours originally anticipated. It was specifically the first question which asked the participants about their lives with disability that took a lot of time.

In the case of piloting the interview schedule for **church leaders**, I conducted only one pilot interview. This was with a pastor at an inner city church of Pietermaritzburg. He was an English-speaking person that attended the meeting of 18 February 2009 and had a positive attitude towards people with disabilities and therefore availed himself for the interview. The interview took place at his church office and it confirmed that no questions needed to be changed or added. What was revealed in this part of the pilot study was the practical situation of the difficulty pastors had to fit an interview into their busy schedules (cf. Strydom, 2005c:208).

2.5.2.2 Pilot focus group meeting

A focus group was done with five Zulu speaking people with disabilities from the Imbali township. The meeting was planned with the help of Mrs Bongzi Zuma, a member of *disAbility ConneXion* (see section 2.3.4). The two of us had a preparation meeting a few days ahead of the planned date and talked through all aspects of the meeting:

- Invitations: the invitation letter was delivered by Bongzi Zuma during the course of her work in the township.
- Participants who met the purposive sampling criteria, and were available, were invited to the meeting.
- The venue was the community hall in Imbali as arranged by Mrs Bongzi Zuma.
- The time of the meeting was set as convenient for everybody at 10.00.
- I arranged to have refreshments available after the meeting.
- Seating was arranged in a circle so that all participants and the facilitator could have eye contact.
- The meeting was planned to last about two hours.
- We discussed that we as facilitators needed to be unbiased as far as possible, and assure the participants that they would be free to give their honest opinions.

Concerning the facilitation of the meeting, we confirmed that I would be the main facilitator with Mrs Zuma doing the Zulu translations and where necessary, she would step in to probe for more responses from the group. We also brushed up on some group facilitation techniques.

At the time of the actual meeting there were political upheavals in the township, so Mrs Zuma deemed it necessary for the meeting not to take place in the township, but rather at the CREATE office which is in an easily accessible area of town. I reimbursed the attendees for their transport fare.

Group facilitation techniques like clarifying questions, probing and making sure that everyone's contribution is heard, enabled a lively group process (cf. United Nations University 1993:6). Participants were eager to talk and responded well to the questions. Their responses to the first question on their life with disability took very long and I realised that the question may have to be left out in the further groups.

The data from this group discussion were incorporated with all other findings in chapters three and four.

In summary, the group members were interested in the topic and my motivation for the research. They felt that in all their years in the disability movement nobody had ever spoken about how disability is perceived in the church. I explained the work of *disAbility ConneXion* and our commitment to promote the inclusion of people with disabilities in faith communities.

The lessons learnt from the pilot study were as follows:

- The questions as planned were appropriate. The first question to people with disabilities, namely about their life with disability would not be practical in the groups, because it would take too long. Therefore the introduction in the groups should rather be around their participation in the church.
- Some participants did not understand how research is done and needed explanation in this regard, e.g. some had the perception that they should give “correct” answers
- Getting the commitment of church leaders to participate and avail themselves for interviews might prove difficult because of their hectic time schedules and, in some cases, apathy about the topic.
- Facilitation of the Zulu speaking groups would be done with the help of the translator who could act as a co-facilitator to some extent. This needed to be well prepared for each of the groups.

The above lessons learnt confirmed Strydom’s description (2005c:215) of the purpose of a pilot study being to ensure that the main investigation itself will be worthwhile. A pilot study can give indications of which errors to avoid and which provisions to make for the actual study.

2.5.3 Data collection

Three methods were used to collect data from the participants, namely individual interviews, focus group discussions and observations.

The section is divided into the following sub-sections:

- Individual interviews with people with disabilities
- Focus group interviews with people with disabilities
- Individual interviews with church leaders
- Focus group interviews with church leaders
- Focus group interview: Mixed group of people with disabilities and church leaders

2.5.3.1 Individual interviews with people with disabilities

Interviews were chosen as one data collection method that suits the qualitative research approach of this study as explained in section 1.8.2.2, according to the interview schedule as set out in section 1.8.2.4.

Finding the participants was done in collaboration with the core group members as described in section 2.4.2.

Fourteen individual interviews were conducted with people with disabilities, by myself, in Afrikaans and English.

The following table gives a summary of the representativeness of the people with disabilities, interviewed individually, with regard to their gender, disability, church affiliation, language group and place of abode.

Table 2-2: Biographical profile of people with disabilities interviewed individually

	Name	Gender	Disability	Cause of disability	Church group	Language	Place of abode
1	AR	Male	Physical and Sensory: Blind	Accident	Mainline: Methodist	English	City, Suburb
2	KB	Male	Physical: mobility, amputation	Illness	Mainline: Dutch Reformed	Afrikaans	City Care centre
3	MB	Female	Physical: mobility	Ageing	Mainline: Dutch Reformed	Afrikaans	City, Care centre
4	CZ (parent)	Male	Intellectual: brain damage	Accident	Mainline: Pentecostal	Afrikaans	City, Suburb
5	FH	Female	Physical: contractures	Illness	Mainline: Baptist	English	City, Suburb
6	KG	Male	Physical: hemiplegia	Accident	Charismatic	English	City, Suburb
7	LD	Male	Physical: quadriplegia	Accident	Mainline: Pentecostal	Afrikaans	City, Suburb
8	LY	Female	Physical: contractures	Accident	Mainline: Anglican	English	City, Suburb
9	MN	Female	Physical: paraplegia	Accident	Mainline: Catholic	English	City, Suburb
10	PN	Female	Physical: quadriplegia	Illness	Mainline: Pentecostal	English	City, Suburb
11	PS	Female	Sensory: hearing	Congenital	Charismatic	English	City, Suburb
12	SM	Female	Physical: paraplegia	Accident	Charismatic	English	City, Suburb
13	SI	Female	Physical: paraplegia, mobility	Illness	No specific church	Afrikaans	City, Suburb
14	ZC	Female	Physical: paraplegia, mobility	Illness	Charismatic	English	Township

Following is a summary of the representativeness of the people with disabilities, interviewed individually regarding their gender, disability, church affiliation, language and place of abode:

Fourteen people with disabilities were interviewed individually, all in the adult age group. In terms of **gender** there were five males and nine females giving a good balance.

In terms of the **different disabilities** the majority were physically disabled which is usually the second biggest group of disabilities, after people with visual impairments (South Africa, 2005:14). People with physical disabilities, include those with mobility impairment involving the use of their hands or in other cases wheelchair users. One interviewee had two disabilities because of his accident, namely the impaired use of his hands as well as being blind. People with intellectual disabilities were not well represented.

Amongst the **causes of disability**, vehicle accidents counted for half of the sample. One parent had a child with an intellectual impairment caused by a serious bus accident. A woman had a hearing impairment as a congenital condition.

The different **church affiliations** were represented as follows: Nine people from mainline churches, four from Charismatic churches and one person did not belong to a specific church. Representation of church affiliation did not include African Independent churches, as this part of the sample was mostly from the Afrikaans and English cultural groups. The Zulu and African cultural groups were included in the focus group interviews.

Language representation was: nine of them were English speaking people and five Afrikaans.

Concerning the **place of abode** of the participants, most were living in their own homes in suburbs or in a care centre in a suburb. Participants from townships were not interviewed individually, as they were included in the focus groups.

All the interviews were conducted at the homes of the people with disabilities at a time convenient for them. The interviews took place as follows:

The researcher gave some background information and explained the purpose of the study.

I then put the questions as clearly as possible, ensuring that the participants felt capable of responding to them. Open-ended questions were utilised to allow the participants to respond in their own way. The opening question of asking about the person's life with disability proved to be a good starter as most of them responded

with much detail of their story. In some cases, I used clarification questions, where I was not sure of what was meant, like “Would you mind to expand on that please?” Probing was used to get information that is more specific where necessary. While I encouraged participants to talk as they wished, I needed to maintain some focus on the purpose, as some of them occasionally got side-tracked. I returned the attention to the questions by clarifying the purpose of the interviews, namely gathering the data that would really help me to gain understanding of their experiences about inclusion in faith communities. Using these interview techniques optimised data gathering (cf. Greeff, 2005:288).

All interviews were recorded on a **digital voice recorder**, which enabled me to concentrate fully on the interview, without having to make notes. This was done with the consent of the participants and nobody seemed to be disturbed by it.

In summary, the individual interviews proved to be useful in getting the perceptions and opinions of the participants. The open-ended questions provided an opportunity for them to talk at length about their experiences, though in some cases they were a bit too long-winded. Some participants felt free to express their emotions about their hurtful experiences from oppressive practices in churches (cf. Nieuwenhuis, 2007a:88).

2.5.3.2 Focus groups interviews with people with disabilities

Doing focus groups to collect data was chosen as it fits into the qualitative research approach and has the advantage of encouraging people to talk about sensitive issues, the stimulation of talking about things which they do not remember otherwise, and it helps the researcher to collect data from many participants in a short time. (Yegeedis et al. 1999:128)

Convening the focus groups was also done in collaboration with the core group of *disAbility ConneXion* as described in section 2.4.

The following five focus group interviews were conducted with 25 people with disabilities:

- The pilot group, as already discussed but incorporated here in terms of the total number of participants. The findings of this group will also be portrayed in chapters three and four.
- Imbali group
- Sobantu group
- Group of Deaf people
- Group of Blind people

The following table gives an overview of all the participants in the five groups, including the pilot group, Imbali, Sobantu, group of Deaf people, and the group of Blind people.

Table 2-3: Biographical profile of people with disabilities in five focus groups

Name of the group	Gender		Disability		Cause of disability		Church affiliation		Language	Place of abode
Pilot group	Female	2	Albinism	1	Congenital	1	African Independent	3	Zulu, translated to English	Imbali Township
	Male	3	Physical	2	Not revealed	2	Mainline	2		
			Parent of child with intellectual	1	Illness	1				
			Care giver of stroke patient	1						
Imbali group	Female	2	Physical	1	Not revealed	7	Mainline	7	Zulu, translated to English	Imbali Township
	Male	5	Visual	4						
			Speech	1						
			Intellectual	1						
Sobantu group	Female	4	Physical	3	Not revealed	6	Mainline	2	Zulu, translated to English	Sobantu Township
	Male	2	Intellectual	1			African Independent	3		
			Deaf	1			No church	1		
			Not revealed	1						
Group of Deaf people	Male	3	Hearing impairment: Deaf	3	Congenital	3	No church	3	Translated between Sign language and English	Imbali Township

Name of the group	Gender		Disability		Cause of disability		Church affiliation		Language	Place of abode
Group of Blind people	Female	2	Visual impairment: Blind	3	Not revealed	3	Mainline	3	English	Various Townships
	Male	1								
Total		2 4								

In summary, a total of 24 people with disabilities participated in five groups. Ten were female and fourteen males. The kind of disability with the highest number were people with visual impairment, namely seven; then people with physical impairment were six, hearing impairment were four; with albinism and intellectual one each. There was also a parent of a child with intellectual disability and a caregiver of a person who had had a stroke. The causes for disability were mostly not revealed. Participants were asked to write them on their consent forms, but eighteen of the 24 did not. Of the six people who did reveal the cause of their disability, four had a congenital disability and two had suffered an illness.

The church affiliations of the participants were represented as follows: fourteen were from main line churches, six from African Independent churches and four did not reveal their church affiliation.

Finding the participants

Finding the participants was done in the same manner as for the pilot meeting, with the help of *disAbility ConneXion* core group as explained in section 2.4 above.

Conducting the FGI in Imabli and Sobantu

As with the pilot focus group meeting (described section 2.5.2.2) Mrs Bongzi Zuma helped to select the sample and prepare them for the focus group interviews. She visited the participants (as she works in the Imabli and Sobantu townships), explained the research project and delivered the letter of invitation. When participants agreed to take part, a time and venue was set as convenient to them.

Given the limited knowledge of isiZulu of the researcher, Mrs Bongi Zuma also assisted with isiZulu translations in the focus group interviews for people with disabilities.

Bongi Zuma then co-facilitated these two group interviews conducted in Sobantu with six people and one in Imbali with seven people, at their respective community halls.

Apart from the above planned groups, I also conducted two other groups, namely a group with Deaf people and a group and blind people.



Photo 2: Participants of the Imbali focus group interview

Focus group interview with Deaf people

When we could not communicate with a Deaf person in the Sobantu group as described above, I explored the idea of interviewing Deaf people with a Sign language interpreter. I discussed this with the core group and Bongi Zuma put me in touch with the Sign language interpreter, Mrs Lindiwe Duma, in order to arrange a FGI with Deaf people from Imbali. Mrs Duma and I met at her office to prepare for the FGI. She is a social worker and knows Sign Language since her previous job was with Deaf people. We arranged to deliver letters of invitation, a time and venue to meet with the three Deaf people that she knew. I then conducted the group interview at the Imbali community hall, with Mrs Duma translating between Sign language to English. This FGI did not reveal much since the interpreter's skills were limited. Talking about their experiences of not having access to a

church was outside of her sign language skills and the discussion did not reach much depth.

Focus group interview with blind people

Because I was aware of a blind man from the townships, working in the disability sector, who would not necessarily attend the groups in Sobantu and Imbali, I discussed the idea of doing a FGI with blind people with the core group members. They were in agreement and I then arranged with him to invite his wife and a friend (who are both blind). This group interview was conducted in English by myself and we met in a coffee shop.

Facilitating all these groups was done in the same manner as described above for the pilot focus group (section 2.5.2.2). Using group facilitation techniques, translating between Zulu and English, and the use of the digital voice recorder all contributed to constructive discussions in all groups except the group with Deaf people.

Questions used in the groups were the same as for the individual people with disabilities, with the exception of the first question, which was left out because it would take too much time for everybody in the groups to tell the story of their own disability. See list of questions in section 1.8.2.4.

In summary, the advantages of FGI as described by Yegidis et al. (1999:128) proved to work quite well in the data collection. Participants expressed their experiences in an honest way, for example, their expectations of the church. They seemed to be stimulated, and in some cases stayed behind after the groups and asked me questions about the research. Some others did not seem to understand the research process so well, and I had to make extra effort to use the techniques of probing and explanation (Holloway and Wheeler 1996:148).

The findings of all these focus groups will be discussed in chapters three and four.

2.5.3.3 Individual interviews with church leaders

The reasons for using individual interviews were the same as described in chapter one, section 1.8.2.2 for the qualitative research. In some cases of interviewing the

church leaders, it was difficult to get their commitment for the interview. However, using interview skills like encouragement and challenging (Greeff, 2005:290), mostly led to their becoming interested in the topic and giving rich descriptions of their experiences with people with disabilities and the church.

Finding the participants from the sample of church leaders in Pietermaritzburg was done with the help of the core group members as described in section 2.4.2.

Eight individual interviews were conducted with church leaders, in Afrikaans and English, at either their homes or their church offices at a time convenient for them.

The following table gives a summary of the people interviewed.

Table 2-4: Biographical profile of church leaders interviewed individually

	Name	Gender	Language	Church group	Place of abode
1	AB	Male	English	Mainline	City, suburb
2	BvA	Male	Afrikaans	Mainline	City, suburb
3	GS	Male	English	Mainline	City, suburb
4	JvN	Male	English	Charismatic	City, suburb
5	LS	Male	Afrikaans	Mainline	City, suburb
6	NS	Female	English	Charismatic	City, suburb
7	PRB	Male	English	Mainline	City, suburb
8	PM	Male	Afrikaans	Mainline	City, suburb

In summary, the profile of the church leaders that were interviewed individually is as follows:

Eight people were interviewed individually. Six of them were the leader pastors in their church, while two were prominent leaders with youth or women.

Seven were males, and one female.

Five were English speaking, while three were Afrikaans speaking. Pietermaritzburg is predominantly English speaking with not many Afrikaans-speaking churches (in personal communication with one of these church leaders).

They represented the following church affiliations: six from main line and two from Charismatic churches. This group of church leaders did not include anybody from

the African Independent churches, since these were to be included in the isiZulu speaking group interviews.

The church leaders were all from the suburbs of the city of Pietermaritzburg.

An interview schedule was prepared together with the core group members of *disAbility ConneXion* as previously explained (chapter one, section 1.8.2.4).

All the interviews were conducted in the same way as the individual interviews with people with disabilities described in section 2.5.3.1, using open-ended questions and techniques for exploration of the opinions of the participants.

As with all the other interviews, these were also recorded on digital voice recorder and transcribed afterwards (Greeff, 2005:298).

Topics covered in these interviews were an urge from the church leaders to people with disabilities to become part of the faith community; opinions about the oppressing theological ideas of certain churches and perceptions about the accessibility of their churches.

In terms of representatives from the various church affiliations, the larger main line churches were well represented. This was partly because they were prominent leaders in the church circles and easier to contact. Smaller denominations churches were not represented.

In summary, the purpose of qualitative interviews worked out quite well in the interviews with church leaders. They provided rich descriptive data which helped me as the researcher to understand their perceptions of the inclusion of people with disabilities in their faith communities (Nieuwenhuis, 2007a:87).

2.5.3.4 Focus group interviews with church leaders

The focus group method was chosen to collect data from church leaders in the isiZulu speaking community, because of the advantages of having access to several participants simultaneously and the stimulation in a group that will get participants to talk about sensitive issues (Yegidis et al. 1999:128). Furthermore, since a translator was needed to assist in the interviews with isiZulu speakers, it

was much easier to obtain this service for two FGI's as opposed to several individual interviews.

Convening the focus groups was done with the help of the core group members as described in section 2.4.2 and section 2.5.1

Two focus group interviews were planned with church leaders, although nobody turned up for one meeting. This was in spite of the invitations being extended by Pastor Hina and arrangements being confirmed to meet at the Imbali community hall. Follow-up was done by pastor Hina to try to establish the reasons. However, either the invitees could not be found or they said that had other commitments to attend to.

The other FBI for church leaders took place at Imbali Presbyterian Church and the following table gives an overview of the participants that attended:

Table 2-5: Biographical profile of participants in the Imbali church leaders group

	Name	Church group	Place of abode	
1	EM	Mainline	Imbali township	Church leader with mobility impairment, using a wheelchair
2	JM	African Independent	Imbali township	
3	MH	African Independent	Imbali township	Co-facilitator
4	ON	African Independent	Imbali township	
5	PN	Mainline	Imbali township	
6	PZ	Mainline	Imbali township	
7	WN	Charismatic	Imbali township	

Seven church leaders attended the FGI in Imabli. One of them was the co-facilitator of the discussion. Three church leaders were from the African independent church affiliation, three from mainline churches and one from a charismatic church. One pastor had a disability himself, as a result of an illness and he is using a wheelchair. This pointed out the problem of the inaccessibility of the church building where the meeting was held. He had to be carried up and down the steps to get into the church.

The **questions** asked in the groups were the same as those for the individual church leaders as listed in Appendix 10, with translations to Afrikaans and isiZulu, appendices 11 and 12.

Pastor Hina and I co-facilitated the discussion, with him taking the lead in introducing the research project, the questions and proceedings of the discussions. Where necessary I clarified the questions, probed for more responses and explored for underlying reasons for opinions. Bongzi Zuma was the observer and made notes during the meeting. She and I discussed her observations afterwards.

The discussion was done in English and isiZulu, with Pastor Hina doing the translation. All proceedings were recorded on the digital voice recorder with the consent of the participants.

Pastor Hina introduced the topic, as we were all aware that it was a new topic that the participants had never talked about before. I wrote the questions on a flip chart to help us focus on the questions and explained that everyone had the freedom to share their honest thoughts about the topic.

Flowing from the questions, topics covered in the FGI were around the absence of people with disabilities in the church; church leaders feeling there is not a problem for people with disabilities to be part of the church; uncertainty regarding people with disabilities and marriage; and the discrimination experienced by people with disabilities.

2.5.3.5 Focus group interview: Mixed group of people with disabilities and church leaders

The questions discussed were the same as originally set for the church leaders.

To help finding the participants, Pastor Hina was not available, so we asked the help of one young pastor who attended the above-mentioned church leaders group, Wanda Ntshela. We made the same preparations with him, as previously with pastor Hina. He did the invitations and agreed to co-facilitate the meeting with me.

The participants decided that the discussion could be conducted in English as all the participants were comfortable conversing in English. Pastor Wanda took the lead in the proceedings while I ensured that the focus was kept on the questions and explored points made by participants. Mrs Bongzi Zuma again acted as an observer and the proceedings were recorded as for the rest of the data collection.

The following table illustrates the profile of the attendees:

Table 2-6: Biographical profile of participants in the mixed group

	Name	Gender	Position	Church	Disability	Language	Place of abode
1	B W	Female	Leader of disAbility ConneXion	Charismatic	Physical	English	City Suburb
2	FY	Female	Church member	African Independent	Physical	Zulu	Imbali Township
3	JM	Male	Pastor	African Independent	No	Zulu/ English	Imbali Township
4	JM	Male	Elder	African Independent	No	Zulu/ English	Imbali Township
5	JN	Male	Pastor	Mainline	Physical	Zulu/ English	Imbali Township
6	MK	Female	Pastor. Member of disAbility ConneXion	Mainline	Physical	English	City Suburb
7	ON	Male	Pastor	African Independent	Physical	Zulu/ English	Imbali Township
8	WN	Male	Pastor. Co-facilitator	Charismatic	No	Zulu/ English	Imbali Township
9	ZC	Female	Member of disAbility ConneXion	Charismatic	Physical	Zulu/ English	Imbali Township

There were ten participants in total: Six church leaders with three of them having disabilities. Four other people with disabilities attended.

In terms of gender, there were six males and four females. Those with disabilities all had physical disabilities. The type of churches were two from main line churches, three from charismatic churches and four from African independent churches. Two people were English speaking and eight were isiZulu speaking.

The people with disabilities who attended were mostly from the *disAbility* *ConneXion* team plus one other person from the community. Regarding the attendance of church leaders, it was again disappointing for the *disAbility* *ConneXion* members that only five turned up, four of whom were already in the previous meeting of Imbali pastors (section 2.5.3.4). The following reasons for this poor attendance were given by some of the participants:

- Older church leaders do not support young pastors and their efforts in the community (pastor Ntshela who did the invitations for this meeting is a young pastor).
- Church leaders are oblivious of the plight of people with disabilities.
- Some church leaders do not want to be confronted with the issues of disability, for example there is a perception that all people with disabilities should be prayed for and be healed from their disability. Some church leaders do not know what to do if their prayers for healing are not answered and therefore they avoid the issue.

Issues covered in the FGI were: the ignorance of church leaders and –members concerning disability, the problem of perceptions of healing that cause people with disabilities to feel confused and the fact that church buildings are not accessible.

In summary, this section described the data collection process for the individual interviews and focus groups. The following paragraph will describe how data was collected through observations.



Photo 3: Participants at an accessible entrance to a church building

2.5.4 Observations as part of the data collection

As described in section 1.8.2.3 observation was part of the qualitative research approach. To this end I kept the research question, its goal and objectives in mind and looked for anything that might lead to a better understanding of the experience of exclusion of people with disabilities in faith communities (Nieuwenhuis, 2007a:84). For the main part my observations were done by spending time with participants before and after interviews and group meetings. At the group meetings there was mostly the opportunity to do so while having refreshments together after the meetings. I showed interest in the life situation of the participants by asking them about their daily living or I followed up on comments that were made during the interviews. After each session I made notes of what I had observed. The audio recordings also helped in this regard because, I could pay full attention to the dialogue and could pick up when participants became quiet or restless.

Because the individual interviews took place at the homes of participants who were people with disabilities, I also had opportunities to observe their surroundings, their level of independence, interaction with family members and events as they occurred in their own setting.

In two group meetings Mrs Bongzi Zuma agreed to be an observer. She afterwards shared observations with me, which were captured with my own notes.

The findings of these observations were integrated in the write up of all the findings in chapters three and four.

2.5.5 Capturing the data

As planned in chapter one, section 1.8.2.4, the data collected in the interviews and focus groups were recorded in audio format as suggested by Greeff (2005:298). The device was usually put in the middle of the circle of participants, but in an unobtrusive place. In some cases this was a problem where people spoke less clearly. Background noise was also a problem on a few occasions.

All the recordings were downloaded from the digital voice recorder onto my computer and transcribed into text format with a unique number assigned to each line for reference in the analysis. The identity of each participant was kept confidential by using only their initials.

2.6 DATA ANALYSIS

In order to establish how the collected data of a research process answered the research question, it needed to be analysed as planned in section 1.8.3. Data analysis is the process of establishing how participants make meaning of the phenomenon under study, including analysing their perceptions, attitudes, understanding, knowledge and values (Nieuwenhuis, 2007b:99)

As described in chapter one the data collected was analysed according to the steps as suggested by Tesch (1990:142). I did this by **coding** the data in the following way:

- I read through all the transcribed texts to get an overall meaning of what participants have shared and made notes of the overall impressions and themes that emerged.
- I began the coding process by looking at the more underlying meanings in one of the rich transcriptions and I made notes of these meanings. This process was repeated with a few other transcriptions. Tesch (1990:142) calls this the process of looking for “What is this about?” in terms of underlying meanings.

- These notes and impressions were re-worked to formulate major themes and some sub- themes that could serve as 'framework' to analyse the whole collection of data. As Tesch (1990:142) suggests, I allocated a code to each
- With this list, I worked through all the data to analyse it according to the major themes, sub-themes. In several cases subthemes were also divided into categories and sub-categories.
- I then compiled a table of all these themes, each with its sub-themes, categories and sub-categories together with substantiating story lines from the data. The first table was about the experiences of people with disabilities and church leaders, see chapter, three section 3.2 and for the table regarding suggestions to inclusion, see chapter four, section 4.1.
- I left the work for a period of about two weeks and then followed the same procedure again with a new set of print outs of the text transcriptions.
- I then aligned the two sets of tables with themes, sub-themes and categories and prepared the tables of themes to be discussed with my study supervisor.

For financial reasons, I did not make use of an independent coder, but agreed with my study supervisor that she would co-code and also analyse the data, following the above method. The above-mentioned tables of themes was then discussed with my study supervisor in order to reach a consensual meaning of the data and formulate the themes as clearly as possible. Partly because of the large amount of data, this was a very time consuming process. I also consulted with a qualitative research expert at the Department of Social Work, Unisa, as a sounding board towards a clearer formulation and outline of the themes.

As planned in chapter one, section 1.8.3, the findings of the study were subjected to a literature control. With the assistance of the subject librarian Mrs T. Erasmus at the Unisa library several library searches were done, utilising various electronic databases (Academic research primer; Google searches; Nexus data base of current and completed research in South Africa; Oasis; SocINDEX with full text).

From these literature searches, it appeared that a relatively small volume of literature is available on the topic, namely the inclusion of people with disabilities in faith communities *from a social work perspective*. Literature from a theological perspective based on research in the USA and Europe is readily available, but no South African literature could be found from a social work perspective. Furthermore, the available literature focuses on theological issues and changes to be made in churches without the perspective of integral roles of people with disabilities in churches.

The findings from the above-mentioned analysis will be discussed in two chapters of this report. Chapter three will present the experiences of people with disabilities and church leaders regarding inclusion and exclusion in the church. Chapter four will present their suggestions to promote the inclusion of people with disabilities in faith communities.

2.7 DATA VERIFICATION

The collected data had to be verified to ensure the trustworthiness of the research project as described in chapter one, section 1.8.4. The model of Guba (in Krefting, 1991:214-222) was used and the application is set out according to the following methods:

- Truth value
- Applicability
- Consistency

2.7.1 Truth value

To enhance the truth value of the data, I regularly reflected on the research process and made notes of my observations, feelings and thoughts. While I developed fairly close relationships specifically with the core group members of *disAbility ConneXion*, I realised that I was able to keep an objective position back in Johannesburg while being away from Pietermaritzburg. It was as if the geographical distance helped me to look at the research process and the data from a wider perspective.

Some 'member checking' also happened when experiences of focus groups were discussed with core group members. This was especially helpful in cases where a core group member had been part of the focus groups with people with disabilities.

Interview techniques such as reframing and cross checking helped me in many situations to get a better understanding of the meaning of responses. I often used the question: "Did I understand you correctly, did you mean . . .?" and I would give in my own words what I had heard (see chapter one, section 1.8.2.2 on interviews).

Triangulation to enhance the truth value of the research was applied in several ways. The three ways of data collection, namely individual interviews, focus groups and observation helped to bring together multiple perspectives. The triangulation of data sources, was achieved by including people with disabilities, church leaders and literature sources. For example in one core group meeting the members realised for the first time that it is often the case in the church that plans are not implemented, and that this does not apply only to the issues of people with disabilities. The "bringing together" of people with disabilities and church leaders showed that on both sides there is a continuum between willingness and withdrawal, which implies that both interest groups need to learn from one another.

2.7.2 Applicability

As stated in chapter one, section 1.8.4, Krefting (1991:216) indicates that applicability refers to the extent to which the findings can be applied to other contexts and settings. This is possible through the strategy of transferability, which is the ability of the research findings to fit into contexts other than that of the study situation, but with some degree of similarity. In this study two strategies were employed to ensure this transferability:

The core group members acted as a 'panel of judges' to help select a nominated sample of participants who were representative of the phenomenon of people with disabilities feeling excluded from faith communities.

Furthermore, the detailed description of the participants in the sample (see sections 2.4.2 and 2.5.3) indicating the parameters how participants were

selected, their demographic data, as well as the description of the methodology allow others to check the transferability of the findings.

2.7.3 Consistency

Consistency is achieved when a study is replicated using the same participants or a similar context and still reach the same findings (Krefting, 1991:216). In order to reach such consistency the strategy of dependability was employed in the following ways:

- A dense description of the methodology, as presented in this chapter, can enable someone else to follow the same method to collect and analyse data.
- I repeated the coding process two weeks after the first exercise. This helped me to take a fresh look at the data, re-consider the identified themes and align the two coding processes.
- For financial reasons the plan to use an independent coder did not materialise, but extensive time was spent in discussions with my study supervisor and the qualitative research expert in order to reach consensus on the meaning of the data.

2.8 ETHICAL ISSUES

Ethics in research include a set of moral principles that ensures the most proper ways of conduct of the researcher in terms of dealing with data and participants (Strydom, 2005a:56).

Given the possibility of using the results of the study to develop a resource pack, it was imperative to work with high ethical values and integrity. The research results have the possibility of becoming widely known in the country and I wanted to protect its credibility at all costs. Therefore, the following principles were applied as far as possible:

2.8.1 Avoidance of harm

It is the ethical obligation of a researcher to ensure that no research activities will cause emotional harm or physical discomfort for its participants (Strydom, 2005a:58).

I was aware that for some people with disabilities it could be emotionally disturbing to be asked to talk about negative experiences. I therefore repeatedly explained that they could opt out of the process. In two cases persons who were invited to participate, later phoned me to opt out. They felt they did not want to expose themselves and their stories. I re-assured them that this was completely acceptable. I also gave some emotional support where I felt it was necessary, for example, staying a while after the interviews, making small talk. I thanked most of the participants, sometime after my contact with them, either with a card or a phone call. All of them were delighted by this gesture, expressed their appreciation, and some of them described the interviews as a stimulating experience.

2.8.2 Informed consent

According to Strydom (2005a:59) participants in research need to be adequately informed of all possible advantages and disadvantages of taking part in such research project. In this study, the invitation letter distributed to all participants explained the research project in detail (see appendices 1 and 7, invitation letters to persons with disability and church leaders). This was mostly received with interest, although many of the illiterate participants were simply happy to accept the goodwill of the project. Consent forms, in English, Afrikaans and isiZulu, were signed by all participants, stating their voluntary participation. See appendices 13, 14 and 15.

2.8.3 Prevention of the deception of participants

Deception of participants may happen when the researcher finds it necessary to disguise the real goal of a study, or hide the experiences that participants may go through in the research (Strydom, 2005a:61). However, in this study, I found it easy to be completely open with all participants. The fact that I was constantly in

touch with the core group members helped to keep all information in the open for all to know about it. However, I do realise that in spite of my explanations of what research is, some participants may have had expectations of personal benefits by giving consent to participate. At the end of each interview I tried to again confirm the purpose of the study and that participants might benefit from it in churches that are disability-friendly.

2.8.4 Anonymity and confidentiality

In this study it was not possible to keep all participant names anonymous, since core group members suggested some of the names in the snowball sampling. Therefore, I explained to them that the data collected had to be kept confidential (Strydom, 2005a:61).

A further way of keeping the data confidential was in transcriptions of all the interviews. Only the initials of each participant were used to ensure that no participant could be recognised by anybody other than myself. These texts were only available to my study supervisor and myself. Because the data could possibly be used in future research, I will keep these transcriptions in a safe place where nobody else will have access to it. If it so happens that the data could be used again, I will ask permission from the participants, although it may be difficult to trace all the participants. Strydom (2005a:63) points out that most matters in social science could never have been researched if the privacy of participants was not encroached upon to some degree. Researchers therefore have to commit themselves to a process of negotiation under all circumstances.

2.9 CONCLUSION

This chapter explained how the research methodology was applied in the practical situation of the research context. The qualitative research approach, the explorative and descriptive research designs presented the voice of people with disabilities for their inclusion in faith communities. The chapter also explained how the analysis technique of Tesch (1990:142) was applied and adapted to analyse and interpret the data.

In looking back on this process of applying a qualitative research approach, I can draw some conclusions:

The qualitative approach suited the situation perfectly. It allowed for personal engagement with people who had a lot to say about their experiences. They were eager to talk about the topic, since it was the first time to address the issues of disability in the church.

The role of the core group members of *disAbility* ConneXion was significant in that they were “a point of reference” right through the process.

The focus group interviews in the townships had some weaknesses in terms of interruptions, background noise, and people not used to research processes.

The findings of the application of this research methodology and data collection will be described in the following two chapters.

3 CHAPTER 3: FINDINGS OF THE STUDY: EXPERIENCES OF PEOPLE WITH DISABILITIES IN FAITH COMMUNITIES

NARRATING THE JOURNEY (1)

3.1 INTRODUCTION

The original research question of this study was:

What are the experiences, perceptions and suggestions of people with disabilities and church leaders regarding the inclusion of people with disabilities in faith communities on which practice guidelines for inclusion can be based and developed?

Chapter one included the events that led to the motivation for doing this study, namely the social problem of the exclusion of people with disabilities of faith communities, as encountered in my work as social worker with the Leprosy Mission.

The qualitative research approach was selected to address the **primary goal**, namely, to gain an in-depth understanding of the experiences, perceptions and suggestions of people with disabilities and church leaders regarding the inclusion of the former in faith communities on which to base the development of guidelines for inclusion. This primary goal was broken down into the following objectives, which determined the questions that were asked to participants:

- To explore and describe the experiences and suggestions of people with disabilities relating to their inclusion in faith communities.
- To explore and describe the experiences and suggestions of church leaders with regards to disability and the inclusion of people with disabilities in faith communities
- To explore and describe the suggestions of people with disabilities and church leaders for practice guidelines for the inclusion of people with

disabilities in faith communities, in order to develop guidelines for the inclusion of people with disabilities in South African churches.

Chapter two outlined the process of the research itself, elaborating on the research approach used.

Following the exploratory, descriptive, contextual, and to a lesser extent, participatory designs, data was collected using qualitative research methods. Focus groups, individual interviews and observations were employed as data collection methods. The researcher conducted the following:

People with disabilities: Fourteen individual interviews

Five focus group interviews, with a total of 25 people.

Church leaders: Eight individual semi-structured interviews

One focus group, with eight people

A mixed group of people with disabilities and church leaders including ten people: Four people with disabilities

Three church leaders

Three church leaders with disabilities

Thus, the total number of the sample was 65 participants (see table 2.1 in section 2.4.2, overview of the sample). The biographical data of the participants appear in chapter two, section 2.5.3 together with an explanation of the data collection process.

Subsequently the data was analysed according to the eight step method of Tesch as described in chapters one and two (Creswell, 2003: 191-193), while focusing on how the data answered the research question and the research goal.

Chapters three and four will present the findings that emerged from this analysis. The findings will be presented as themes, sub-themes, categories and unique themes in tabular and narrative format with a literature control where possible, in which the data is compared or contrasted with existing literature or knowledge.

From the data analysis eight themes emerged. The first four themes are related to the **experiences** of people with disabilities and church leaders regarding the former's inclusion in their faith communities. The second four themes relate to their **suggestions** of how to enhance the inclusion of people with disabilities in faith communities. The first group of themes, namely the experiences, will be presented in this chapter and the second group, the suggestions, will follow in chapter four.

3.2 PRESENTATION AND DISCUSSION OF THEMES

As is applicable in qualitative research, in presenting these themes I will provide story lines or quotations from the transcribed interviews. Furthermore, comparison with the literature will contribute to the credibility of the study.

From the participants' answers to the questions in semi-structured interviews and focus group interviews, and the resultant processes of data analysis by the researcher, the following four themes concerning experiences of people with disabilities emerged:

- Theme one: The lived experience of a person born with disability or becoming disabled.
- Theme two: Significant others of people with disabilities experience changes in family relationships and life-style as a consequence of disability.
- Theme three: The person with disability's experience of the environment of the faith community.
- Theme four: How people with disabilities in faith communities experience others' perceptions of disability and healing.

These four themes were divided into sub-themes, categories and sub-categories as set out in the following table.

Table 3-1: Themes of experiences of people with disabilities

THEME 1: THE LIVED EXPERIENCE OF A PERSON BORN WITH A DISABILITY AND BECOMING DISABLED		
Sub-themes	Categories	Sub-categories
1.1 Emotional responses to the onset of disability	1.1.1 Participants responded to the onset of their disability with depression	
	1.1.2 The reaction to the onset of disability may be shock and disbelief	
1.2 Making meaning as one journeys on the road of disability	1.2.1 Journeying as a metaphor for meaning making	
	1.2.2 Re-constructing one's identity	1.2.2.1 Affirming one's personhood 1.2.2.2 Developing confidence in spite of disability
	1.2.3 Seeing purpose in living with a disability	
	1.2.4 Experiences of despair and hope	
	1.2.5 Dealing with questions about becoming disabled	
	1.2.6 Journeying on the continuum of acceptance and peace	
1.3 Being disabled: the challenges of daily living	1.3.1 Loss of relationships with friends	
	1.3.2 Loss of independence	
	1.3.3 Being marginalised and made to feel insignificant	1.3.3.1 Being absent from society because of immobility 1.3.3.2 Being absent from society because of inaccessible buildings 1.3.3.3 Being hidden by family
	1.3.4 Social isolation as a consequence of disability	
	1.3.5 Compounded and complicated process of ageing	
	1.3.6 PWD experience work-related challenges	

Sub-themes	Categories	Sub-categories
	1.3.7 Added financial burdens	
THEME 2: SIGNIFICANT OTHERS EXPERIENCE CHANGES IN FAMILY RELATIONSHIPS AND LIFE-STYLE AS A CONSEQUENCE OF DISABILITY		
2.1 The nature of parenting is changed		
2.2 Spouses of PWD have to take extra responsibilities		
2.3 Adult children of parents with disability have to take additional responsibilities		
2.4 Some families hide a disabled family member		
THEME 3: THE PERSON WITH DISABILITY’S EXPERIENCE OF THE ACCESSIBILITY OF THE ENVIRONMENT OF THE FAITH COMMUNITY		
3.1 The PWD experiences the physical environment of the faith community as inaccessible	3.1.1. Experiences related to the accessibility of transport	3.1.1.1 Accessibility of transport in well resourced communities 3.1.1.2 Accessibility of transport in less resourced communities
	3.1.2 Experiences of inaccessible church buildings	3.1.2.1 General comments on inaccessibility of church buildings 3.1.2.2 Inaccessibility of entrances 3.1.2.3 Inaccessibility of toilets
	3.1.3 Seating and other arrangements in the worship service are not conducive for participation	3.1.3.1 The lack of choice to sit in a comfortable place 3.1.3.2 Other unsuitable arrangements
	3.1.4 Times of services and meetings are inconvenient for people with disabilities	
3.2 PWD experience a general lack of awareness of their needs for accessibility in the physical environment	3.2.1 “There are no PWD in the church”	

Sub-themes	Categories	Sub-categories
	3.2.2 People are insensitive about the needs for accessibility for disabled people	
	3.2.3 In some places there is a growing awareness	
	3.2.4 People with disabilities are impatient about other people's lack of understanding	
THEME 4: HOW PEOPLE WITH DISABILITIES IN FAITH COMMUNITIES EXPERIENCE OTHERS' PERCEPTIONS OF DISABILITY AND HEALING		
4.1 Theological ideas that have an oppressive influence on the PWD's in faith communities	4.1.1 The perception that God meant everybody to be healthy and 'normal'	4.1.1.1 Everything must be 'normalised' 4.1.1.2 PWD become victims of healing practices 4.1.1.3 The compulsion to be healed
	4.1.2 The PWD is held responsible for lack of healing and the reality of suffering is ignored	4.1.2.1 Sin is regarded as the cause of disability and confession the requirement for healing 4.1.2.2 The person with the disability is blamed as being responsible for not being healed 4.1.2.3 The reality of suffering is ignored
	4.1.3 Biblical interpretations that portray PWD in a disrespectful way	
4.2 Theological ideas having a liberating influence on PWD's in faith communities	4.2.1 A spiritual focus in the church which does not emphasise the disability 4.2.2 PWD can make a contribution in the faith community	
4.3 Practices in faith communities that hamper the inclusion of PWD	4.3.1 Expectations regarding dress code for church	
	4.3.2 Cultural perceptions and rituals present in the faith community	4.3.2.1 People with disabilities cannot become leaders 4.3.2.2 Disability is an indication of punishment, relating to dissatisfaction of ancestors

Sub-themes	Categories	Sub-categories
		4.3.2.3 Disability is an indication of problems in the family relationships
	4.3.3 Oppressing messages communicated to PWD regarding marriage	
	4.3.4 The lack of respect for the person	4.3.4.1 Labelling and generalising 4.3.4.2 Using offensive terminology
	4.3.5 The lack of understanding disability	4.3.5.1 The perception of total incompetence of persons with disability 4.3.5.2 Being disregarded and being regarded as “different” 4.3.5.3 Church leadership are perceived as not understanding disability 4.3.5.3 Non-disabled church members are perceived as not understanding disability
	4.3.6 Patronising attitudes and behaviour hampering the inclusion of people with disabilities	4.3.6.1 Giving unwanted sympathy 4.3.6.2 Being insincere and expressing patronising appreciation 4.3.6.3 Making assumptions, “thinking <i>for</i> me” 4.3.6.4 Being judgemental 4.3.6.6 Being impatient in engaging with PWD

The above themes will be described in the following section, with direct quotes from the participants, and compared with literature.

3.3 THEME ONE: THE LIVED EXPERIENCE OF A PERSON BORN WITH DISABILITY OR BECOMING DISABLED

This theme, “the lived experience”, is understood in terms of Rogers’s explanation of “experiences” (cited in Grobler and Schenck, 2009:16). For Rogers, human

experience includes perceptions, needs, behaviour, emotions and values. These experiences cannot be separated from each other or from the person that has such experiences. In the sub-themes below, feelings of people with disabilities are understood as part of such human experiences.

This theme portrays the responses of participants to the following question:

I am interested to know more about your life, living with a disability, will you tell me more?

These experiences can be divided into three sub-themes, of which some also have categories and sometimes sub-categories:

- Emotional responses to the onset of disability
- Discovering and making meaning as one journeys on the road of disability
- Being disabled: the challenges of daily living

3.3.1 Sub-theme 1.1: Emotional responses to the onset of disability

An emotional response can be described as the feelings a person experiences as a result of an event (Oxford Advanced Learners Dictionary 2010: s.v. “emotional”). As mentioned above, Rogers includes emotions as part of the experiences of a human being (Grobler and Schenck, 2009:16).

This sub-theme is divided into the following categories:

- Participants responded to the onset of their disability with depression
- The reaction to the onset of disability may be shock and disbelief.

3.3.1.1 Category 1.1.1: Participants responded to the onset of their disability with depression

In depression related to loss and bereavement a person may feel hopeless about the future, feel he cannot go on living and tends to withdraw from family and friends (Kaplan and Sadock, 1991:59).

The following excerpts from the transcripts attest to this:

“I was in a bus accident with several of my family members . . .I became paralysed . I still had the use of my upper limbs . . . but I was so depressed that I stayed in bed for three years, not having the emotional energy to go out and face the world. I told my children to lock me up in the house; I just could not accept what [had] happened to me”.

“Sometimes I feel depressed . .I cannot do anything about my situation. Some days I wake up saying to myself, it is not worthwhile to carry on”.

Depression and related feelings of hopelessness and powerlessness are confirmed by Ross and Deverell (2007:39) as normal and a necessary part of the grieving process after becoming disabled. When people with disabilities are allowed to experience the depression, it gives them the opportunity to separate from the dreams they had for their lives.

3.3.1.2 Category 1.1.2: The reaction to the onset of disability may be shock and disbelief.

The following storylines illustrate this reaction:

A father who had three children involved in a bus accident narrated as follows:

“My daughter died, my one son suffered severe brain injuries and is ever since intellectually and physically severely disabled. My other son had several physical injuries and refused to talk for a whole week after the accident . .[a shock reaction to the accident]”.

A young father said to himself after being paralysed in an accident:

“This can’t happen to me, I will walk out of this hospital”.

He could not believe that he would be paralysed and denied the fact that he actually could not walk anymore.

These experiences are confirmed in the literature. Ross and Deverell (2007:36) state that responses of shock and disbelief are to be expected in the early stages of disability, when the disability is seen as the great spoiler of dreams. Kaplan and

Sadock (1991:59) state that grief after significant loss is often manifested as a state of shock that may be expressed as disbelief.

In summary, the above-mentioned emotional responses of people with disabilities, at the onset of their disability need to be seen as part of a wide range of possible emotional responses. Other emotional responses to the onset of disability mentioned by Ross and Deverell (2007:38) are denial, bargaining, guilt, anger, anxiety and acceptance. However, it was not the focus of this study to delve into all the emotional experiences of the participants.

3.3.2 Sub-theme 1.2: Discovering and making meaning as one journeys on the road of disability

Making meaning refers to a process of finding a sense of purpose that makes one feel that your life is valuable and makes a difference to others (Oxford Advanced Learner's Dictionary, 2010: s.v. "meaning"). This process of making meaning can be seen as part of what Rogers refer to as the reconstruction of the self (Grobler and Schenck, 2009:101). For Rogers this is a process of psychological adjustment when the self can assimilate its experiences into a consistent relationship with the concept of the self.

In a reflection session, after helping with a focus group, one of the core group members in the data collection process, gave her explanation for finding the meaning for living with her disability. She felt that finding such *"reason why you are a person with a disability helps you not to stay angry about it. I had to know the reason why I as one of six sisters in the family must be the only one with a disability. This reason keeps the anger away"*. This woman is now an empowered person and works as an advocacy officer in a disability organisation and helps to promote the rights of people with disabilities (Zuma, 2010).

This sub-theme on making meaning manifested in the following seven categories that will be discussed in the rest of this section. These will include:

- Journeying as metaphor for meaning making
- Reconstructing one's identity

- Seeing purpose in living with a disability
- Experiences of despair and hope
- Dealing with questions about becoming disabled
- Journeying on the continuum of acceptance and peace

3.3.2.1 Category 1.2.1: Journeying as a metaphor for meaning making

Journeying was used as a metaphor to make meaning of living with loss and traumatic experiences. The essence of metaphor is understanding and experiencing one kind of thing in terms of another. In this way metaphors are vehicles for understanding, and mediating what is known and what is unknown (Reisfield and Wilson 2004:4024).

Examples of mentioning their journey were:

“It depends where you are on your journey . . . [whether you have insight into your own situation]”.

“In my journey with disability, I realised how ignorant I was [regarding disability] before I became disabled, so we have to be patient with non-disabled people”.

A church leader supporting a person with disability: “What can you tell yourself in moving to the future? [implying a journey to a future goal of accepting living with a disability].

The metaphor of journey is universal. Reisfield and Wilson (2004) confirm that people with traumatic experiences have referred to their journeys in coming to terms with them. All people are moving on the freeway of life to some destination. An interruption, like becoming disabled, has been described as an exit from the freeway. Exploration and struggle may then be referred to as *“it depends where you are at”*. A byway to get back on track again can be personal growth as insight develops *“I realised how ignorant I was”*. Roadblocks, crossroads and forks may be metaphors for setbacks on the road of recovery from a traumatic experience,

which keeps the person still aiming for the destination of meaningful life (Reisfield and Wilson 2004:4026).

3.3.2.2 Category 1.2.2: Reconstructing one's identity

The task of re-constructing and gaining confidence in their altered view of self, is part of the process of making meaning of having a disability. This category also relates to Rogers' reconstruction of the self (Grobler and Schenck, 2009:101) as mentioned at the beginning of section 3.3.2.

This category has two sub-categories namely:

- Affirming one's personhood
- Developing confidence in spite of disability

a) Sub-category 1.2.2.1: Affirming one's personhood

For some people with disabilities who were not born impaired, there seems to be a process of adapting to a new identity. This seems to happen by affirming themselves in who they are.

Examples were found in the responses of participants to their friends who had withdrawn from them after becoming disabled:

"Come' on guys I'm still your friend. I mean, it's just my body that has changed".

"I am still the same person" – [implying that he is adapting to a new body after amputation].

"I mean, I am a person, you do things differently and cannot do everything that others do . . . [but I have the same needs as any other person]".

Those living with their impairment from a young age seem to have completely assimilated their different body image as was described by the following storylines:

A core group member of disAbility ConneXion:

“My wheelchair is part of my body, therefore don’t push my wheelchair around without asking my permission”.

A woman who walks with difficulty, but has become completely independent:

“I take charge of my own life, and I tell you how I want my life to be run”.

In a focus group discussion, a young person with disability encouraged others to accept themselves. She said to a church leader who also has a disability and who struggled to understand whether he would be healed or not:

“God does not look at us as disabled or not, we are all the same before God”.

b) Sub-category 1.2.2.2: Developing confidence in spite of disability

For some people with disabilities, finding meaning in their disability means to focus on developing confidence in what they can do, as illustrated in the following examples:

A man who is bedridden because of his quadriplegia:

“I teach myself computer skills. My brain is my strongest muscle, I must keep it in good shape, or it will waste away”.

A young mother:

“I home school my two young boys, I’m confident; I am capable of making a contribution to society. It may take me a little longer”.

Shakespeare (1996:103) confirms that this task of revisiting one’s identity in living with a disability is an intense process with obstacles. People with disabilities are socialised to think of themselves as inferior. The self-image of many people with disabilities is dominated by negative messages of society, which reinforce their physical difference and personal deficit. Shakespeare (1996:104) quotes Paulo Freire who noted self-depreciation as a characteristic of people who are oppressed. They so often hear that they are good for nothing, know nothing and are incapable of learning anything, that in the end they become convinced of their own unfitness.

Finally, on the role of one's identity in meaning making Ross and Deverell confirm the constant struggle of people with disabilities to lead valued lives and maintain definitions of self that are positive and worthwhile. With a difference in bodily appearance and function, it is possible that a chronic disabling condition can pose a threat to the person's identity and self-concept to make meaning of living with a disability. The onset of a disability therefore may mean a re-thinking of the self-concept (Ross and Deverell, 2007:15).

3.3.2.3 Category 1.2.3: Seeing purpose in living with a disability

Part of the process of making meaning of a life with disability can be an inner process of finding purpose for one's life. (Eksteen, 2007:16) Eksteen refers to Frank's explanation of quest stories. The owners of such stories claim new qualities of self, as a result of their illness or disability. For them such personal growth become the purpose of their lives with disability (Eksteen, 2007:16).

The following examples illustrate various ways of searching for or finding purpose:

"Maybe my disability is for a reason" or "There must still be a reason for me to be here on earth, I don't know what it is", referring to the search for purpose.

"What he [God] has done with my character, outweighs what he has done in my body", referring to personal development.

Others find their life purpose in what they can contribute to the lives of other people. Examples from participants were as follows:

"I know I still have a lot to offer, I have a nice big smile to give you, I do know that I want to make people aware of us [people with disabilities]."

"I was so very lucky . . . to be alive . . . my story had to be known", my life is a demonstration of God's help, through the trauma, becoming a teacher while using a wheelchair and living with paralyses".

A church leader made the point of how important it is for all people, but specifically people with disabilities, to find a purpose. She stated:

“A Deaf person in our church experienced more hope and personal growth. That was when we made him aware of his purpose”.

The role of finding purpose in the life of a person with disability is supported by Rogers and Rogers (2004:7) who are both people with psychiatric disabilities. They have both experienced the liberating effect of either doing voluntary work or being employed again after their hospitalization. The mere fact that the voluntary work was for the benefit of others in society gave them a sense of purpose which released in them the energy to become self-directed again. They also refer to the role of meaning and spirituality in this process of recovery and finding purpose.

3.3.2.4 Category 1.2.4: Experiences of despair and hope

Experiencing despair and hope is part of the journey of making meaning of life with disability. Kearney and Griffin define hope as “a belief in possibilities” (Kearney and Griffin, 2001:587).

People with paralysis and quadriplegia expressed their despair at feeling humiliated by losing their privacy, being totally dependent on others for the most personal tasks, and being desperate to find healing. Examples of these were:

“Lying in nappies, having to be changed, . . . crying out for help”.

“In desperation to be healed, I went to be prayed for, the pastor slapped me in my face [trying to show his power], I was even more desperate, [because I felt humiliated], I ran away”.

On the other hand people with disabilities also have days of hope when new doors open and they find strength to face life within the limitations of the disability, as expressed in the following examples:

“By God’s grace I didn’t lose my mind”.

“I know how dependent I am on God, with His help I could overcome”.

“With God’s help I have overcome”.

There is also the experience of fluctuating between hope and despair in the lives of people with disabilities:

“I am in bed now for 17 months, because of a pressure sore. Some days I want to bring my life to an end . . . other times I do realise my life has a purpose”. – a man living with quadriplegia.

A woman who is profoundly deaf and struggles with communication, and therefore also with relationships, commented:

“Some Sundays I stay for tea after church and try to make friends, but on other days I feel why bother?, people do not understand [me]”.

Kearney and Griffin (2001:582) state that the experiences of parents of children with disabilities vary between the extremes of hope and no hope, defiance and despair, and often include tension between the extremes.

3.3.2.5 Category 1.2.5: Dealing with questions about becoming disabled

Asking questions about why one has a disability, may relate to finding meaning in living with a difference (see introduction of section 3.3.2).

In this research project, participants also expressed their urge to ask *“Why am I like this?”* An example was a women with profound hearing loss.

“I tend to blame God, I still have a lot of questions, why this has happened. On other occasions I go to Bible study and church services, looking to myself, asking, where I have gone wrong”.

Some people with disabilities feel that they never find an answer, but live the question in peace with God.

“I feel there is no point in questioning God, since we don’t understand Him”.

Other participants found peace in leaving the question to God. Illustrating story lines were:

“If God can use me the way I am, I’m ok with that”.

“Often one sits with the question “Why”, but then I think one should not ask, “Why?”

“To me God is God, one day he will tell you all these things that you are sweating about now”.

Treolar (2000:8) confirms that in most religions “why” questions are asked in relation to suffering like having a disability: What or who causes disability? Am I responsible? Will a strong faith take it away? For those who can find a Biblical understanding of disability there are several benefits. They may discover why God does not heal, it may alleviate the stress that they endure, and they may find the energy to adapt to the challenges. This may be helpful in the search for making meaning in living with disability.

In contrast to the above storylines of living in peace with questions, Treolar also points to possibly ending up with a “bewildering variety of possible answers” without finding a clearly articulated answer, which can be a spiritual dilemma (Treolar, 2000:18)

3.3.2.6 Category 1.2.6: Journeying on the continuum of acceptance and peace

Making meaning of living with disability may imply growing towards acceptance of the situation. A mother of a child with Down’s syndrome (Hubach, 2006:99) defines acceptance as follows: Acceptance in the context of disability means developing peace about the presence of disability in the life of the family.

A male participant, about 60 years old, expressed his journey on the continuum of acceptance in a rich way, mostly related to his submission to God. He is a person with quadriplegia who is bedridden for very long periods, and has considered suicide:

“But it does not work like that; Life and death are in the hands of the Lord; But it is a constant battle, you’ve got to fight every fight of fame; You have to find that inner space within yourself [to accommodate your limitations], which is often a battle; Yet, the human being is the most adaptable being on earth; I still have desires and needs and aspirations that I cannot attain, but I can attain something else; I experience it as a gift . . . [the acceptance] is given to me”.

An elderly couple, both with disabilities, find peace in considering the circumstances of others whom they regard as worse off:

“Other people who have it much harder than us”.

The intervention of friends can also play a role in finding peace and acceptance.

“After my accident [and becoming paralysed] I stayed in bed for three years, a friend came to sit with me and massaged me, she gave me hope, and one day I got up again [and could face the world] ”.

Following on from her definition of acceptance (beginning of section 3.3.2.6), Hubach confirms the experiences of participants. Acceptance is not a static condition, because acceptance is not an event or a place. It is rather a process of embracing each situation as it is right now and the willingness to embrace reality as it will be when the future becomes present (Hubach, 2006:99).

In summary, this process of making meaning and finding purpose in the lives of people with disabilities, is supported by Kaye and Raghavan (2002). When people with disabilities deal with life issues like illness and disability, it is possible for them to find a sense of power in believing that their life still has a purpose and spelling out what they deem as the meaning of their lives with disability (Kaye and Raghavan, 2002:235).

The above aspects on making meaning in living with a disability can also be related to the theory of psycho-emotional aspects of disability as described by Watermeyer and Swartz (2008:600). Such aspects include the internal conflict, the ambivalence, the collusion and sometimes confusion described in the above paragraphs as helplessness, despair and tough questions. However, Watermeyer and Swartz also point to the potential of re-examining self-identities, working through ambivalence and reclaiming in a new way one's personhood, which relates to the reconstruction of identities and seeing purpose, as described above by the participants above. This positive potential can lead to finding personal power, which means to be free of allowing others to define the meaning of living with a disability (Watermeyer and Swartz 2008:609).

3.3.3 Sub-theme 1.3: Being disabled: the challenges of daily living

Living with a disability brings several practical challenges to daily living, as adaptations have to be made because of limitations. Cohen and Napolitano (2007:144) use the words of a young woman with quadriplegia after an accident: “It was like starting life all over again”.

Challenges pointed out by participants in the current research project are presented as the following categories of this sub-theme:

- Loss of relationships with friends
- Loss of independence
- Being marginalised and made to feel insignificant
- Social isolation as a consequence of disability
- Compounded and complicated process of ageing
- People with disabilities experience work-related challenges
- Added financial burdens

3.3.3.1 Category 1.3.1: Loss of relationships with friends

Some people with disabilities reported the change in relationships after the onset of their disability as a big challenge with which to cope. It seems that the fear of the unknown often makes friends withdraw from a person that has become disabled.

“After my [bi-lateral leg] amputations, my friends did not visit anymore. They say it is too hard for them to see me in this condition. . . and yet I am still the same person . . . I did not change. I do miss friends now; nobody comes to sit and chat with me; one becomes lonely”.

“After I became paralysed. . . people treated me differently, like I’m an invalid and even talked to me loudly. And I said, listen, there is nothing wrong with my

brain, I'm a normal person, even friends, close friends didn't know how to approach me".

Thompson (2007:2) confirms that the lack of understanding and not knowing how to communicate withholds non-disabled people from interacting with people with disabilities. Cohen and Napolitano (2007:148) give an example in their research of a young woman who had the same experience of people not being able to see beyond her wheelchair and relate to her as they did before her disability.

3.3.3.2 Category 1.3.2: Loss of independence

Being dependent on others for several personal tasks is often a disconcerting experience for people with disabilities. Examples of these given by people with paraplegia dependent on others for personal care are:

"I felt humiliated, one's privacy is invaded and you have to realise that it's going to be part of your life".

"When you soil yourself, lying in nappies, waiting for somebody to come and change you, and then they treat you if you are worth nothing".

Cohen and Napolitano (2007:145), confirm these experiences. Losing one's independence in self-care could be one of the most intense experiences of disability. Having to adapt to being dependent on others assisting one with personal tasks like ablution and feeding, is often experienced as degrading and humiliating.

During data collection, I observed the complications of this dependence.

A middle-aged woman's physical limitations are of such nature that she cannot transfer herself from her wheelchair to the toilet, to a car or anywhere else. She is totally dependent on her husband and son. When they are not available, she cannot attend meetings as she would like to do.

Other examples of dependence are: a father with visual impairment who cannot fulfil certain tasks concerning looking after his children, a bedridden quadriplegic who has to be fed, a Deaf person being dependent on Sign Language

interpretation and dependence on accessible transport for people using crutches and wheelchairs.

This reality of dependence and its complications is confirmed by Ross and Deverell (2007:184) as a risk for the person of losing his sense of autonomy. Feelings of hopelessness because of the loss of control can set in.

3.3.3.3 Category 1.3.3: Being marginalised and made to feel insignificant.

Marginalisation can be defined as a process by which a group or individual is denied access to important positions of economic, religious or political power within a society (Scott and Marshall 2009: s.v. “marginalisation”). In the case of people with disabilities, such marginalisation is often a challenge of their daily lives. The various reasons for the marginalization are:

- Being absent from society because of immobility
- Being absent from society because of inaccessible buildings
- Being hidden by families

a) Sub-category 1.3.3.1: Being absent from society because of immobility.

In observing the participants and their environments during data collection, it was evident that some people with mobility impairment do not always have the devices and help that they need. These include wheelchairs, accessible transport and caregivers. In many cases, this means that they simply cannot get out and often stay at home for very long periods without participating in any events.

“When the ladies of our church go on an outing, I would like to go along, but there is no accessible transport available”.

b) Sub-category 1.3.3.2: Being absent from society because of inaccessible buildings

Inaccessible buildings and transport render people with disabilities housebound and thus they are not visible in society:

“We can’t get out! If you compare our society with that of for example, Australia, you see many more people with disabilities in society there, simply because they have the facilities to get around!”

“At the post office I can’t see over the counter from my wheelchair, which means I am always dependent on somebody else to do my business for me. So I am invisible to the clerk and he is never aware of me”.

c) Sub-category 1.3.3.3: Being hidden by families

An empowered young woman with a disability who has done much work to improve the lives of other people with disabilities said:

“In our society [African] people with disabilities are kept in the house, the family is only concerned about your grant”.

“In my work in the community [with disabled people], I often see how children with disabilities are not included to participate with others”. (Zuma, 2010).

The phenomenon in some African communities of hiding people with disabilities is confirmed by Chataika (2011:8). Parents may believe that the child with disability is a curse, and so they hide the child as a way of coping with the affliction.

In summary, the ‘invisibility’ of people with disabilities in society seems to be the case in churches as well. Many participants, people with disabilities as well as church leaders, commented that there are very few people with disabilities in churches. One church leader portrayed an attitude of apathy in this regard by saying:

“There are no people with disabilities in my church; we are still waiting for them to come”.

In a personal communication, a woman working in the government disability sector and having mobility impairment herself, made the following remark about people with disabilities being marginalised by the church:

“Very few of them go to church, many are despondent because of the way they are treated there”. (Manthipe, 2010).

Statistics confirm the low numbers of people with disabilities included in churches. Only 5 – 10 % of the more than 600 million people with disabilities in the world are involved in the church (Eareckson-Tada and Oppenhuizen, 2005:7)

3.3.3.4 Category 1.3.4: Social isolation as a consequence of disability

Physical impairments often result in the person not being able to get out and therefore being isolated.

An elderly couple with disabilities expressed their experience:

“We miss our friends, since we came to the care centre, our friends do not come to visit any more, . . . and we can’t go to them”.

A bedridden man with quadriplegia:

“I’m often bedridden for long periods at a time, I need friends, “I do not always have somebody to talk to”.

Another experience of isolation and loneliness is that of being deaf or living with a hearing impairment.

A woman with hearing impairment shared her experience:

“I was ill for two weeks, . . .nobody phoned or came round to show concern”.

In an interview with three Deaf young men, through a Sign language interpreter, it also appeared that they are limited to the social context of the Deaf community, which seemed not strong in their area.

“We are unemployed, there is no church with Sign language, we can’t make friends with people who do not know Sign Language”

The Encyclopaedia of Disability (2005: s.v. “isolation”) confirms the experience of isolation of people with disabilities. Apart from not being able to leave their home, and/or the inaccessibility of places where they would like to participate, there is also the psychological condition of not being able to establish satisfactory relationships with others in their community. Being isolated because of one’s disability may result in the experience of loneliness.

Regarding experiences of isolation and loneliness that are common problems among Deaf people, Hitching (2004:2) confirms that this relates to Sign Language being a scarce skill. However, people’s unhelpful attitudes further exacerbate the isolation and marginalisation of Deaf people.

3.3.3.5 Category 1.3.5: Compounded and complicated process of ageing

The following storylines refer to the compounding factors of ageing and disability:

“I am now getting older, and my disability doesn’t make it easier, I’m often not able to get up in the mornings, with all my health problems, I have become immobile before my time”.

An elderly couple: “We are now just in our room and we can only go to the dining room on our floor. We do not even go to the ground floor for the church service once a week, because we don’t want to use the toilet there”.

Factors that influence the lives of elderly people with disabilities are physiological and psychological. Physiological changes may include conditions that cause bodily aches and pains that limit their physical mobility. Psychological ageing has to do with the individual’s coping capacities in his life situation. This may present itself in a feeling of powerlessness (Ross and Deverell, 2007:183). Both these aspects were evident in the above storylines. I also observed that while physical conditions indeed bring limitations, psychological ageing means not having the emotional power to do what may still be physically possible. This is exemplified by the elderly couple who actually are physically capable of going to the ground floor of the care centre, but find “excuses”.

3.3.3.6 Category 1.3.6: People with disabilities experience work-related challenges

A small number of people with disabilities who participated in this research project were employed. Challenges mentioned had to do with holding an existing job, but also finding employment.

“I came back to my job as manager of a production line, I had to adapt to doing my work amidst my mobility impairment, or risk being kicked out . . . the boss said: you better make a decision, you’re not coping”.

“It is hard process to find a job, I am dependent on public transport and was let down by employers who won’t give fulltime employment because of my disability” – a young lady who is eager to work and improve her skills.

“We are Deaf, we had small part time jobs, but as soon as the contract is finished, we are unemployed again, it is now many years since we last had a job” – three young men.

It is often the experience of people with disabilities that they are excluded from a job, not because they are unable to do it but because others assume they can’t (Swartz and Schneider, 2006:234). The growing reality is that many are inadequately skilled for the labour market and thus a mere 1% are employed (Swartz and Schneider, 2006:235).

Other work challenges not mentioned by participants are the lack of accessible public transport to get to a place of work, inaccessible buildings at the place of work, a shortage of skills development programmes and few opportunities to actually be employed in the open labour market (Seirlis and Swartz, 2006:365).

3.3.3.7 Category 1.3.7: Added financial burdens

Devices, caregivers and alterations to houses add to the cost of living of people with disabilities.

Participants expressed their experiences in the following ways:

A person from an under-resourced community:

“I need a new wheelchair, the old one has given problems for a long time. We spent a lot of money on repairs, and yet it still does not work properly. But how will I afford a new electric wheelchair?”

Persons from an average income community:

“We made alterations to our house, for my [severely disabled] son to have his space where he can be cared for”.

“My child with brain injuries needs a caregiver 24 hours a day. Now we transferred him to a care centre, still the monthly fees are high”.

The above experiences confirm what has been listed as the expenses of disabled people: motorized wheelchairs, structural changes to the house, bathrooms and cars, hearing aids, special computer software and special schools for children with disabilities (Cohen and Napolitano 2007:147).

In personal communication with a disability expert with a mobility impairment, information was shared that the cost of living for a person with disability is at least 2.5 times higher than the average of others. For taxpayers a limited portion of these costs can be claimed as tax-rebates (Howitson, 2011).

In terms of the poverty contexts of South Africa where the majority of people with disabilities live, compounding financial factors are distances to special schools, inaccessible transport, great distances to rehabilitation services and scarcity of employment. The monthly disability grant is mostly used to feed and house a whole family and not for the specific needs of the individual with disability (Graham, Selipsky, Moodley, Maina and Rowland, 2010:17).

This section on the constant challenges of daily living for people with disabilities can be summarised as follows: loss of relationships and independence, being marginalised, having to adapt to major changes in self-care, coping with isolation and complications of ageing. The young woman with quadriplegia in Cohen and Napolitano’s research (2007:144) expressed it as “It was like starting life all over again”.

The harsh realities of people with disabilities in South Africa are confirmed by Graham et al. (2010:14): Despite the comprehensive policy landscape and the extensive work of the disability rights movement in South Africa, people living with disabilities still face a range of challenges that compound their lives. The majority of them are still exposed to restrictive environments and barriers that continue to marginalise and exclude them from main line society and its social and economic activities.

3.4 THEME TWO: SIGNIFICANT OTHERS EXPERIENCE CHANGES IN FAMILY RELATIONSHIPS AND LIFE-STYLE AS A CONSEQUENCE OF DISABILITY.

The participants in the study portrayed some of the effects that disabilities have on their family life. These were not the focus of the study and the experiences of significant others of people with disabilities are therefore not elaborated on. The experiences mostly had to do with changed roles in the family.

The following sub-themes illustrate the experiences of significant others of people with disabilities:

- The nature of parenting is changed
- Spouses of persons with disability have to take on extra responsibilities
- Adult children of parents with disabilities have to take on additional responsibilities
- Families respond in different ways to (not) accommodate a disabled member

3.4.1 Sub-theme 2.1: The nature of parenting is changed

When a parent with young children acquires a disability, there seems to be an impact on the parenting role.

“I have two very busy young boys, I can’t always see what they are up to and when they are out of order. This puts more strain on my wife who also has a disability”. – a father who became blind.

“After my accident, I came home after many months . . I was a different person ja ja . . , so disciplining the children was also difficult . .” - a young man with paraplegia.

These two participants, who were young fathers with disabilities, referred to a difference in disciplining their children.

A blind father in the African community, whose wife had died recently, said:

“My son is 20 years old, he has epilepsy. He gets very bad seizures; I always have to look after him”

“Our child [22 years old] has severe brain injuries, he needs full time care. At one stage, I worked night duty for eight years to care for him during daytime.

The above two cases illustrated adaptations of parenting where adult children with disabilities are still in the care of their parents.

In both these cases of adult children with disabilities, I observed how in spite of the adult children’s limited or no communication abilities, the parents displayed loving relationships. For these parents, despite the low functioning of their adult children, they were in the first place persons with whom they have family relationships, needing constant care even as adults.

This kind of relationship is confirmed by Clapton (1997:425) who sees the ‘otherness’ of a disabled family member as centred, not around the notion of the distress and suffering of the person, but on the relationship as a family member.

3.4.2 Sub-theme 2.2: Spouses of persons with disability have to take extra responsibility

During data collection, I observed how spouses of people with disabilities often have to take on extra responsibilities. Wives with severe physical impairments, unable to do any household chores, depend on their husbands and parents to shop for the household, look after children, and drive the children to their school activities.

In other cases, I observed how these families have adapted to the situation. An example is a woman with severe disabilities and a mature personality playing a strong role in the emotional and spiritual well being of the family, while her husband takes care of many household tasks.

In contrast to the above examples of spouses appearing to cope well in taking sole responsibility, there is also the risk that this may cause strain for the non-disabled spouse. The non-disabled spouse can feel anger and grief because the loss of dreams with the spouse or experience feelings of intense loneliness (Ross and Deverell, 2007:259).

3.4.3 Sub-theme 2.3: Adult children of parents with disabilities have to take additional responsibilities

Examples of responses were:

“Our daughter visits us almost every day, she checks what we need and looks after all the details of our lives. This is a big responsibility for her, together with her own household”.

These responsibilities of taking care of adults with disabilities can, however, also be enriching. A woman who participated in a focus group, is the caregiver of her mother who had a stroke.

“In caring for my mother, I became aware of the needs of people with disabilities in our community. So I became involved in disability support groups, where I can now make a contribution in the lives of others”.

A church leader told a story of a family who live with ageing as well as disability.

“In our church we have ‘Bernard’, a young man with intellectual disability. He looks after his elderly mother. Everybody knows about ‘Bernard’, for his smile and the special way he cares for his mother, [in spite of his intellectual disability]. He actually sets an example for all of us”.

3.4.4 Sub-theme 2.4: Some families hide a disabled family member

As mentioned in section 3.3.3.3 c in some families the disabled person hardly ever leaves the home. Examples from the African community were:

“They [the family] are not concerned about your soul, so on Sunday you don’t go to church with the others. You only get out on the day to collect your grant [once a month]. Then after that, you are nothing”.

“You are something kept in a room. I never understood why I didn’t go to Sunday school with my brothers and sisters”.

Some African families are of the view that people with disabilities are an economic and social curse and thus a burden to the family. Therefore, particularly women and children with disabilities are often left alone at home and undervalued by those around them (Disability Action Research team, 2006:2). A report on the non-English-speaking cultural situation of people with disabilities in Australia also confirms cases of children with disability being hidden, since the family regards it as a shame (Multicultural Disability Advocacy Association, n.d.)

In summary, family responses to having a disabled member results altered roles for spouses, parents and children. These responses are influenced by cultural beliefs, family values, interacting patterns and functional priorities (Ross and Deverell, 2007:268).

3.5 THEME THREE: THE PERSON WITH DISABILITY’S EXPERIENCE OF THE ACCESSIBILITY OF THE ENVIRONMENT OF THE FAITH COMMUNITY

In the context of the field of disability, the term “accessibility”, refers to physical access, communication access, and social access to facilities, services, training, and jobs. Physical access means that people with disabilities can, without assistance, approach, enter, pass to and from, and make use of an area and its facilities without undue difficulties (Christian Blind Mission, 2007:33). In the context of churches, accessibility for people with disabilities would imply access to the buildings and all its facilities. Furthermore, communication and social access

would imply that worship services and all other activities and interaction in the life of the church are accessible for people with impairments.

This theme covers two sub-themes, namely:

- The person with disability experiences the physical environment of the faith community as inaccessible.
- Persons with disabilities experience a general lack of awareness of their needs for accessibility in the physical environment.

3.5.1 Sub-theme 3.1: The person with disability experiences the physical environment of the faith community as inaccessible

The sub-theme portrays the experiences of the participants in the physical environment of churches according to their different disabilities and needs.

In the presentation of this sub-theme there is very little literature control as no literature could be found on the experiences of people with disabilities regarding the accessibility of church buildings in South Africa, except for one short article (Razaka 2005:42), which will be referred to at the end of section 3.5.1.4.

This sub-theme is divided into the following categories:

- Experiences related to accessibility of transport
- Church buildings that are inaccessible
- Seating and other arrangements in the worship service which are not conducive to participation.
- Times of services and meetings which are inconvenient for people with disabilities.

3.5.1.1 Category 3.1.1: Experiences related to the accessibility of transport

Two sub-categories are presented:

- Accessibility of transport in better resourced communities

- Accessibility of transport in less resourced communities

These are discussed below.

a) **Sub-category 3.1.1.1: Accessibility of transport in well resourced communities**

Participants described various circumstances of the situation regarding transport:

Their own physical inability:

“I simply can’t get into a car anymore; it is too difficult to transfer from my wheelchair into a car”.

Many vehicles are inaccessible:

“Many cars are too small to take my wheelchair, so I just don’t go to church anymore”.

Inconsiderate people:

“When outings are planned by the women’s group, I would like to go along, but nobody comes to me and asks how they can help me with my wheelchair. I feel the church should think of that”. - a wheelchair user and active member of the women’s group.

Parking arrangements at churches:

Although participants with disabilities did not comment specifically on parking at churches, frustration was expressed regarding public parking:

“At public parking lots there are forever non-disabled people who abuse the accessible parking for people with disabilities”.

A church leader reported:

“We have accessible parking for people with disabilities and the elderly”.

b) **Sub-category 3.1.1.2: Accessibility of transport in less resourced communities**

In the less resourced communities, participants did not expand on the issue of transport, except for two examples.

The general lack of transport:

“Very few people have cars and of course there is no public accessible transport to go to church”.

“I hardly ever go to church because of the transport problem” – a man with severe mobility impairment.

People who are not helpful in providing transport:

“People in our churches who do have cars, are not considerate to pick up people with disabilities who are walking to church with great difficulty”. – an elder from a township community who is very concerned about people with disabilities.

3.5.1.2 Category 3.1.2: Experiences of inaccessible church buildings

This category includes the following three sub-categories:

- General comments on accessibility of church buildings
- Inaccessible entrances
- Inaccessible toilets

a) **Sub-categories 3.1.2.1: General comments on inaccessibility of church buildings**

The experience of people with disabilities is that, in general, making church buildings accessible is not a priority for the church. The following quotations from participants attest to this:

“Plans [to make church buildings accessible] are not implemented”.

“I liked the people in the church but they were lazy to make the adaptations”.

“Not many churches are accessible; I often have to be carried into a church with my wheelchair”.

“At our church there are no facilities, so we have to carry my son into the church”.

“Some churches say they will not build ramps since they do not have persons with disabilities in their midst. It seems they are not aware of the people that simply do not attend because of the inaccessibility”

A female teacher who are very active in her church (a wheelchair user), said:

“When I go to places and there are stairs and blocked entrances, they are telling me they don’t want me here. They have not thought about me”.

People with disabilities feel that the inaccessibility of church buildings also affects other people in society, like the elderly, mothers with prams and people who may have temporary difficulty in walking. A person who has lived with disability almost all his life said:

“I have seen it so often; the inaccessibility is a problem for many other people as well [the elderly or people in general all like to use ramps instead of stairs].

b) Sub-category 3.1.2.2: Inaccessibility of entrances

Some churches do not have ramps at the entrances.

“For years we had to carry my son up the stairs

In some cases, an accessible entrance is at the back, as reported in a core group meeting (22 February 2010):

“The entrance for wheelchair users is sometimes in an awkward place. It reminds me of apartheid, when black people had to enter at the back”.

“Why must we always be different? It may be the reason why other people with disabilities do not come to church”.



Photo 4: A participant in the church leaders' group, using a wheelchair at an inaccessible church entrance

c) **Sub-category 3.1.2.3: Inaccessible toilets**

Participants commented specifically on the inaccessible toilets at churches.

“At our church the toilets are really not accessible, I don’t use it, I have to use a catheter when I go to church”. - the comment of a person that became a church goer after she became disabled.

Another example was the church in Imbali township where a focus group interview was held for the research project. The church leadership became aware of wheelchair users and built a ramp at the front entrance. However, they did not think of the need for accessible toilets. On the day of the meeting, the wheelchair users spoke openly about this problem:

“You have a nice church building, but we cannot get into the toilets”.

In my observations, I noticed several churches in well-resourced communities have demonstrated their consideration of people with disabilities by making toilets accessible.

In other cases, it appears that the National Building Regulations are not followed (South African Bureau of Standards 2011). These regulations spell out the full requirements for the needs of people with disabilities. These will be discussed in chapter four.

3.5.1.3 Category 3.1.3: Seating and other arrangements in the worship service are not conducive to participation

People with specific limitations find it difficult to participate in worship services. Their experiences are spelled out in the following sub-categories:

- The lack of choice to sit in a comfortable place
- Other unsuitable arrangements

a) Sub-category 3.1.3.1: The lack of choice to sit in a comfortable place

Wheelchair users often do not have any other choice than to sit in the aisle.

“One is regarded as ‘different’; it seems you stick out like a sore thumb”.

“Sometimes the church floor is sloped, there is lack of space to turn my wheelchair. And sometimes one can’t see on the electronic board when others stand to sing”.

Some participants have been told by other church members:

“You can’t sit here [in the aisle], let me push you to the side where you are in nobody’s way”.

Some people with hearing loss have specific needs.

“I need adequate lighting for lip reading. It is sometimes difficult to find the right place [in the church auditorium]”.

b) Sub-category 3.1.3.2: Other unsuitable arrangements

People with hearing loss sometimes have specific problems in the worship service that limit their communication access:

“In some churches the music is just too loud [for people using hearing aids]”.

“When the preacher walks up and down and sometimes even turns his back on the audience, it is impossible to do lip-reading”.

In my observations during the research, I noticed a few more difficulties:

Concerning the needs of people with hearing loss, many church buildings do not have a loop system that can accommodate hearing aids. Also, for Deaf people it is rare to find a church where a Sign Language interpreter available.

Concerning the needs of people with visual impairments, including some of the elderly, I have noticed problems of not being able to read the electronic boards often used in modern churches. The few blind people who use Braille hymnbooks find that not enough time is allowed for them to find the right place in their books.

3.5.1.4 Category 3.1.4: Times of services and meetings are inconvenient for people with disabilities

A few participants had comments about times of services.

“The 8 o’clock service is so early, it is too cold, and my body is so stiff”.

“People with low eyesight can’t see well in the evening, so to have bible study at 18.30 . . . [is not helpful]”.

Participants were aware that churches organise the times of services and meetings to be convenient for the majority of its members.

In confirmation of this sub-theme of experiences of inaccessibility in church buildings and worship services, Razaka’s survey revealed the (in)accessibility of churches in Pietermaritzburg. She points out that while only a few churches did meet the necessary standards, most others needed only minor changes to be accessible. The few accessible entrances were found to be not well signposted, since they were in awkward places. With regard to seating in the church, most churches had pews that forced wheelchair users to sit either at the back, or front, or in the aisles. In some churches, the floor was on a slope, which is problematic for wheelchairs. Toilets were inaccessible in most churches and emergency exits were not according to standard. Concerning altars in churches and serving Holy Communion there, these were always found to involve some steps, which makes them inaccessible for people with mobility impairments. Church leaders reasoned that communion could be taken to where the person is seated in the pews. Razaka

comments that in this way the actual significance of Communion is missed, since it is a symbol of unity and persons with disability need to be included like everybody else (Razaka 2005:47).

In summary of this section, the inaccessibility of church buildings and other arrangements are experienced as problematic for people with disabilities. A comment was:

“Churches don’t understand that people with disabilities won’t come to their services if they can’t get in”.

The lack of accessible transport, inaccessible entrances and toilets, seating arrangements in the worship service and times of services and meetings are all factors that complicate the participation of people with disabilities who want to be included in the church.

3.5.2 Sub-theme 3.2: People with disabilities experience a general lack of awareness of their needs for accessibility in the physical environment

Persons with disabilities experience that their needs for access to church buildings and worship services are not considered and acted upon.

Categories in this sub-theme are:

- “There are no people with disabilities in the church”
- People are insensitive about the needs for accessibility for disabled people
- In some places there is a growing awareness
- People with disabilities are impatient about other people’s lack of understanding

3.5.2.1 Category 3.2.1: “There are no people with disabilities in the church”

People with disabilities feel that churches argue that they do not need an accessible environment because they do not have any disabled people in their congregation. Responses to this were:

“They don’t have people with disabilities there, because we can’t get into their church”.

“But that [argument] is wrong. I might just be visiting there and I would want to attend a service or wedding at that church” – a wheelchair user.

3.5.2.2 Category 3.2.2: People are insensitive about the needs for accessibility for disabled people

“I often had to be carried into a church because there were no ramps. People don’t understand what it feels like, others intruding on your personal space”.

A church leader said to a wheelchair user

“We have the Bible study meeting upstairs; there are enough people to carry you upstairs”.

3.5.2.3 Category 3.2.3: In some places there is a growing awareness

Church leaders mentioned that efforts are made to make buildings accessible.

“Recently we built a new accessible toilet in order for it to be ready for Disability Awareness Sunday. Even if it may be used only once a year, we’ve got it”.

A church leader who is responsible for welfare services (including care for people with disabilities) in his denomination, reported:

“During my many visits around the KwaZulu-Natal province I have seen several churches that are more aware now, who have built ramps.

3.5.2.4 Category 3.2.4: People with disabilities are impatient about other people's lack of understanding

The experience of people with disabilities is that mostly there is very little awareness of their needs regarding the physical environment of the church. Examples of these are:

"In my own vicinity I know the few churches that are accessible. But whenever I want to attend a funeral or wedding [elsewhere], I have to send my husband beforehand, to assess if the place is accessible". - in personal communication after the interview.

"Decision makers are not aware of this priority for people with disabilities. It takes a paradigm shift, otherwise nothing changes".

Ignorance plays a role in the lack of taking action. Some comments of the people with disabilities were:

"They are slow in the uptake, they may make plans but by Friday they have forgotten all about it. Some changes are not so insurmountable, but people simply don't buy into the idea".

The experiences of inaccessibility of the faith community described above, contradict guidelines for required access of buildings as spelt out in the South African National Standard Building Regulations, Part S: Facilities for people with disabilities (South African Bureau of Standards SABS 2011). It is a common experience of people with disabilities that these guidelines are not implemented in plans of new buildings and also not in old buildings that need structural changes. In chapter four, I will explore these guidelines together with the suggestions of participants.

3.6 THEME FOUR: HOW PEOPLE WITH DISABILITIES IN FAITH COMMUNITIES EXPERIENCE OTHERS' PERCEPTIONS OF DISABILITY AND HEALING

This section will deal with the experiences of people with disabilities resulting from perceptions of disability held by other members in the faith community. It includes the following three sub-themes:

- Theological ideas that have an oppressing influence on people with disabilities in faith communities
- Theological ideas that have a liberating influence on people with disabilities in faith communities
- Practices in faith communities that hamper the inclusion of persons with disabilities

3.6.1 Sub-theme 4.1: The theological ideas that have an oppressing influence on people with disabilities in faith communities

From the responses of the study, it appeared that people with disabilities often encounter perceptions in society and in faith communities that complicate their lives. They experience these perceptions as oppressing, leaving them with the idea that their lives may not thrive.

These perceptions are described by Hitching (2004:1) as the oppressing experiences of Deaf and other disabled people in the church. The oppression consists of dealing with difference inappropriately, which deprives Deaf people and others with disability of their dignity. They are seen as different to the norm (as defined by non-disabled people) and categorised as lacking something.

In order to develop an understanding of this oppression it is helpful to look at a model of oppression as described by Rule (2008:22). This concept of oppression indicates that a group of people is oppressed when they are subjected to any of the following conditions: exploitation, marginalisation, powerlessness, cultural imperialism and violence. In the rest of this section, the experiences of participants are described as related to these concepts of oppression.

The oppressive ideas experienced by participants are presented below as categories with some sub-categories.

- The perception that God meant everybody to be ‘normal’.
- Sin is regarded as the cause of disability.
- Biblical interpretations that portray people with disabilities in a disrespectful way.

3.6.1.1 Category 4.1.1: The perception that God meant everybody to be healthy and ‘normal’

One of the issues most talked about among people with disabilities who participated in the study was their experience of views in the church that disability is not acceptable and that the condition should be healed.

“You actually feel less of a person in the way people treat you”.

In the context of the church this perception reveals itself in various ways, presented below as three sub-categories:

- Everything must be ‘normalised’.
- People with disabilities become victims of healing practices.
- The compulsion to be healed.

a) Sub-category 4.1.1.1: Everybody must be ‘normalised’

Responses from participants in objection to this were:

“I’m not accepted as I am . . . [all must be] rectified, must be normalised.

“That word ‘normal’, we better take a look at what that really means”.

These storylines illustrate people’s experiences that in some Christian circles there is a perception that having a disability or an imperfect body cannot be reconciled with a strong faith and therefore it needs to be normalised and rectified.

The view that everybody should comply with a “normal” appearance or function is strong in society. Reynolds (2008:60) refers to this as the “cult of normalcy”. Differences of body appearance and function are marked as being out of place, incomplete and actually ‘do not belong’ in society.

Other participants “defended” their ‘normality’ in explaining to their friends:

“I said [to my old friends] listen there is nothing wrong with my brain, I’m a normal person”.

“I have to explain to people, I am normal, it’s just that I can’t walk”.

Reinders (2008:7) describes how parents of children with disabilities point out that they simply live by a different standard of ‘normal’. In the case of a child with disability, success in reaching certain capabilities happens at a different pace. Their perception of “normal success” is much wider than is usually accepted. Many things that “normal” children learn relatively easily in a short period, may take longer for a child with intellectual disability to master. Reinders (2008:69) also refers to Marks, saying that disability, and therefore “normality”, can be understood as a result of perceptions rooted in social practices, which mark some differences as being “abnormal”.

It appears that the perceptions of what is normal and abnormal, as defined by the majority of society, is an oppressing experience for people with disabilities in the church when these lead to theological ideas in which they do not feel accepted.

b) Sub-category 4.1.1.2: People with disabilities become victims of healing practices

Some churches conduct special services to pray for the healing of people, and people with disabilities are often invited to such services.

Some participants expressed their experiences in this way:

“They prayed for me, without asking my permission, took off the footrests of my wheelchair and started pushing and shouting at me, WALK!”

“I used to accept invitations to crusades, but they scared me stiff and I did not go again”.

People with disabilities sometimes accept such invitations, because either they feel morally obliged to do so or they earnestly seek healing.

Sometimes people with disabilities experience this over-emphasis on prayer for their healing in an ordinary church service, which they had simply attended for spiritual nourishment. They feel there is an inappropriate focus on them as people with disabilities because when it is prayer time during the service,

“They are on top of you, assuming that you want to be prayed for healing of your disability, which may not be the case at all”.

“When they see you, you are like a target . [to be prayed for].”

A young woman from Imbali township with a disability that affects her physical appearance quite severely, was slapped in the face and kicked while being prayed for. Her understanding is that the church leader tried to show the power of God. She was not healed, still feels confused and hopes that God will heal her.

c) **Sub-category 4.1.1.3: The compulsion to be healed**

Stemming from the views of everybody for all to be ‘normalised’, people with disabilities experience that there is a compulsion for them to be healed. An illustration is the story of a young lady:

“I think they [church members] misunderstand. When they see disability, they think they must perform miracles. They are only concerned about physical healing and not about my soul”.

These practices have a serious effect on the lives of people with disabilities. One participant summarised her feelings in this way:

“When they see me they always ask, can I pray for you? Out of respect I say yes, but I don’t like it, nothing happens, and you begin to hate yourself”.

A church leader from a main line church expressed his experience:

“The theological understanding of healing in some churches causes great confusion for people with disabilities”.

In contrast, one participant states her theological understanding differently:

“I feel God heals in His own time. If he can use me just as I am, I am okay with that. People want to see miracles on demand. But healing is not up to us”.

These negative and oppressing experiences in the Christian community where people with disabilities are looking for support, seem to have a long and widespread history in the Christian church. Literature shows that the confusion about prayer for healing of disability seems to have its roots in differences in interpretation of Biblical texts. Treolar (2000:7) points out that these interpretations go along with historical attitudes of disability, how the judgement of God is perceived and views on adequacy of faith and miraculous healing. Through the ages, the public has been fascinated by the possibility of physical healing through miraculous means, despite widely varying claims of its efficacy.

3.6.1.2 Category 4.1.2: The person with disability is held responsible for lack of healing and the reality of suffering is ignored

This category includes three sub-categories, namely:

- Sin is regarded as the cause of disability and confession the requirement for healing.
 - The person with the disability is blamed as being responsible for not being healed
 - The reality of suffering associated with disability is ignored
- a) **Sub-category 4.1.2.1: Sin is regarded as the cause of disability and confession the requirement for healing.**

People with disabilities experience that in some churches people seem to see a relationship between sin and disability.

Responses from people with disabilities were:

When a mother of a disabled child brought her offering, she was told:

“You must confess your sin, why the child is disabled?, your offering will not be accepted until you confess”.

“They [church leaders] are normally saying: we are disabled because of our sins, or our parents’ sins or God is punishing us for doing bad things, which is why we are disabled”.

Sin is regarded as a cause of disability, therefore the person with a disability is blamed for his/her condition. Confession of sins is then made the requirement for healing.

A church leader narrated an experience with a Deaf family member:

“He was told by another church leader that he is demonised”. [19290]

These views that sin and disability are related, is confirmed in the writings of Bowers (2004:1). She uses the examples of parents of a baby with disability. Their own immediate reaction as well as their friends, often revolves around a retribution approach asking: *“Who was guilty?; Who was at fault”*. Even in cases of a wanted child who was prayed for even before conception, the instinct is to blame either oneself or someone else. For people of faith the retribution question is often directed to God: *“Why did God allow this?”*

b) Sub-category 4.1.2.2: The person with the disability is blamed as being responsible for not being healed.

People with disabilities who do not get healed after prayer practices are sometimes blamed for not having enough faith or are simply left with guilt feelings. This is the cause of great distress for many of them. The young church leader who himself has a disability mentioned above, stated in a group discussion:

“ . . .they want to pray for me, so nothing happens and I’m told, I have a lack of faith. So then I just don’t want to go anymore, I feel ill-treated”.

Others confirmed the experience of feeling blamed:

“If you do not become healed they leave it to you that it is your faith, you get blamed”.

In a group discussion, the verdict was:

“Nothing happens, and you begin to hate yourself”.

Literature on the topic of healing from disability coincides with the experiences of the participants of this study. Treolar (2000:9) writes that unfortunately those who are not miraculously healed must deal with others' allegations that they did not have enough faith. The danger is that people with disabilities may come to feel that they are sinful, faithless or that God had rejected them. In extreme cases, these feelings can turn into rebellion against organised religion or against God.

c) Sub-category 4.1.2.3: The reality of suffering associated with disability is ignored

In the focus group interview of church leaders and disabled people together, some of the church leaders had physical disabilities themselves. In this discussion the point was raised that disability and suffering is part of an imperfect world.

A female church leader stated:

“Some churches completely ignore the reality of imperfection and suffering in this world. They do not understand that in this world we will not have everything perfect”.

The discussion led to related perceptions of a success oriented church or theology.

“As a church leader I drive an old car and I'm not married yet, and I know that some churches disapprove of this. They believe that real faith results in success like having a smart car and a respectful wife”.

Abraham and Abraham (2007:47), the parents of a girl with severe brain injuries, confirm their experience in coming to terms with the reality of their suffering. Once they had come to the understanding that such suffering is not a punishment from God, they stopped asking, “Why does God do this?”

The reality of suffering is part of the vulnerability of all human beings, as they are open to being wounded, which brings suffering. This reality of suffering is complex, with many consequences and human beings find themselves powerless to avoid it (Reynolds, 2008:108).

3.6.1.3 Category 4.1.3: Biblical interpretations that portray people with disabilities in a disrespectful way

Some participants with disabilities feel that certain texts of the Bible portray them in a disrespectful way. Other problematic issues for them are the sacrificial offerings of the Old Testament that had to be without any blemish.

In a group discussion with three blind people, the following statements were made:

“The big things done by blind people are not mentioned in the Bible. Paul was blind while doing all his work, and so was John when he wrote the book of Revelations”.

“They focus on that Biblical part which depicts us as needy people. For instance that cripple man and another blind Bartholomew, so every time we do come to the fore, we are depicted as needy, for some support”.

“I don’t go to church anymore. I am not asked to make a contribution there. I guess the leaders feel I am not capable of doing so.

“In isiZulu a blind person is called ‘impumphuthe’, which means ‘to fiddle around with no direction’. Preachers often use this term as an illustration of a person that has no direction in life”.

Bruce (2005:4) notes that the way that the Bible is read and interpreted affects the participation in the church of people with disabilities. Constructions of disability in the Bible continue to shape attitudes and it needs to be considered that these constructions have an ambivalent effect on people with disabilities. An example is the emphasis in the New Testament on healing, together with a general silence about those who were not healed or reconstructing the lives of people with disabilities. Bruce (2005:6) suggests that an investigation into the attitudes around disability will show that not everyone subscribed to the dominant discourse of

disability at the time and not everyone had the same experience about disability. Furthermore, knowledge of disability in the first century, the literary modes of reading and analysis of stories and characters may open up transformative and empowering possibilities for our understanding of disability today.

3.6.2 Sub-theme 4.2: Theological ideas that have a liberating influence on people with disabilities in faith communities

In contrast to the above there are also theological ideas that have a liberating influence in the lives of people with disabilities in faith communities and enhance their inclusion in the faith community.

The two categories are:

- A spiritual focus in the church which does not emphasise the disability
- People with disabilities can make a contribution in the faith community

3.6.2.1 Category 4.2.1: A spiritual focus in the church which does not emphasise the disability

Story lines which confirm this category, are as follows:

“In my church my [paralysed] legs are not the focus, my heart is the focus”.

“What is more important, my physical image or my soul? [implying the latter].”

One church leader also emphasised a wider spiritual focus, away from the focus on physical healing:

“Healing is not only physical healing, it is about a holistic work, of finding peace”.

A woman with severe disability confirmed that:

“There was the bigger healing, the healing of my heart”.

3.6.2.2 Category 4.2.2: People with disabilities can make a contribution in the faith community

The paradigm of including people with disabilities in the faith community at all cost may be rare, but is effectively implemented in some churches. A pastor from a main line church illustrated how they include people with disabilities

“A young man with Down’s syndrome was confirmed as a member of our church. He was able to confess his faith in such a touching manner that there was no doubt that he is part of the community of believers. He now plays in the brass band in church. The fact that it is sometimes a little out of tune is not important. What is more important is that he participates, is well accepted and makes his contribution in the church”.

This contribution of people with disabilities in the church was also illustrated by a member of disAbility ConneXion, being assertive regarding her equal position in the church.

“I am often asked to do the prayers in church . . . my gift is recognised”.

Literature confirms that people with disabilities need not only be the recipients of care in the faith community, but they indeed have the capacity to make a meaningful contribution. Treolar (2000:22) mentions that these roles can include teaching others about disability, advocating for the inclusion of other marginalised groups and promoting an environment of awareness, acceptance and sensitivity.

3.6.3 Sub-theme 4.3: Practices in faith communities that hamper the inclusion of persons with disabilities

Practices in society can be seen as the common way of doing in a particular situation (Oxford Advanced Learner’s Dictionary, 2010: s.v. “practices”). In faith communities, practices are for example how people relate to each other, how social phenomena are interpreted or what attitudes are held towards people who are different.

This sub-theme consists of the following categories of practices in faith communities that hamper the inclusion of people with disabilities:

- Expectations regarding dress code for church.
- Cultural perceptions and rituals present in faith communities.
- Oppressing messages communicated to people with disabilities regarding marriage.
- The lack of respect for the person.
- The lack of understanding of disability.
- Patronising attitudes and behaviour hampering the inclusion of people with disabilities

3.6.3.1 Category 4.3.1: Expectations regarding dress code for church

In the African Christian circles there seems to be an expectation that women should not wear trousers. In a group discussion with church leaders in Imbali township a woman with disability said:

“Women who use wheelchairs find it difficult to wear a dress or a skirt”.

In a core group meeting the point was confirmed:

“We [women with disabilities] feel there is an expectation in the church that this [to wear trousers] is not acceptable. But it is never talked about, so we feel uncomfortable”.

The church leaders responded:

“We don’t know about that”.

In my observation, the church leaders in the African faith community seemed oblivious of congregants’ attitudes and did not have any further comments.

3.6.3.2 Category 4.3.2: Cultural perceptions regarding disability present in faith communities

Some traditional beliefs in society and the church regarding disability, tend to hamper the participation of people with disabilities in the faith community.

“There are many cultural beliefs regarding anything that is out of the ordinary, e.g. having twins. These beliefs get transferred into the church context”.

Participants conveyed their experience of cultural beliefs in the church in terms of three sub-categories:

- People with disabilities cannot become leaders.
- Disability is an indication of punishment related to dissatisfaction of ancestors.
- Disability is an indication of problems in family relationships.

a) **Sub-category 4.3.2.1: People with disabilities cannot become leaders**

Some people with disabilities feel that they have no chance of becoming leaders in churches.

“People with disabilities don’t become leaders in the church. They seem to undermine us. I don’t know of any person with disability that has been asked to do a prayer in church”.

“Some churches believe that leaders in the church should be married. But, people with disabilities find it difficult to get married, because of cultural beliefs and practical circumstances, therefore we never become leaders.

b) **Sub-category 4.3.2.2: Disability is an indication of punishment related to dissatisfaction of ancestors**

Some cultural perceptions of disability have to do with the belief that ancestors are not honoured or pleased with family affairs and therefore a person is punished with a disability:

“In our [Zulu] culture, disability is perceived to be caused by having done bad. So, in the church, a person with disability is expected to confess the sins that caused the disability”.

“In the Zulu culture, when a child is born with a disability the family often blames the woman for possibly being unfaithful to her husband, and therefore she is being punished by God or the ancestors”.

“If you became disabled by for example an accident, it may be seen as someone was jealous and bewitched you”.

c) **Sub-category 4.3.2.3: Disability is an indication of problems in family relationships**

A leader of a Zulu speaking church shared from his experience:

“The ancestors play an important role in everyday life and disability can be caused by an ancestor that is not satisfied with a family”.

This was confirmed by a person with albinism:

“With disability it is often said, there is a problem in the family”.

The above data corresponds with Chataika’s (2011:1) presentation on the realities of cultural and religious beliefs regarding disability. She states that cultural and religious explanations for disability want to:

- Give the reasons why some people are disabled - *“. . because of your sin”*
- Determine how people with disabilities should be treated - *“. . blamed for being unfaithful”.*
- Prescribe which rights people with disabilities are entitled to or deprived of - *“People with disabilities do not become leaders in the church”*

Furthermore, the above-mentioned story lines are also confirmed by the Multicultural Disability Advocacy Association in its list of cultural and religious explanations for disability:

Blaming appears to be one of the most common factors in explaining disability, irrespective of whether religious or medical explanations dominate. The blame is often directed towards women, as was reported in the Zulu context of this study

Almost all religions and belief systems seem to incorporate some notion that disability is a punishment “*for having done bad*”. Many religious texts even have stories and parables, which link moral imperfection and sin with divine retribution in the form of a disability.

Cultural beliefs and superstition may vary between good and evil. Some people believe for example, that parents of a child with disability have special abilities and therefore are given “an angel”, to care for. In other cases, such beliefs are related to evil like bewitching a person because of jealousy. (Multicultural Disability Advocacy Association: n.d.).

From the above story lines and literature it appears that cultural and religious beliefs have a direct influence on perceptions of people with disability and thus have a hampering effect on their inclusion in faith communities.

3.6.3.3 Category 4.3.3: Oppressing messages communicated to people with disabilities regarding marriage

Although rarely talked about, it appears that there is a cultural belief that people with disabilities are not supposed to get married. A case was presented by a woman with disability in a group of church leaders in the Imbali township:

“I know of a woman with disability who went to her pastor for marriage counselling. She was told: ‘Why did you get married in the first place? You are disabled’.”

Some comments from pastors in this group discussion in Imbali were:

“We don’t know where this belief comes from and whether the belief is correct”.

“We don’t know if it is a law of the country, or does it come from the Bible?”

“I know of another pastor who refused to marry a disabled woman, asking: How will she have children?”

Oppressing messages like the above are indicative of society’s inability to accept people with disabilities as persons like all others. Fischer (2006:1) confirms the

views about disability, marriage and sexuality and points out that the nature of their impairment constantly exposes people with disabilities to the attention of others. They are seen as outside of the individualistic self-determined nature of the rest of society, and are therefore perceived as different. One of the consequences of this is that a person with a disability may be deprived of intimacy, sexual expression and relationships. This deprivation is rather tragic if it is considered that brokenness can be healed in the presence of relationships with people usually marginalised and disregarded by society (Fischer 2006:2).

It appears that some of these complexities around disability and marriage are also present in the African church context.

3.6.3.4 Category 4.3.4: The lack of respect for the person

In several ways, some people with disabilities experience that they are actually not respected as persons. They feel that many non-disabled people respond to them according to set ideas about disability or stereotypes that are actually out of touch with their reality of living with a disability.

The sub-categories are:

- Labelling and generalising.
- Using offensive terminology.

a) Sub-category 4.3.4.1: Labelling and generalising

People with disabilities feel others often refer to them in too general and sometimes unfair and incorrect ways which are problematic for them.

“We are identified by our physical appearance. ‘Oh Sarah, the disabled lady’ is the way people refer to me”.

People with disabilities also note the habit of non-disabled people to lump groups of people with disabilities together as if they are all the same.

They often experience being labelled as “the disabled” or “the blind” which does not regard them as unique individuals. This response from non-disabled people is

confirmed by Watermeyer (2006:33) as “othering” which means that identity is created via distinctions, which people draw between themselves and others who are different. In this way, a social construct is created by identifying the ‘other’ as ‘different’ and actually devalued. Labels such as “the disabled’ therefore imply a convenient way to refer to the ‘different’.

b) Sub-category 4.3.4.2: Using offensive terminology

Certain terms are experienced as offensive terminology for most people with disabilities. Examples in the English language are:

“We do not like to be referred to as being ‘crippled’ or ‘the handicapped’ ”.

“For us these terms focus on an impairment of my body and do not consider my many normal abilities”.

In various interviews, core group meetings and personal communication with isiZulu speaking people reference was made to terms used for people with disabilities, which have derogatory meanings. Examples were:

- a blind person is called “impumputhe”, derived from the verb “phuphutha” which means to “fiddle around without direction”.
- a person with a mobility impairment is called “isilima”, meaning “an idiot”.
- a person with albinism is called “isishaywa”, meaning “one who is punished”.
- The word for a person with albinism is “inkawu” which means monkey. This word is used in isiZulu as well as isiXhosa.

These terms were confirmed by an isiZulu-speaking disability expert (Mdunyelwa, 2011). People with disabilities find that the use of these derogatory terms is no different in the church, which leads to experiences of exclusion. The National Council for Persons with Physical Disabilities of South Africa (NCPPDSA) has addressed these experiences of people with disabilities with publications on politically correct terminology for the disability sector (NCPPDSA 2010). I will refer to these again in chapters four and five.

In summary of this category, some people with disabilities experience their personhood as often not really respected in the ways that non-disabled people respond to them. The responses of labelling and offensive terminology can be seen as “othering” (Watermeyer, 2006:33) which is a self-constructed norm of the non-disabled person to identify people according to their different physical appearance.

3.6.3.5 Category 4.3.5: The lack of understanding of disability

Further experiences that hamper the inclusion of people with disabilities in faith communities is the perceived lack of understanding of disability by non-disabled. Several “uninformed” perceptions seem to persist in society and the church expressed as the following sub-categories:

- The perception of total incompetence of persons with disability
- Being disregarded and being regarded as “different”
- Church leadership is perceived as not understanding disability
- Non-disabled church members are perceived as not understanding disability

a) Sub-category 4.3.5.1: The perception of total incompetence of persons with disability

As mentioned in the previous section the perception of total incompetence of people with disabilities seems to be deeply embedded in society. Responses from people with disabilities were:

“Having had polio, I use crutches, and sometimes a wheelchair. I had a successful career as an administrator. However, I’m still sometimes treated as an imbecile, as if I can’t think for myself”.

“At church they don’t utilise you, they seem to think I can’t do anything”.

“I would like to organise the youth at church, it seems they think I can’t do it”.

This perception of total incompetence is confirmed by the Disability Action Research Team (DART 2006:2) when they describe some of the challenges faced by people with disabilities. There is the perception in society that disabled people are incapable, ill and a social and financial burden.

b) Sub-category 4.3.5.2: Being disregarded and being regarded as “different”

Stories of participants pointed out experiences of being disregarded:

“It irritates me with my wheelchair, people talk over your head to whoever is with you. But when I confront them, they feel so guilty for not having acknowledged me”.

“. . .always being treated as different. It seems we stick out like a sore thumb”.

“We are always regarded as different, as if your body can’t do things”, said by a courageous young man who has the drive to achieve his life goals.

c) Sub-category 4.3.5.3: Church leadership is perceived as not understanding disability

A pastor from the Zulu speaking community, who has a disability, commented:

“Church leaders in general do not show any interest to learn about disability. Why have so few of them turned up at this meeting? [focus group discussions for the research], I feel it is an illustration of the point”.

Some participants from the Zulu speaking community felt that many church leaders do not understand disability and are not open to being informed. I also observed a lack of interest in some of the focus group interviews with church leaders in Imbali township. While serious issues were brought to the table, there was very little effort by some to involve themselves in the debate.

Further comments from church leaders were:

“Some church leaders are not informed [about disability], they argue that [for example] AIDS is a curse from God”.

“Church leaders steer away from the issues of disability, because they don’t want to sit with the problem”.

“We often get too busy with full programs that we do not slow down enough to hear what people’s needs are”.

“If pastors don’t have the answers, they feel belittled”.

d) **Sub-category 4.3.5.4: Non-disabled church members are perceived as not understanding disability**

There seems to be a tendency of church members to shun people with disabilities without making the effort to get to know their circumstances. An example of how non-disabled people remain passive about getting to know disability was shared by a woman with profound hearing loss.

“In my Bible study group the leader has never learnt to speak up clearly for my sake. He talks down to himself and fiddles with his papers while announcing the verses to be read. I try to catch up with those sitting next to me, but I often feel left behind, because I cannot comment on the discussion”.

Further comments from the same person:

“Also, none of the other group members make an effort to help improve the situation. I feel people don’t put themselves out, I sometimes feel they need to be shaken”.

With these experiences, the issue of assertiveness of people with disabilities comes to mind. A young woman with mobility impairment who is assertive in teaching others about disability, made a comment:

“It takes so much effort [to make people to understand]. At my church they just don’t understand disability, they all treat you as if you are fragile”.

The above experiences concur with the opinions of several authors.

Church leaders lack understanding of disability. Pity and practical support is usually rendered, but this happens at the expense of understanding and sharing in the realities of the lives of people with a chronic condition (Treolar, 2000:12).

The lack of understanding is also related to the fact that churches may wrestle with relating to people who are unfamiliar and unknown (Carter, 2007:32).

Webb-Mitchell (1996:86) illustrates the lack of understanding with an example of including a child with intellectual disabilities in a Sunday school. The parent gave guidance to the Sunday school teacher on how to deal with his child, with seemingly good results. The teacher, other children and the child in question seemed to be happy. After a while, without consulting the parent, the teacher asked the pastor to write a letter to the parent, asking her not to send the child to the Sunday school anymore. No amount of explanation by the parent could make the Sunday school teacher and church leaders grow in understanding and acceptance of the child. Webb-Mitchell calls the chapter where this story is narrated “Letters to a disabled church” (1996:85).

In summary of this category, it appears that the lack of effort of non-disabled people to know and understand disability plays a role in the experiences of exclusion of people with disabilities.

3.6.3.6 Category 4.3.6: Patronising attitudes and behaviour hampering the inclusion of people with disabilities

Patronising attitudes are experienced by people with disabilities in the sense that they feel treated as if they are less intelligent or knowledgeable than non-disabled people (Encarta dictionary, 2011: s.v. “patronising”).

From the experiences of the participants, such attitudes consist of the following sub-categories:

- Giving unwanted sympathy
- Being insincere and giving patronising appreciation
- Being assumptive, “thinking for me”
- Being judgemental
- Being impatient in engaging with people with disabilities

a) **Sub-category 4.3.6.1: Giving unwanted sympathy**

To be at the receiving end of unwanted pity is a problematic experience for people with disabilities. Their responses are:

“People say ‘Ag shame’, and I want to ask them, ‘What is so shameful about my life?’”

“This kind of pity is a terrible hindrance for us, they think my mind is also disabled”.

McDougall’s (2006:388) interviewees confirm these responses of pity as a disregard of one’s personhood. The habit of many non-disabled people of displaying unwanted sympathy to people with disabilities is one end of a spectrum of responses. At the other end is admiring the person in an inappropriate way, as explained in the following sub-category.

b) **Sub-category 4.3.6.2: Being insincere and giving patronising appreciation**

A blind person shared how people project their own feelings of uncertainty on him:

“What is very patronising is when people tell me, ‘Oh, you are so wonderful’ . . . so I avoid them”.

A young woman with mobility impairment also experiences it as patronising since she feels that she is not regarded as an equal person:

“Sometimes people admire me too much, I don’t like it. Just accept me as a person, please”.

Patronising appreciation is the other end of a dichotomy between being seen either as pitiable or as ‘superheroic’ (McDougall, 2006:387). This is also described as idealisation which is the attribution of excessive and unreal positive characteristics to a person with disability (Watermeyer, 2006:37).

c) **Sub-category 4.3.6.3: Being assumptive, “thinking for me”**

While some people with disabilities may be dependent on specific help from others, they do want to be as independent as possible. In the first place, this means to think for themselves and take their own decisions. A woman with a strong personality expressed her feelings as follows:

“I don’t want people to think for me, and sometimes pastors have their own heresies [so I take my own decisions]”.

Another young man who became paralysed recently suggests that churches should be wise in dealing with people with disabilities:

“Allow them to include themselves on their own terms. Don’t assume, and act according to what you think their needs are”.

Non-disabled people in the church are prone to think that the disabled, as well as other people who have been relegated to the margins of society, are powerless and voiceless, and that we must speak out on their behalf. However, by insisting on speaking *for* them, in the name of “defending” them, their victimization is actually intensified (Steele, 2010:77).

d) **Sub-category 4.3.6.4: Being judgemental**

The attitude of being judgemental as experienced by people with disabilities, relates to the views about sin as a cause for disability and/or not being healed from a disability (as discussed in section 3.6.1.2).

A comment in this regard was,

“I feel the church is judgemental regarding healing issues”.

In other discussions, society’s attitudes towards disability was seen as being the same as attitudes towards HIV/AIDS. The feeling of the group members (church leaders and people with disabilities) was:

“Church leaders judge people who have HIV/AIDS. We have no reason to believe that they have any better attitudes towards people with disabilities”.

Reynolds (2008:12), a professor of theology at Toronto School of Theology in Toronto, Canada, and the father of a child with multiple disabilities, expresses his own experience of having to endure judgement being passed on them as parents. Well-meaning friends indicated that he and his wife had not responded well to their son's unique needs.

e) **Sub-category 4.3.6.5: Being impatient in engaging with a person with disability**

The lives of people with disabilities sometimes follow a different pace to that of others. This may be a source of frustration. A pastor who has some understanding of this, expressed his concern:

"I have seen a family arriving late at church because they have to accommodate the [disabled] grandmother who is slow, and others show some irritation for this."

"After my accident, I came back to church as a paralysed person. Then I noticed the young man with speech impairment. Most people in the church find it difficult to follow a conversation with him, so they refrain from relating to him. I decided to engage with him. I sit with him, ask him to speak as clearly as he can, you can actually have a conversation with him and laugh at him as well".

One pastor noticed impatience with elderly and disabled people in his church.

"The old people walk slowly and do everything slowly. Others find it difficult to cope with. This is unfortunate, that they respond in such a way, however, the elderly [and those with disability] are also part of the church, and it is our challenge to accommodate all".

In conclusion of this category on patronising attitudes, there seem to be attitudes in churches that hamper the inclusion of people with disabilities. Non-disabled people giving unwanted sympathy, being insincere in appreciation, being assumptive, judgemental and impatient do not help people with disabilities to feel included and free to participate in the church.

In summary of this theme on how people with disabilities experience others' perception of disability, the three sub-themes spell out how participants portrayed their experiences: theological ideas that either have an oppressing or liberating influence on them, as well as practices in the faith community that hamper the inclusion of people with disabilities.

3.7 CONCLUSION

In concluding this chapter, a summary is given by comparing the findings regarding the original themes with the existing body of literature and with the different contexts of the study.

3.7.1 Comparison between original themes of discussion mentioned by *disAbility ConneXion* and findings of the research

This chapter explained the experiences of people with disabilities in their faith communities as described by themselves. The four themes that emerged from the data collection coincided largely with the initial discussions among *disAbility ConneXion* members and participants at an exploratory meeting before the research process began (see chapter one, section 1.3).

The problem of inaccessibility of church buildings was confirmed in the research, but expanded to the inaccessibility of liturgy in worship services that do not accommodate the needs of wheelchair users, people with visual or hearing impairments and people with intellectual disabilities.

What was originally (chapter one, section 1.3) presented as experiences of exclusion, emerged in the research as patronising attitudes of giving unwanted sympathy and being assumptive towards people with disabilities.

Psychological issues of people with disabilities emerged in the research as part of the many challenges of daily living like reconstructing one's identity after the onset of a disability.

The oppressing practices that *disAbility ConneXion* members originally pointed out were confirmed in the research as part of theological ideas and faith practices that

hamper the inclusion of people with disabilities in faith communities. The original problem of lack of etiquette for interacting with people with disabilities was shown in the research to be part of the practices of not considering the needs of people with disabilities.

3.7.2 Comparison between the findings and the literature

Most of the findings were confirmed and/or supported in the literature. Examples were themes one and two of the experiences of living with a disability and the experiences of the significant others of people with disabilities. These themes have been well described in the literature and for participants this is a significant part of their lives.

Comparing the findings of theme three of the accessibility of the church environment with literature, revealed only one article on the situation of South African churches (Razaka, 2005). No literature was found on the accessibility in South Africa churches in relation to the National Building regulations. Part S: The needs of people with disabilities.

3.7.3 Findings from the different contexts of the research

Some findings were context specific while others were common to all contexts.

Several findings applied specifically to the African isiZulu speaking community, for example, cases of disabled family members being hidden, dissatisfaction of ancestors and family problems being the reasons for a disability. Other findings in relation to the church were restrictions about dress code at church, ideas that disabled people are not supposed to get married and cultural perceptions about disabled people not being chosen as leaders in the church. Terminology used in the isiZulu language to refer to people with disabilities is experienced as derogatory, for example, a person with mobility impairment is called “isilima” which means “an idiot”.

The sub-theme of making meaning of living with disability was expressed only by the Afrikaans and English speaking white participants who referred to processes of being on a journey, finding a new identity, a life purpose and acceptance. The

isiZulu speaking participants did not mention anything about meaning making. This does not imply that they do not have the same struggle in finding meaning in living with a disability. This could possibly have a number of explanations. Meaning making surfaced as a theme in the individual interviews with Afrikaans and English speaking participants. The situation of an individual interview possibly created the opportunity to mention such individual nuanced experiences. The experience of meaning making could possibly have been lost in translation of the isiZulu group interviews. The group situation may have been somewhat limiting to the freedom of expression of those participants. See also section 3.3.2 on a core group member's explanation for a finding a reason for one's disability.

The following chapter will deal with the suggestions regarding inclusion of people with disabilities in faith communities.

4 CHAPTER 4: FINDINGS OF THE STUDY: SUGGESTIONS FOR INCLUSION OF PEOPLE WITH DISABILITIES IN FAITH COMMUNITIES

NARRATING THE JOURNEY (2)

This chapter continues with the action to present the findings of the study, namely the *suggestions* of the participants for the inclusion of people with disabilities in faith communities.

4.1 PRESENTATION AND DISCUSSION OF THEMES

As in chapter three, I present the themes, with story lines or quotations from the transcribed interviews. This confirms the analysis of the data. I again compare the findings with literature, which adds to the credibility of the study.

Following are the four themes of experiences in chapter three, themes five to eight detail the suggestions for inclusion.

Theme five: Suggested strategies for the inclusion of people with disabilities in faith communities.

Theme six: Suggestions for accessibility of church buildings and worship services.

Theme seven: Creating awareness about disability: methods and content.

Theme eight: Suggestions of how people with disabilities can contribute to their inclusion.

These four themes were divided into sub-themes, categories and sub-categories as set out in the following table:

Table 4-1: Themes of suggestions for inclusion

THEME 5: SUGGESTED STRATEGIES FOR THE INCLUSION OF PEOPLE WITH DISABILITIES		
Sub-themes	Categories	Subcategories
5.1 Practicing unconditional acceptance of PWD at all levels in faith communities	5.1.1 Accepting people with disabilities first requires a changed mindset	
	5.1.2 Allowing people with disabilities to be involved on their own terms	
	5.1.3 Displaying confidence in the abilities of people with disabilities	
	5.1.4 Creating opportunities for people with disabilities to take leadership roles	
	5.1.5 Being mindful of people with disabilities at all times in all activities	
	5.1.6 Exercising patience	
	5.1.7 Practicing hospitality towards PWD	
5.2 Building relationships between disabled and non-disabled people	5.2.1 Building friendships between disabled and non-disabled people	
	5.2.2 Interacting with people with disabilities as persons with <i>abilities</i> and not completely disabled or helpless	
5.3 Providing practical support	5.3.1 The attitude with which support should be given	
	5.3.2 The types of support needed	

Sub-themes	Categories	Subcategories
	5.3.3 Church leaders' suggestions for improving practical support	
5.4 Creating awareness about oppressive perceptions and practices regarding disability in faith communities	5.4.1 Challenge the perception that people with disabilities are so different that they cannot be regarded like other people	
	5.4.2 Challenge cultural beliefs about disability and develop Ubuntu	
	5.4.3 Create awareness that people with disabilities are primarily concerned about their spiritual growth like other church members	
	5.4.4 Challenge oppressive views regarding disability, sin and confession	
	5.4.5 Create awareness of the effect of the portrayal of disability when preaching	
	5.4.6 Create awareness of how to help a person with disability spiritually	
THEME 6: SUGGESTIONS FOR ACCESSIBILITY OF BUILDINGS AND WORSHIP SERVICES		
6.1 Create awareness of importance of accessibility to buildings and worship services for PWD	6.1.1 Create awareness of a more inclusive meaning of accessibility for PWD	
	6.1.2 Create awareness of the importance of consulting PWD about accessibility	
6.2 Activate a transport service		
6.3 Provide accessible parking at church		

Sub-themes	Categories	Subcategories
6.4. Comply with regulations for accessible entrances at church		
6.5 Ensure suitable seating and participation in the worship service	6.5.1 Allow for choice	
	6.5.2 Consider seating requirements for wheelchair users	
	6.5.3 Consider people with hearing loss	
	6.5.4 Consider people with visual impairment	
	6.5.5 Consider people with intellectual impairment	
6.6 Provide accessible toilets		
6.7 Display signs that help PWD to find their way independently		
6.8 Be mindful of the challenges of old church buildings		
6.9 Be mindful of times of services and meetings		
THEME 7: SUGGESTIONS FOR CREATING AWARENESS ABOUT DISABILITY: METHODS AND CONTENT		
7.1 Methods: Facilitate interactive processes between PWD and non-disabled people	7.1.1 Establish opportunities for dialogical processes	7.1.1.1 Ensure the interchange of views 7.1.1.2 Accept the equality of participants in dialogue 7.1.1.3 Aim for a transformative and challenging process
	7.1.2 Facilitation of the dialogue	
	7.1.3 Comprehensive involvement of target groups	

Sub-themes	Categories	Subcategories
7.2 Suggested content of an awareness process	7.2.1 Include information to enable understanding of different kinds of disability	
	7.2.2 Promote the use of terminology that affirms the dignity of PWD	
	7.2.3 Etiquette for interacting with PWD	
THEME 8: SUGGESTIONS OF HOW PWD CAN CONTRIBUTE TO THEIR INCLUSION		
8.1 People with disabilities to take responsibility to make known their readiness to serve in the church		
8.2 People with disabilities to avail themselves for leadership		
8.3 People with disabilities to share their wisdom and knowledge to create awareness		
8.4 People with disabilities to develop willingness to be accommodating		

The suggestions subsumed in the four themes emerged from different types of storylines. Firstly, there were the positive experiences of people with disabilities, which implied suggestions of what churches can build on to enhance inclusion. Storylines of negative experiences, implied suggestions for counteracting these. In other cases, the storylines presented direct suggestions for the enhancement of inclusion. Responses of church leaders sometimes provided the context for applying the suggestions.

4.2 THEME FIVE: SUGGESTED STRATEGIES FOR THE INCLUSION OF PEOPLE WITH DISABILITIES IN FAITH COMMUNITIES.

For the purpose of this study, social **inclusion** is understood as when people with disabilities are not discriminated against because of their impairments and are fully part of the faith community in all its dimensions.

Some questions to participants were aimed at their perceptions of what real inclusion is. People with disabilities were asked about their positive experiences and what make it easy for them to feel included. Church leaders were asked what they thought helps the inclusion. The responses to these questions indicated specific strategies to be followed in order to enhance the inclusion.

The five sub-themes for the strategies for inclusion are as follows:

- Practicing unconditional acceptance of people with disabilities at all levels in faith communities
- Building relationships between disabled and non-disabled people
- Providing practical support
- Creating awareness about oppressive perceptions and practices regarding disability in faith communities

4.2.1 Sub-theme 5.1: Practicing unconditional acceptance of people with disabilities at all levels in the faith community

The unconditional acceptance of people with disabilities would mean welcoming them without any limits to be part of the church community (Oxford Advanced Learner's Dictionary, 2010: s.v. "unconditional").

A description of the categories of this suggestion follows. In most cases, these were as portrayed by persons with disability to which the suggestions from church leaders were added.

- Accepting people with disabilities first requires a changed mindset
- Allowing people with disabilities to be involved on their own terms

- Displaying confidence in the abilities of people with disabilities
- Creating opportunities for people with disabilities to take leadership roles
- Being mindful of people with disabilities at all times in all activities
- Exercising patience
- Practicing hospitality towards people with disabilities

4.2.1.1 Category 5.1.1: Accepting people with disabilities first requires a changed mindset

Responses from participants indicated that acceptance of people with disabilities firstly requires a change of mindset.

A telling example was that of a church where a young woman, a wheelchair user, is a member. She narrates:

“The church has taken my needs fully on board and considers my needs under all circumstances. When the church moved to new premises, they first asked: ‘What about [‘Sally’] ? We will build ramps’. So I know I am thought about”.

The father of a disabled child was asked when he really felt accepted in his faith community. His response was:

“When people really understand [implying a mindset that accommodates disability]”.

A man with long years of experience living with his disability puts it this way:

“It is a conscious decision . . .to make the paradigm shift”.

A church in the city centre of Pietermaritzburg has learnt to accommodate in their worship services people from diverse backgrounds who live in the inner city. The pastor says:

“They [people with intellectual disabilities] are also part of our diverse community. So we don’t shun them”.

4.2.1.2 Category 5.1.2: Allowing people with disabilities to be involved on their own terms

A person who became disabled not long ago, explained that the church sometimes responds in a pressurising way, for example, with regard to the healing practices as spelt out earlier in chapter three. This makes people with disabilities feel uncomfortable.

Responses in this regard were:

“I go the church to thank God for my life, not to seek healing for my disability, as so many people assume”.

“It is their own choice, [how people with disabilities involve themselves] it depends on the person”.

Implied in the following negative experience is further confirmation of this suggestion:

“I am not involved in church at the moment, because I have a problem with the church theologically, and that has nothing to do with my disability [therefore don't assume my absence is because of my disability]”.

The suggestion was therefore to allow people with disabilities to become involved in the church on their own terms, and not according to the ideas of others who want to “help” them.

4.2.1.3 Category 5.1.3: Displaying confidence in the abilities people with disabilities

Participants with disabilities spoke of their positive experiences when church members showed confidence in their abilities.

“One lady put a vote of confidence in me, and asked me to lead the women's group”.

“I am often asked to do prayers in the church [meaning my gifts are utilised]”.

A pastor also demonstrated this confidence in the contribution of people with disabilities in the community life of the church:

“People with disabilities also have tasks to do in church, a man with intellectual impairment is part of the maintenance team of the church, and the lady with mobility impairment leads the mom’s group”.

The above positive experiences of people with disabilities implied the suggestion that meaningful inclusion is enhanced when church members display confidence in the abilities of people with disabilities, by asking them to take responsibility for tasks in the church and considering their opinions.

These experiences of and the necessity for having confidence in the potential of people with disabilities is confirmed by Erik Carter, Professor at the Department of Rehabilitation Psychology and Special Education at the University of Wisconsin-Madison, USA. Carter (2007:17) points to the need for people with disabilities to exercise their gifts in the faith community. Disabled and non-disabled believers are interdependent in that their gifts will complement each other and works in tandem for a greater purpose. It therefore follows that practicing confidence in the contribution of persons with disabilities is focussed beyond what a person can *do*, but rather on the “being” of a person, for example, a person with intellectual disabilities who is simply friendly to everybody, and thus evokes a friendly response from others (Carter, 2007:18).

4.2.1.4 Category 5.1.4: Creating opportunities for people with disabilities to take leadership roles

While this category relates strongly to the one above, the following positive experiences implied a suggestion regarding leadership roles of people with disabilities in the church.

A young man was a leader in the church before an accident that left him paralysed.

“I am a deacon in the church, and even after my accident, I continued . . . Ramps were built to get me into the church. It took some doing, people treated

me as fragile, but eventually they realised I am still the same person and I continued my leadership role”.

A young man wanting to serve more in the church:

“I do serve on the committee of my church, my mobility impairment does not influence my willingness and abilities to serve in the church”.

Leadership roles for people with disabilities in faith communities are not discussed in the available literature. However, Carter (2007:31) states that faith communities who are serious about the inclusion of people with disabilities would not only think about what the church can offer to disabled people, but, more importantly, would strive to discover all that people have to offer to the church.

4.2.1.5 Category 5.1.5: Being mindful of people with disabilities at all times and in all activities

People with disabilities described how the mindfulness of church members enhances their inclusion. With the following positive experiences, they implied a suggestion for the church to expand these practices.

“At church summer camp, they tried to include me with my wheelchair, I felt they considered me”.

“We have a nice church, there is no favouritism, our priest likes us all to be involved, so I am included and they make provision for my wheelchair”.

“When my child was born with severe disabilities, the pastor came to my house to pray for the child and baptised her. This was enough for me to become an active member of the church. I realised my disabled child also has a place”.

A negative experience of a wheelchair user illustrates the result of not being mindful:

“I used to do hospital visits with the women’s group. But since there is no accessible transport anymore, nobody considers me anymore”.

Church leaders confirmed their mindfulness with the implied suggestion that this can be a growing process.

“We are mindful that we still make mistakes, but we are learning”.

“We try to include people with disabilities in the rituals and sacraments. With that we illustrate that we are all vulnerable, anyone can become disabled”.

A woman with mobility impairment, who is a pastor herself of a mainline church stated:

“Inclusion means all must be able to come in. A church should always ask themselves, how mindful are we of the people with disabilities. Do they have access to the church?”.

Carter (2007:17) supports the suggestion of the church needing to be mindful of people with disabilities. The church’s invitation to society to become involved in the life of the church can never be diminished by disability.

4.2.1.6 Category 5.1.6: Exercising patience

Patience can be seen as the ability to stay calm and give full attention to something that is important (Oxford Advanced Learner’s Dictionary, 2010: s.v. “patience”). The following storylines illustrate examples of being patient as part of the suggestion of unconditional acceptance of people with disabilities.

“In our church is a man with an intellectual disability, he sometimes walks in and out of the service, or talks about Bible verses which do not always make sense, but we have realised all he needs is to feel accepted, so we have learnt to be patient with him”.

“In our church a person with a speech problem often gives testimony . . .we wait for him, until he finds the words and he continues to testify”.

In a mixed group of people with disabilities and church leaders (of whom some also had disabilities), this suggestion was strengthened:

“Non-disabled people can learn from disabled people if they can exercise patience in situations where things go at a different pace”.

4.2.1.7 Category 5.1.7: Practicing hospitality towards people with disabilities

According to Reynolds (2008), the church can be seen as the household of God. Hospitality in this household means opening up space to provide and care for another whose place of origin is elsewhere. It is the practise of making room to include the stranger, an act of sharing with and for another as oneself. Hospitality furthermore neither condescends out of pity nor forces the other to conform to the household rule (Reynolds, 2008:241).

A participant with a disability testified to her positive experience of hospitality and thus implied a suggestion for this kind of welcome to be expanded in the faith community.

"[At that church] . . .there was no pressure on me, they didn't ask for the impossible. They just allowed me to be comfortable and the bigger healing to take place inside of me".

Several church leaders shared their experiences of making the church as hospitable as possible for everybody who wants to be part of it.

"We want people to be at home with us. If the service is too long you must feel free to go out, or we must find you a more comfortable chair if that can help you".

"Please communicate with us what your needs are, we don't want to do silly things that are uncomfortable for you"

"We want new-comers and people with disabilities to feel our love and friendliness. We realise that a relationship of trust must develop, so that people will come home here".

The above positive experiences, therefore presented suggestions for church members to demonstrate unconditional acceptance of people with disabilities.

Carter (2007:29) confirms the role of hospitality in the inclusion of people with disabilities in faith communities. Physical accessibility to buildings may be a starting point, but above all, it is an attitude of welcome that is practised in

relationships with people with disabilities. Carter points out that faith communities also need to go beyond easy hospitality like greetings and remembering a name once a week. It is in authentic and substantial gestures that personal hospitality is demonstrated. These could be spending time together, celebrating successes, coming alongside in difficult times and nurturing close relationships.

In summary, this sub-theme makes suggestions for practicing unconditional acceptance of people with disabilities in faith communities. Developing a mindset of inclusion, allowing disabled people to be involved on their own conditions, displaying confidence in and making space for their contributions and gifts, and exercising patience in some situations, can create a hospitality in which all members will thrive.

In a way, all the above suggestions can actually be seen as practicing the three components of hospitality as described by Reynolds (2008:245). For him, hospitality is firstly, recognising the presence of persons with disability. This implies more than an occasional greeting once a week, but rather becoming attuned and available to the presence of others and the diversity of their gifts and needs. Secondly, hospitality means accommodating others as uniquely precious persons, acting for their benefit, making space for them to flourish, and receiving their contribution. Thirdly, hospitality means advocacy in reaching out *with* and not only *for* persons with disability, standing with them at the margins, understanding their world and working together with them for their well-being. However, true hospitality is not a matter of “us” serving “them”. Rather it is a matter of becoming a more inclusive and interdependent “us” fostered within relations of mutual giving and receiving.

4.2.2 Sub-theme 5.2: Building relationships between disabled and non-disabled people

This subtheme can be divided in two categories:

- Building friendships between disabled and non-disabled people
- Interacting with people with disabilities as persons with abilities and not completely disabled or helpless

4.2.2.1 Category 5.2.1: Building friendships between disabled and non-disabled people

People with disabilities suggested the cultivation of friendships built upon each person's unique ability to contribute towards the relationship – i.e. focus on strengths and gifts.

Some participants reported their positive experiences of friendships in the church:

"I have wonderful friends in my church now. I am their friend and that's it. They don't see my wheelchair anymore".

"Everybody knows me now and they make friends with me".

4.2.2.2 Category 5.2.2: Interacting with people with disabilities as persons with abilities and not completely disabled or helpless

Participants with disabilities suggested that since they are not completely helpless, they have a part to play in building relationships and friendships.

"Me too, I should not be prejudiced [towards non-disabled people]. Perhaps they don't know how much they are missing [by not relating to disabled people]".

Others felt they could offer meaningful friendships:

"Come, get to know me, I can show you how to love me, I can show you how it is done [building a friendship]".

In summary, the suggestion emerged that relationships between non-disabled and disabled people requires perceiving persons with disability as people with *abilities* and not as (completely) disabled or helpless.

However, church leaders suggested the need to be aware that building relationships can be a challenge for both disabled and non-disabled people:

". . . sometimes we [non-disabled people] throw money at things, but it's the actual relationships [that count]".

“People with disabilities sometimes build walls around them, but the challenge is to build trust with people [implying relationships]”.

Relationships between disabled and non-disabled people are often referred to in the literature. Clapton (1997) issues a challenge to the church to imagine a new moral fabric, which embraces embodied difference. A refigured relationship between people with disabilities and the church can provide a rich medium for exploration, which embraces new relations with God, one’s own body and with “different” others within the notion of “community”. Such a community is full of promise and the possibility of exploring how the gift of life can be expressed, embodied, shared and celebrated (Clapton, 1997:424).

It is also helpful to take cognisance of the approach to life of Cyril Axelrod, a Roman Catholic priest who was born profoundly deaf and became blind in his adulthood. He writes: “I have learnt to travel alone in the UK. Sometimes it was too much for strangers to comprehend that I could be travelling alone. I could sense their astonishment when they found out that I was a priest and that I had worked all over the world. They could see my deaf-blindness, but not my capabilities”. In spite of the fact that he is very dependent on others for all his communication, Axelrod’s *abilities* lie in his mindset of making meaningful life for himself and others. He continues: For non-disabled people to understand the *ability* in disability, even in just a small way, can be very helpful in building relationships that are reciprocally enriching (Axelrod, 2005:192).

4.2.3 Sub-theme 5.3: Providing practical support

Giving practical support to people with disabilities can go a long way to realising their inclusion in the faith community as suggested by the following categories:

- The attitude with which support should be given
- The types of support needed
- Church leaders’ suggestions for improving the support

4.2.3.1 Category 5.3.1: The attitude with which support should be given

Suggestions from participants indicated that practical support includes emotional support:

“The church really supported us at the time of the accident of my children. Even people from other churches reached out to us. And even now, many years later, they still remember us”.

Emotional support also implies helping with an attitude of equality and not being condescending:

“Support that respects the person, regardless of his limitations . . . it knows a unique way of “give and take”. It gives rather empathy than sympathy, and is appropriate in terms of what is really needed and not what the able-bodied person thinks and wants to do and give.

Practical help to persons with disabilities should not marginalise disabled people from the rest of the church community.

“Father does come to serve communion at home, but it is not the same . . . [as being with others in the church]” – a person who would like to go to church but does not have transport.

This attitude of help is confirmed by the Leprosy Mission’s quote from Kunc and Vander Kliff’s Credo of Support. This is a suggestion of an approach to equity and respect for the person:

“Do not be charitable to me. Be my ally against those who exploit me for their own gratification.

Do not help me even if it does make you feel good. Ask me if I need your help. Let me show you how to better assist me.

Do not admire me. A desire to live a full life does not warrant adoration. Respect me, for respect presumes equity.” (The Leprosy Mission International, 2009:2)

4.2.3.2 Category 5.3.2: The types of support needed

Providing transport can make a huge difference in the life of a person with disability:

“In our church there is regular transport to Sunday services for people who need it”.

“At the moment, I do not have anybody to take me to church; I don’t want to ask my children, they are too busy” [implying the need for a church member to be mindful of her need].

The challenge of providing transport to less-resourced communities is, however, different, therefore the expectation and suggestion is also different. The suggestion was:

“We will appreciate if transport can be arranged occasionally for people with disabilities to be picked up for church. This will demonstrate to the people with disabilities that they are thought about”.

Visiting people who are housebound is another type of support:

“Our church has well-organised programmes to visit the members who cannot come to church regularly”.

“As I am bedridden I wish the pastor will visit me more often. I feel the need to talk to him”.

Financial support for devices for people with disabilities is sometimes needed:

“ . . . if there is a poor person in the church, they will ask contributions. But if a disabled person needs a new calliper, nobody in the church will ask contributions for that to help the disabled person”.

A church leader confirmed this:

“We sometimes try to help members financially to pay for their devices, take them to hospital for fitting the devices”.

Helping with **small tasks** that make life easier:

“In our church there are a number of people who simply sit with a lady who is deaf helping her to follow the service”.

4.2.3.3 Category 5.3.3: Church leaders’ suggestions for improving practical support

A church leader who is in charge of a big church welfare program in KwaZulu-Natal suggested:

“Local congregations can organise task teams to give practical support to people with disabilities who are cared for in their own homes. For example, each person in the group takes a turn to visit a family three times a week to give whatever help is needed”.

Another suggestion was in terms of equipping church members for support tasks:

“Some elders for example, need more training, in how to spend time with people who are housebound”.

Relating these suggestions to the need of people with disabilities (section 3.6.3.5) not to be regarded as completely dependent and helpless, practical support should be rendered in a manner that is not condescending. Their inherent value when help is extended is to be recognised (Carter, 2007:18).

4.2.4 Sub-theme 5.4: Creating awareness about oppressive perceptions and practices regarding disability in faith communities

As explained in chapter three, section 3.6.1, several beliefs in the faith community have an oppressing influence in the lives of people with disabilities. The following categories give suggestions for changing these beliefs.

- Challenge the perception that people with disabilities are so different that they cannot be regarded like other people
- Challenge cultural beliefs about disability and develop Ubuntu
- Create awareness that people with disabilities are primarily concerned about their spiritual growth like other church members.

- Challenge oppressive views regarding disability, sin and confession
- Create awareness of the effect of the portrayal of disability when preaching
- Create awareness of how to help a person with disability spiritually

4.2.4.1 Category 5.4.1: Challenge the perception that people with disabilities are so different that they cannot be regarded like other people

People with disabilities object to the idea that the perception of 'normal' does not include living with a disability and therefore suggested that such ideas be challenged.

“That word ‘normal’, you better check what that means [implying that ‘normal’ is not a narrow perception]”.

“It is very hard for people to understand that you are normal, you only cannot walk”.

“If a disabled man arrives at the gate of the church, don’t run to him as if he cannot help himself, just treat him as a normal person”.

One person with paralysis mentioned the television advert about a cheetah that lost his leg in a trap. The cheetah’s response was

“Just because I lost my leg does not mean that I’m not a cheetah anymore”.

With these words, the participant wanted to emphasise that he is a normal person in spite of his physical limitations.

In terms of perceptions of “normality”, Hubach (2006:25) describes several views of disability. The historical view regards disability as an abnormal part of life in a normal world. A postmodern view would see disability as a normal part of life in a normal world. However, Hubach suggests a biblical view that sees disability as a normal part of life in an abnormal world. With this suggestion, Hubach means that what God originally made good, is not perfect anymore and the world became ‘abnormal’. Hubach thus sees disability as a normal part of an abnormal world.

Confirming a view of people with disabilities as a normal part of society, Treolar's research participants also say: "People with disabilities are just like us" (Treolar, 2000:19)

4.2.4.2 Category 5.4.2: Challenge cultural beliefs about disability and develop Ubuntu

In mentioning their negative experiences of some cultural beliefs participants with disabilities by implication suggested that oppressive beliefs about disability be replaced with an attitude and approach that liberates their lives. A white church leader who works in a Zulu speaking community expressed this need for change by suggesting an emphasis on the positive aspects of the Ubuntu philosophy.

"I feel the Ubuntu approach to life has much potential to enhance inclusion and brotherhood [fellowship]. I have seen in our church how members are willing to make efforts to bring a person with disability to church, to make space for them and to exercise patience with a person that have for example intellectual impairments. This approach can be strengthened in the church in order to combat the beliefs that disability stems from ancestors who are not satisfied with the family".

Nolte-Schamm (2006:370) writes about Ubuntu as a reconciliatory paradigm in South Africa. She summarises Tutu's views of Ubuntu as follows: Ubuntu is about unifying apparent opposites, joining instead of separating entities. Ubuntu offers no room for "us versus them" thinking. It focuses rather on "us" and "our" humanity. Ubuntu means people are interconnected in a network of interdependence and togetherness. Nolte-Schamm (2006:377) also refers to Tutu's Ubuntu theology, which includes that the fullness of humanity only becomes manifest in *koinonia*, in community. In his Ubuntu theology, Tutu declares: "God has made us so that we will need each other. We are made for a delicate network of interdependence".

4.2.4.3 Category 5.4.3: Create awareness that people with disabilities are primarily concerned about their spiritual growth like other church members.

A person with a disability wants to be accepted as a spiritual being like everybody else. Several participants with disabilities pointed out that they have made peace with their disability and are involved in the church for their spiritual needs, and not for physical healing :

“I go to church to thank God for my life”.

“I am concerned about the healing of my soul [not physical healing]”.

“There was the bigger healing, inside of me”.

A pastor with much of experience in working with traumatised confirmed the above suggestion:

“Physical healing cannot be demanded from God, God does not heal everybody according to human expectations, but spiritual healing and finding peace is always possible”.

4.2.4.4 Category 5.4.4: Challenge oppressive views regarding disability, sin and confession

The view that disability is a result of sin and that confession is a requirement for healing, is oppressing to people with disabilities and should be challenged.

Participants who have been at the receiving end of this view, suggested:

“The theologians must sort out this confusion [about the relationship between sin and disability]”.

“There must be a way that people with disabilities can be liberated from these oppressing views. If my disability is a result of sin, what about the results of other people’s sins? In this way more people with disabilities will feel free to be involved in the church”.

4.2.4.5 Category 5.4.5: Create awareness of the effect of the portrayal of disability when preaching

Some people with disabilities feel that when preaching certain church leaders portray people with disabilities in a derogatory way.

“They make insensitive comments about people being spiritually blind or deaf”.

“Some church leaders need to be sensitised to realise the influence of such statements in the lives of people with disabilities”.

4.2.4.6 Category 5.4.6: Create awareness of how to help a person with disability spiritually

Bearing in mind the many emotional and oppressive experiences of people with disabilities as described in chapter three, there were several suggestions.

Church leaders were asked to comment on how they would help persons with disabilities in their spiritual journey. The following suggestions were made by church leaders and confirmed by people with disabilities:

Be a good listener:

“I try to give emotional support that will help people with disabilities to find their own answers”.

“We have to understand that each person’s situation and disability is unique”.

Give spiritual support that can liberate the person:

“We need to become free from feelings of guilt, that my disability is a punishment from God”.

Facilitate a process for the person with disability to find his/her unique purpose for the future:

“You have suffered a great loss, but what motto do you want to develop for your future? How do you want to affirm your own human dignity?”.

“It’s about bringing purpose, finding how you [a person with disability] can be creative”.

Help people with disabilities to contextualise their situation:

“Develop an understanding that many other people in society also have difficulties which urge them to ask “why” questions and wanting to blame God”.

“It is not only people with disabilities who are despised by society. Society has prejudices about many other things as well”.

“Develop an understanding that disability is part of a broken and imperfect world, and therefore a person with disability could not take his disability as punishment for personal sin”.

In summary, of the subtheme of creating awareness about oppressive perceptions and practices the above-mentioned categories of changes in practice in faith communities can be described as ensuring “spiritual accessibility” for persons with disabilities in faith communities. Collins and Ault (2010:116) use this term as a description of the extent to which the spiritual needs of people with disabilities are met. In the context of this study, this would mean challenging all perceptions and practices that limit the full inclusion of people with disabilities in faith communities.

In conclusion of the theme of strategies for inclusion, responses of participants pointed to practicing unconditional acceptance, building relationships, providing practical support and creating awareness of oppressive perceptions.

4.3 THEME SIX: SUGGESTIONS FOR ACCESSIBILITY OF BUILDINGS AND WORSHIP SERVICES

Considering indicators of a welcoming congregation, physical accessibility to the buildings and facilities may be of high priority. Gale (2009:4) states that it is an obligation of churches to do everything possible to ensure that facilities are accessible to all.

The following sub-themes spell out the suggestions of participants on the aspects of accessibility to be considered:

- Create awareness of the importance of accessibility to buildings and worship services for people with disabilities.
- Activate a transport service
- Provide accessible parking at church
- Comply with regulations for accessible entrances at church
- Ensure suitable seating and participation in the worship service
- Provide accessible toilets
- Display signs that help people with disabilities to find their way independently
- Be mindful of the challenges of old church buildings
- Be mindful of the times and services of meetings

4.3.1 Sub-theme 6.1: Create awareness of the importance of accessibility to buildings and worship services for people with disabilities.

The suggestion to create awareness of the importance of accessible church buildings consists of two categories:

- Create awareness of a more inclusive meaning of accessibility for people with disabilities
- Create awareness of the importance of consulting people with disabilities about accessibility

4.3.1.1 Category 6.1.1: Create awareness of a more inclusive meaning of accessibility for people with disabilities

Participants pointed out their negative experiences and by doing so, suggested creating awareness of what inaccessibility means to people with disabilities.

“Plans to make changes [for buildings to be accessible] are often not implemented; this is so frustrating for us. You get a message that people with disabilities are not considered. Just understand that many changes are not insurmountable. Often the held-up is purely the attitude of the leadership”.

“It is no use saying ‘We have no people with disabilities in our church’; [you need to realise that] people with disabilities will not go there because of the inaccessibility”.

“Even if there is one person with a disability, he is important enough to make the changes required for him/her to get into the buildings”.

Apart from accessible buildings, an example of meaningful accessible communication was a church with many people from other countries who have English as their second language. The church decided to use simpler English to accommodate the foreigners. When a group of people with intellectual impairments started to attend the services, they said,

“We like it here because we understand the sermons”.

4.3.1.2 Category 6.1.2: Create awareness of the importance of consulting people with disabilities about accessibility

Participants implied this suggestion of consultation by expressing the effects of making buildings and worship services accessible in the wrong way.

“I could not use the toilets. Next time you want to make your place wheelchair friendly, please contact me”.

People with disabilities can be asked what they really need and exactly what structural changes should be made. A positive example was:

“We had a wheelchair user in our church, and we said to her, please prompt us when we do silly things; we want to work with an open invitation to people”.

In relation to the above suggestions, I observed during the study, that some churches have a long-standing practice of making their buildings accessible because of many elderly people or people with disabilities being active members

of the church. Other churches have more recently become aware of these needs and have slowly started to change buildings. However, it appears that a lack of awareness of accessibility still affects the inclusion of people with disabilities in churches. A lack of accessibility leaves people with disabilities feeling left out while accessible buildings and communication enhance their inclusion.

The following paragraphs give practical suggestions for faith communities to consider in becoming more accessible for people with disabilities.

4.3.2 Sub-theme 6.2: Activate a transport service

As in the rest of the South African society, accessible transport to church for people with disabilities is either scarce or non-existent. Participants in the study suggested that churches try to address this problem according to what is available in their community:

In well-resourced communities where most people have cars, a transport service could be organised:

“Our church already has a pick-up service where people with cars help those who need transport to the church”.

“There are practical complications. Some cars are too small for our wheelchairs”.

“Where people are committed, they will always find a way to help a person with disability [with transport]”.

In less-resourced communities people with disabilities face difficulties because few people have their own cars. They therefore suggested:

“If at least the church can demonstrate that they think of this problem. For example, arrange a transport service once a month”.

An Australian organisation which promotes the inclusion of people with disabilities in churches suggests the use of accessible transport that may be offered by local disability organisations (Gale, 2009:7). This could mean a van where wheelchair users can ‘drive in’ with their wheelchairs. However, my observation is that this

option is still very limited in South Africa, and especially in rural areas with low resources.

4.3.3 Sub-theme 6.3: Provide accessible parking at church

Accessible parking means that the parking of vehicles is suitable and appropriate in terms of availability, size and distance from entrances of buildings, to be user-friendly for people with disabilities (SABS, 2011:10).

Participants suggested the compliance of church members with the terms of parking arrangements at church:

“Accessible parking needs to be as close as possible to the church building”.

“Accessible parking needs to be available and not taken up by others who do not need it”.

Apart from the above requirements, Gale (2009:7) adds the need for clear signage indicating accessible parking. In South Africa, accessible parking for people with disabilities needs to comply with the National Building Regulations (SABS, 2011:10) which is documented in Appendix 16.

4.3.4 Sub-theme 6.4: Comply with to regulations for accessible entrances at church

Accessible entrances mean that people with mobility impairments, who use devices like wheelchairs, crutches or walking frames, have independent and comfortable access to a building.

Participants made comments that implied suggestions to make entrances properly accessible:

“It is appreciated that some churches do make an effort to make entrances accessible”.

“Please consider how it makes a person with a disability feel, often having to use ‘the backdoor’ which may be the only entrance that is accessible for me.”

For some of us this is a reminder of always being 'different', and not being important enough to enter with everybody else".

"Respect the dignity of people with disabilities; it is not comfortable to be carried up the stairs in my wheelchair [implying the need for accessible entrances]".

An assessment of the accessibility of churches in Pietermaritzburg done by Razaka (2005:47) showed that a fair number of church buildings had adequate entrances. However, this assessment did not include any churches in the townships around Pietermaritzburg.

All entrances should comply with the requirements of the National Building Regulations (SABS 2011), including ramps and doorways that should be wide enough and without obstacles. These regulations are presented in appendix 16.

4.3.5 Sub-theme 6.5: Ensure suitable seating and participation in the worship service

For some people with disabilities seating in the worship service determines the extent to which they can participate in the service. Below are some of the requirements:

- Allow for choice
- Consider wheelchair users
- Consider people with hearing loss
- Consider people with visual impairment
- Consider people with intellectual impairment

4.3.5.1 Category 6.5.1: Allow for choice

As with everybody else, persons with disabilities should be given a choice of where they would like to sit in a worship service. This may be influenced by their specific physical needs. Wheelchair users, people with hearing loss, people with

visual impairment and people with intellectual disabilities may all have different ways in which the worship service can be made accessible to them.

“Ushers in the church should please be mindful to ask us where we will be most comfortable”.

Participants in the study did not go into specific detail about their requirements for seating in the worship service. They focussed more on attitude changes, which would automatically result structural changes being made and programmes being adapted in the church. The following categories include basic suggestions, but full details of requirements for wheelchair users, people with hearing loss, and people with visual impairment is documented in Appendix 16.

4.3.5.2 Category 6.5.2: Consider seating requirements for wheelchair users

“Wheelchair users need to sit at a level space (not on a slope) and preferably with our family members or companions. This means, if possible, not in an aisle where we ‘stick out’ and are regarded as ‘different’.

4.3.5.3 Category 6.5.3: Consider people with hearing loss

The different categories of hearing loss imply that people with hearing impairments have a wide variety of needs. It is therefore necessary to address individual requirements.

“The basic principle is to ask individuals what their needs are and respectfully respond to it”.

“Good lighting is needed”.

“The speaker [preacher] should be aware that we do lip-reading. He should therefore not turn away while speaking”.

“We have a few people that sit with those with hearing impairment, helping them to follow the service”.

One church leader with experience of working with Deaf people cautioned:

“Do not to start a programme for Deaf people that cannot be sustained. This causes great disappointment for them in a sometimes very lonely world”.

“I am looking at possibilities to start sign language classes, but the first focus is to get the buy-in of members in the church”.

Full details of the suggested requirements for people with hearing impairment are documented in Appendix 16.

4.3.5.4 Category 6.5.4: Consider people with visual impairment

Suggestions from people with visual impairment to improve their participation in the worship service were:

“Good lighting is helpful”.

“When announcements are made, we who use Braille hymn books or Bibles need enough time to look up in our Braille books”.

4.3.5.5 Category 6.5.5: Consider people with intellectual impairment

A good example of including people with intellectual limitations was a church that adjusted the level of language used in the service. The response of a group of people with intellectual impairments was:

“We like it here because we understand the sermons”

Relating this sub-theme of suggestions to enhance participation of people with disabilities in worship services to the literature reveals some confirmation by Dicken, Young and Baird (2008:12). An example is that many people simply need a little help and guidance to be comfortable and participate in worship services – as suggested above, help for people with hearing loss. Dicken et al. (2008:12) add a suggestion of being aware of many people having difficulty with reading material, for various reasons and levels of disability. In such cases, handing out material for a service programme or song sheets is not helpful. Church leaders are asked to ensure that both verbal and written communication is appropriate.

In summary of this sub-theme, participants indicated that the following helps them to be more comfortable and participatory in a worship service: Having a choice of where they would like to sit, good facilities for wheelchairs, sufficient lighting, and colloquial language were all suggested to enhance the participation of people with different disabilities.

4.3.6 Sub-theme: 6.6: Provide accessible toilets

Accessible toilets are of utmost importance for the physical needs of many people with physical disabilities. Participants suggested various points to consider:

“Sometimes churches make some changes to make buildings accessible, but they forget about accessible toilets”.

“Please follow the regulations regarding accessible toilets, not what you think the requirements are”.

“Others like elderly people, pregnant women and parents with push cars and small children also benefit from these more accessible facilities”.

The regulations for accessible toilets are documented in Appendix 16.

4.3.7 Sub-theme 6.7: Display signs that help people with disabilities to find their way independently

Signs how to get around a church complex can help people with various disabilities to be independent. An example is finding accessible toilets.

One church leader gave a suggestion that emphasises the importance of signage:

“Notice boards can help to make people feel welcome and at home. If they know where to find a ramp or an accessible toilet, they can become comfortable at church”.

The full requirements for accessible signage are documented in appendix 16.

4.3.8 Sub-theme 6.8: Be mindful of the challenges of old church buildings

It may be difficult to adapt older churches to be fully accessible. A few church leaders made suggestions to be mindful of this reality for people with mobility impairments:

“Our building is a national monument, which limits the extent to which we can make structural changes”.

“Because of our old church building, the only option for an accessible entrance is now through a back door. We are aware of this and try to make an extra effort to make people with disabilities feel welcome”.

4.3.9 Sub-theme 6.9: Be mindful of times of services and meetings

For some people with disabilities, their physical limitations make it difficult to attend church services or meetings at certain times. They suggested more consideration in this regard:

“I do realise that church activities cannot be arranged according to our own needs, but the church can bear in mind that it is difficult to attend early morning and evening meetings”.

In summary of this theme, churches could note that if they take seriously the suggestions of people with disabilities to make their facilities accessible, it is a practical and visual way of demonstrating their commitment to inclusion. When, for example, a ramp provides independent access for a person with mobility impairment, it conveys the message that he was considered, and that his attendance is valued in the church.

For churches to become accessible for people with disabilities, an organisation in the United Kingdom suggests an accessibility audit (Through the Roof: n.d.). Literature searches did not reveal anything like this for the South African context. Furthermore, the National Building Regulations (SABS, 2011) provide full details of the requirements that buildings should meet. These will be discussed under the conclusions and recommendations in chapter five.

4.4 THEME SEVEN: SUGGESTIONS FOR CREATING AWARENESS ABOUT DISABILITY: METHODS AND CONTENT

This theme relates directly to the background, problem statement and goal of this study, as described in chapter one, sections 1.3 and 1.4. The work of disAbility ConneXion in Pietermaritzburg indicated a need for cultural and context specific disability awareness and inclusion processes in South African Christian faith communities. Guidelines for such an inclusion process can be derived from experiences and suggestions of people with disabilities and church leaders, as they emerged from this study. This theme embraces suggestions that could be implemented in such an inclusion process in terms of:

- Method: Facilitate interactive processes between people with disabilities and non-disabled people
- Suggested content of an awareness process

During the data collection, some church leaders pointed out that specific guidelines on processes for inclusion could really fill a need in the church.

“Churches are often asked to participate in awareness programmes of society, but sometimes the appropriate information is lacking”.

“I am very excited at this possibility of having guidelines available. It will help us to grow towards disability inclusion”.

These responses of church leaders correspond with Carter’s challenge to the church to not merely mirror the rest of society when it comes to marginalising people with disabilities. Rather the church can lead in transforming culture and society in the way that people with disabilities are actively included in their activities. (Carter, 2007:17).

The following sections 4.4.1 and 4.4.2, will give the methods and content of a process of change as suggested by the participants.

4.4.1 Sub-theme 7.1: Method: Facilitate interactive processes between people with disabilities and non-disabled people

Early in the data collection process, participants indicated that an awareness programme is about creating interaction between people with disabilities and non-disabled people. This could include dialogue that is facilitated between all stakeholders. Examples of responses from persons with disability were:

“I do believe that all people and . . . church leaders, if given the chance to meet with us [disabled people] . . . and see what we do . . . they will see there is more to a disabled person”.

Church leaders also emphasised the connection between people with disabilities and non-disabled people:

“It is the [building of] relationships between people with disabilities and church leaders and –members that count”.

“Knowing each other better should make a difference towards inclusion [of people with disabilities]”.

This suggestion about interactive processes consists of the following categories:

- Establish opportunities for dialogical processes (section 4.4.1.1)
- Facilitation of the dialogue (section 4.4.1.2)
- Comprehensive involvement of target groups (section 4.4.1.3)

4.4.1.1 Category 7.1.1: Establish opportunities for dialogical processes

Opportunities for dialogue regarding the different views and experiences of disability could contribute to increased understanding between disabled and non-disabled people.

Suggested sub-categories of such dialogical process were:

- Ensure the interchange of views.
- Accept the equality of participants in dialogue

- Aim for a transformative and challenging process.

a) **Sub-category 7.1.1.1: Ensure the interchange of views**

People with disabilities who have experienced the oppressing influence of certain beliefs regarding disability made suggestions about creating opportunities for debate and dialogue about the conflicting views of disability.

“Let us first have intellectual debates, then we come to a practical level”.

“If we want enduring change, it will take a lot of dialogue”.

A dialogical process could expose deep-rooted beliefs to be discussed and altered if necessary, for example the idea that people with disabilities are not supposed to get married. However, nobody in the group could say exactly where the belief came from and a church leader suggested:

“Let us rather get together [as church leaders] and talk straight about these things”.

In developing a way to address the deep-rooted beliefs and learning a more accommodative approach in the interchange of views, Paulo Freire offers key principles of change processes in society (Hope and Timmel, 1996:17, Book 1). Within the space of dialogue, a key principle would be finding the “generative themes” that people feel strongly about, which when brought to the surface, can release energy to work towards change. Applied to the disability and church context, bringing disabled and non-disabled people together in dialogue, strong views that are usually suppressed can be brought to the surface. This could release the energy that is needed to change attitudes, reconcile relationships and transform interaction between disabled and non-disabled people (Hope and Timmel, 1996:17, Book 1).

b) **Sub-category 7.1.1.2: Accept the equality of participants in dialogue**

In order for this dialogue to bring about the expected change, it needs to be understood that nobody is totally ignorant or knowledgeable. Church leaders suggested that all views are valuable for the debate:

“I would plead for maturity and leniency in the church when people with different views have to accommodate one another [implying equality].

“All people are important to the church, regardless of their differences and therefore the challenge is to facilitate dialogue where all opinions can be listened to and where people can learn from one another”.

“Be aware, there can be withdrawal from both sides of the spectrum [disabled and non-disabled people]. One has to build understanding among both disabled and non-disabled people”.

The change process regarding disability issues in the church is no doubt a reciprocal process where everyone’s opinion is equally valuable and needs to be heard and listened to. Webb-Mitchell (1996:40) states that in the community of the Christian faith everyone is supposed to be valued for who they are and not according to outward appearance. Nowhere in the Christian faith is a person praised or rejected on the grounds of physical, mental or emotional abilities or limitations. Rather it is the heart and character of a person that is at stake.

Hope and Timmel (1996:17, Book 1) confirm the view of Freire that no expert has all the answers. Dialogue is needed to draw on the insights of all those concerned in the matter.

c) Sub-category 7.1.1.3: Aim for a transformative and challenging process

It appeared from the data that a process of change towards disability inclusion requires a transformation of thinking and being. Participants suggested:

“At the church it is the way of thinking that needs to change”.

“. . . for this is a hard and long process of inner change”.

Several people with disabilities expressed mature views on how they themselves need transformation in order to contribute to a better common understanding of disability in faith communities. In discussions with core group members of disAbility ConneXion, some comments were:

“We have a responsibility as people with disabilities ourselves to be proactive in the change process”.

“The process of creating awareness of disability in churches is indeed reciprocal. To challenge existing views and behaviour towards a transformed society”.

A woman with mobility impairment, working in an organisation for disability awareness in schools, suggested holding seminars which should include people with disabilities and non-disabled people.

“This can be a space where people can develop a different thinking . . . the change of thinking about disability, . . . is an inner transformation”.

Summarising the discussion on the category on dialogical processes, participants named an interchange of views, accepting the equality of participants and aiming for a transformative process as key elements. Part of this transformation is new ways of thinking and reciprocal change in the lives of disabled and non-disabled people.

This call for a deep level of change in the thinking of all stakeholders corresponds with Freire’s view of radical transformation (Hope and Timmel, 1996:16). For Freire, transformation is based on the hope that life *can* change for the better, which will be a more just society. However, radical change means going to the roots of problems and addressing the values held by society that cause suffering for others. Values such as greed, control and power over people need to be transformed to cooperation, justice and concern for the common good of all. Significantly for faith communities, Hope and Timmel call this transformation process a spiritual process (Hope and Timmel, 1996:16).

4.4.1.2 Category 7.1.2: Facilitation of the dialogue

In order for the suggested dialogue (section 4.4.1.1) to bring about the transformation that is required, it will need to be facilitated. A man who is blind and who has much experience in disability work, pointed out:

“You may have to use facilitators for the process of change”.

A psychologist who is blind commented on the process of addressing perceptions in society regarding disability:

“It will need a constructive process, facilitated by people who understand some of the inner personal processes of how society deals with disability. For this process you will need a facilitator who can help bring the underlying dynamics to the surface”.

In a meeting with core group members, the point was raised that such facilitators could be people with disabilities themselves. This would allow for enriching reciprocal involvement. However, the above-mentioned psychologist cautioned that people with disabilities might have their own prejudices and are not necessarily free to handle debate and uncertainties. Watermeyer and Swartz (2006:6) support this opinion and warn that to engage with the complexity of disability issues requires a certain level of readiness to accommodate debate and uncertainty, because of what sometimes may appear as opposing views.

Further literature searches regarding using dialogue to create disability inclusion in faith communities did not reveal relevant results. Most church awareness programmes (Joni and friends in the USA and Through the roof in the UK) emphasise reaching out to people with disabilities, offering practical help and making church buildings accessible, but do not mention specific dialogue processes.

The views of Freire as described by Hope and Timmel (1996) are helpful for the suggested facilitation process. Freire suggests an action and reflection cyclical process, which can enhance critical thinking and help to get to root causes of problematic thinking. Applied to the disabled – non-disabled context, this may mean that once a dialogue group (consisting of people with disabilities and non-disabled people) has started their engagement and hopefully has made some progress, there needs to be an opportunity to reflect on the dynamics. This could mean asking questions on the possible impact, celebrating successes and critically analysing failures (Hope and Timmel, 1996:20).

4.4.1.3 Category 7.1.3: Involvement of target groups

Several participants commented on the importance of the suggested disability awareness project in churches (See chapter one, section 1.4). The feeling was that this was long overdue and the project should be well planned. One element would be the specific target groups who needed to be engaged in the process. The following target groups were mentioned:

“Church leaders, wives of church leaders, the youth, children, people with disabilities who are already involved in the church, families who have a person with disability among them, members in the congregation”.

In the literature on disability awareness in American churches, Dicken, Young and Baird (2008:11) confirm these target groups, with specific reference to children. With regard to children, the Joni and friends organisation include a Kids’ Corner on their website (<http://www.joniandfriends.org/kids-corner/>), promoting interaction with children with disabilities through fun games, song and ways to befriend a child with disability.

In summarising this theme on creating awareness about disability, it emerged that the methods to create awareness require the bringing together of views in dialogue, creating opportunities for freedom of expression, focusing on deep-rooted causes for those views and facilitating a cyclical process of action and reflection where learning and change can materialise. In this dialogical process people with disabilities and those without, should participate on an equal footing, in terms of contributing their views, but also in terms of taking responsibility for making it work. Promoting disability awareness among children can play a vital role in churches becoming communities of inclusion.

4.4.2 Sub-theme 7.2: Suggested content of an awareness process

Topics to be covered in the process of disability awareness in the faith community were suggested as follows:

- Include information to enable understanding of different kinds of disabilities.

- Promote the use of terminology that affirms the dignity of people with disabilities.
- Etiquette for interacting with people with disabilities.

4.4.2.1 Category 7.2.1: Include information to enable understanding different kinds of disability

Participants who were people with disabilities expressed their negative experiences, implying suggestions for information about disability to be disseminated:

“The way people interact with us, show that they don’t understand disability”.

“People need to learn that one disability does not mean you are totally unable to do anything else”.

Participants in the study did not point out specific knowledge required on disability. However, the following framework presents a guideline on different kinds of disability as part of the content of a disability awareness programme (Van der Veen: 2011).

- Blind and visual impairment
- Psychosocial disability: emotional conditions or a mental illness where the person may experience problems in the way he/she thinks, feels or behaves
- Physical impairment: the incomplete use of upper and lower limbs, or chronic pain, which restricts independence
- Deaf and hearing impairment
- Intellectual disability: having difficulty in learning and/or understanding the world around him/her
- Speech impairment

The last three conditions may also imply communication impairments: when speech is insufficient to meet communication needs.

4.4.2.2 Category 7.2.2: Promote the use of terminology that affirms the dignity of people with disabilities

Language is key to re-defining disability, in order to overcome the insidious power of negative language to which people with disabilities have been subjected (Mackleprang 2010:89). Participants implied suggestions based on their negative experiences:

“Society should do away from demeaning terminology like “the blind”, “a crippled person” or “the handicapped”.

“These words label and define people by their disability as if we are all the same”.

“It is not so difficult to change such terminology. Just put ‘the person first’ when referring to a person with disability e.g. ‘a person with paraplegia’, or ‘a person who is a wheelchair user’ ”.

Using these “person-first” terms is an important mechanism to re-define disability and accept people with disabilities as *persons* in the first place as opposed to their being defined by their disability (Mackelprang, 2010:89). A church leader who is living with paralysis, explained why this is so important: “I don’t want to allow my life to be the object of hasty generalizations by those who are not intimately acquainted with it. Disability is not the defining aspect of my life. It is just one condition among many that contributes to the richness of living” (Molsberry, 2004:57).

The above suggestions are confirmed by the National Council for Persons with Physical Disabilities in South Africa in its publication on politically correct terminology (www.ncppdsa.org.za). The list includes terms not to use, for example, rather say “a wheelchair user” than “wheelchair bound” and a “person with epilepsy” instead of “epileptic”.

4.4.2.3 Category 7.2.3: Etiquette for interacting with people with disabilities

As presented in chapter one, section 1.3.5, there is a need for non-disabled people to familiarise themselves with the etiquette of interacting with people with disabilities. Such etiquette respects the person as a human being and is sensitive to his/her limitations. Suggestions from participants were:

“The most basic thing to be aware of is to interact with a person with disability in the same respectful way as with anybody else”.

“Simply talk to me personally, and ask me if I need help and how I need it”.

The above suggestions are all included in a pamphlet, “Basic hints for interaction with a person with disability” (National Council for persons with physical disabilities, 2010a), which could be widely used in the church context. This pamphlet also gives specific hints for interacting with wheelchair users.

Further guidelines for interacting with people with disabilities are being sensitive, being alert, not making assumptions and being mindful of hidden disabilities³ (United Spinal Association, 2008:4).

³ Be sensitive about physical contact. Some people with disabilities use their arms for balance. Grabbing their arms may knock them off-balance. Also be aware that their devices are part of their bodies, and therefore it is inappropriate to touch their wheelchairs or canes.

Think before you speak. Speak directly to the person and not to his/her companion or caregiver.

Do not make assumptions about what people can or cannot do. They know their limitations and they have the right to decide for themselves.

Be mindful of possible hidden disabilities, like Alzheimer’s or epilepsy.

Summarising this theme on suggestions for creating awareness about disability, findings were made about methods to be used and content to be covered in an awareness-raising programme. Methods must to include facilitated interactive processes between disabled and non-disabled people. This means dialogue that aims for transformation where all participants are regarded as equal. It is furthermore suggested that the content of such a programme includes information about different types of disability, terminology that affirms the dignity of people with disabilities and the etiquette of interacting with people with disabilities.

4.5 THEME EIGHT: SUGGESTIONS OF HOW PEOPLE WITH DISABILITIES CAN CONTRIBUTE TO THEIR INCLUSION IN FAITH COMMUNITIES

In almost all interviews and group discussions participants mentioned the role of people with disabilities in the church. On the one hand this could mean a role of **service**, as fulfilled by others who serve in the church, for example, leadership, taking decisions or doing chores at church. On the other hand, the role could be in the specific area of **disability work**, such as helping other people with disabilities to become part of the church.

These roles can be explained by the following sub-themes:

- People with disabilities to take responsibility to make known their readiness to serve in the church
- People with disabilities to avail themselves for leadership
- People with disabilities to share their wisdom and knowledge to create awareness of disability
- People with disabilities to develop willingness to be accommodating

4.5.1 Sub-theme 8.1: People with disabilities to take responsibility to make known their readiness to serve in the church

Many people with disabilities do realise that they can serve in the church by making their gifts and skills available to the faith community. Some suggestions were:

From a mother with a disability who recently “came out of her cocoon”.

“I know I can make a difference in the mom’s group at church, I must just live it out. So I want to say to other people with disabilities, don’t wait, just do it”

From a woman with hearing impairment:

“In spite of my struggles at church, I offered to be an usher, I stay for tea after the service, and try to be friendly to people”.

From others availing themselves:

“We can help with practical work, maintenance jobs at church”.

“We also have spiritual gifts, we must just use it”.

Persons with disabilities also realise that this willingness needs to be proactively **communicated** to the church. Some examples were:

“We must express ourselves, for others to see me as a person. They will then see I can make a contribution”. - an energetic young lady with mobility impairment, who is eager to be of service to the church.

“I know it is our responsibility to speak up”. - an older man who is a faithful church goer.

Church leaders had suggestions for people with disabilities in terms of being assertive and respondent to an invitation to play a role in church:

“I try to encourage people with disabilities to be assertive”.

“You can make a difference here, what is it that you can do [in the church] that is not limited by your disability?”

“You may lack in one area, but your other senses are well- developed. We need to create a space where this can be utilised”.

Everyone has something unique to offer, and opportunities to do so can be aligned with people’s gifts and passions, and not allocated according to one’s disability (Carter, 2007:83). However, Carter does not specifically point out that people with disabilities should take initiative in this regard, as was indicated by the participants of this study. It appears that these participants feel they can play a significant role in availing themselves for service in the church. While they may need to learn to be assertive, it is also a reality that some church leaders are open to cooperating with them with regard to their inclusion in serving with others in the church.

4.5.2 Sub-theme 8.2: People with disabilities to avail themselves for leadership

People with disabilities suggested that there should be some disabled people among the leadership of the church. This may have an impact in the following ways:

“Having people with disabilities amongst the leaders of a church may draw other people with disabilities to the church”.

“They can add the viewpoint of disability when decisions are taken in church leadership”.

“Having a leader with a disability creates much awareness of disability. It is much more visible and people can grow to accept that disability is part of life”.

“A leader with a disability can also mean much to other people with disabilities in the church, they can relate to him/her and . . . act as a sounding board for them. This is particularly helpful in the case of a hidden disability like being Deaf or having a hearing impairment”.

Church leaders confirmed these suggestions:

“We need their sharp senses, for example when the church plans its programs, a leader with disability can ensure that disabled people’s needs are accommodated”.

“A church leader who for example has personal experience of hearing loss, will naturally accommodate the needs of others with hearing loss, without being told to do so”.

No literature was found regarding people with disabilities as leaders in the church.

4.5.3 Sub-theme 8.3: People with disabilities to share their wisdom and knowledge to create awareness of disability

A lady who is a leader in the disability community said in a group discussion:

“We as people with disabilities need to get past our hurt and be ready to teach the church what they need to know about disability”. [core group discussion 22 February 2010].

Some **people with disabilities** challenged themselves not to hesitate to make the effort and start initiatives in disability awareness.

“We must be proactive, indeed we are responsible for our own lives”.

Church leaders had the following suggestions:

“The work of disAbility ConneXion is an excellent example of the initiatives that disabled people can take in the Christian community”.

“To get more people with disabilities into the church, start with the one that you may have, involve him as wide as possible and people will become aware of what a person with disability can do”.

This role of people with disabilities also relates to what is called in some churches, a “disability ministry”, meaning reaching out to people with disabilities and supporting them in their needs. A person with disability suggested:

“Such ministry should also be aware of an attitude “of doing things for people with disabilities”, as if they are helpless. People with disabilities themselves can run such ministries”.

In terms of educating church members on disability, further suggestions from people with disabilities were:

“I used to get angry about the [silly] things that people ask you, but then I realised I was also ignorant about disability before my accident. The only way they will learn is if I talk to them directly”.

“I think there is a need to urge and empower more people with disabilities to engage with non-disabled people. That can demystify disability issues”

While the focus in this section was mostly on the initiatives of people with disabilities to enhance their inclusion in the church, a suggestion from a white pastor of a Zulu speaking church confirms this in a liberating way:

“People with disabilities have a message to the church, their weakness or vulnerability can speak to the church. However, even so, they can become the ones who care for others, and need not always to be cared for”.

These views are supported by Moltmann saying, a person with disability gives others the precious insight into the woundedness and weakness of human life. But a person with a disability also gives insight into the humanity of his own world. Through persons with disabilities, other people can come to know the real suffering living God, who also loves them infinitely (Moltmann cited in Reynolds, 2008:16).

4.5.4 Sub-theme 8.4: People with disabilities to develop willingness to be accommodating

Many of the people with disabilities participating in this study were amazingly open and honest about their own prejudices and fears. They felt that these also needed to change and gave the following suggestions:

“We are responsible to make it work, by also accommodating others”.

“We have to outgrow your own nonsense, the world does not owe us anything just because of our disability”.

“[Our] fear and a miserable attitude would bring us nowhere.

“Don’t get upset, engage with people in a friendly way and take charge of the situation [where people have to accommodate one another]”.

Literature searches did not reveal specific descriptions of the role of people with disabilities in their inclusion in the church. Two authors refer to related roles. Carter (2007:23) refers to the self-determination of people with disabilities, becoming assertive and skilful in presenting themselves to society, and in this case, the faith community. This can lead to congregations being places where people with disabilities and people without are woven together in common community (Carter, 2007:29).

Webb-Mitchell (2010) also does not spell out the role of people with disabilities in churches in the above terms, but states that real inclusion means moving way beyond simply welcoming people with disabilities and making buildings accessible. Real inclusion means enabling them to be fully active in the life of the church, participating in all activities, including addressing the 'awkwardness' that both disabled and non-disabled people may have in functioning as a real community (Webb-Mitchell, 2010:257).

In summary of this sub-theme, the above categories and storylines present a set of suggestions on the role of people with disabilities in faith communities. Availing themselves and their gifts, playing leadership roles, proactively working on raising awareness and being accommodating themselves, are their own suggestions to overcome their exclusion.

4.6 CONCLUSION

In this chapter, I presented the research findings as related to the *suggestions* for inclusion of people with disabilities in faith communities. The four main themes were:

- Suggested strategies for the inclusion of people with disabilities
- Suggestions for accessibility of buildings and worship services
- Suggestions for creating awareness about disability: the methods and content
- Suggestions of how people with disabilities can contribute to their inclusion

The following paragraphs give some comparison of the findings with the literature.

Most of the findings in theme five on the strategies for inclusion of people with disabilities were confirmed in the literature, an example being the necessity to display confidence in what people with disabilities can do.

All the sub-themes in theme one were summarised in Reynolds' (2008:241) description of hospitality in the church towards people with disabilities. Way beyond merely having people with disabilities present in the church, true hospitality includes a practice of an interdependent "us" that is fostered by relationships of mutual giving and receiving.

The suggestion of using dialogical processes (theme seven, section 4.4) to bring about social change is not new. However, applying this process in the context of disability and the church was not found in the literature (section 4.4.1).

Some findings in the study seemed new as they were not confirmed by existing available literature.

- No description was found in the literature on the urge of people with disabilities to play leadership roles in the church (section 4.2.1.4).
- No literature was found on changing cultural perceptions about disability in churches. A suggestion was to enhance an Ubuntu approach in churches (section 4.2.4.3).
- The awareness of different forms of accessibility for people with disabilities in South African churches does not seem to be described in the literature (section 4.3.1). The National Building regulations do describe the necessary requirements, but these do not seem to be adhered to. Requirements for the participation of people with disabilities in worship services do not seem to be described in the South African context (section 4.3.5).

Some of the findings were specific to the different contexts of the study.

The urge to display confidence in what people with disabilities can do was expressed only by the White and Indian communities.

Persons from the African isiZulu speaking contexts had several specific suggestions. These were:

- Give examples of exercising patience with people with disabilities (section 4.2.1.6).
- Challenge cultural perceptions (section 4.2.4.2).
- Being allowed to fulfil leadership roles in churches (section 4.5.2)

The following chapter states the conclusions and recommendations of the study.

5 CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

REFLECTING ON THE JOURNEY

5.1 INTRODUCTION

This chapter will demonstrate how the research goal was achieved by drawing conclusions and making recommendations. Firstly, the conclusions reached on the research problem, question, primary goal and objectives will be detailed. Secondly, I will state my conclusions on the research methodology, including the approach and designs followed, namely, the qualitative research approach with its data collection methods of individual interviews, focus group interviews and observations.

This will be followed by the conclusions on the findings, which emerged from the data collection process. The findings consist of eight themes. Four themes were about the experiences of people with disabilities in their faith communities and another four themes about suggestions to enhance their inclusion in faith communities.

The chapter closes with recommendations regarding the research methodology, the research findings and possible further research.

5.2 CONCLUSIONS ON THE QUALITATIVE RESEARCH PROCESS

This section draws conclusions on the research process followed in order to answer the original research question (chapter one, section 1.5):

What are the experiences, perceptions and suggestions of people with disabilities and church leaders regarding the inclusion of people with disabilities in faith communities on which practice guidelines for inclusion can be based and developed?

The two sections are:

- Conclusions on the research problem, question and goal
- Conclusions on the research approach and design

5.2.1 Conclusions on the research problem, the research question and the research goal

The **research problem** was stated in chapter one, section 1.4 as follows:

- *disAbility* ConneXion members who are people with disabilities feel excluded from their churches and want to take action to change the situation in South Africa, but knowledge on which to base the action, is lacking.
- Although guidelines for the inclusion of people with disabilities in faith communities are available in other countries, for example the USA, this knowledge is not contextually and culturally appropriate for the South African situation which *disAbility* ConneXion wants to address.
- *disAbility* ConneXion members feel their knowledge and experience is a valuable, but incomplete, starting point for development of such guidelines for South Africa. Although they have suggestions on how faith communities need to be sensitised, they also realise that these suggestions are limited and there is a need to explore the experiences of a larger group of people with disabilities and more church leaders.

This **research problem**, proved to be real since most participants were eager to talk about the topic and were able to give relevant responses that expressed their voices and filled the gap in the knowledge base. These responses contributed to a comprehensive picture about the experiences and suggestions of people with disabilities and church leaders regarding the inclusion of the former in faith communities.

Reponses from participants were of a wide variety, mostly emphasising personal experiences and perceptions. In this way, the **primary goal** was achieved namely

to develop an in-depth understanding of the experiences, perceptions and suggestions of these stakeholders aimed at the inclusion of people with disabilities. Achieving the research goal included working with the **objectives** of the study, namely:

- To explore and describe the experiences and suggestions of people with disabilities relating to their inclusion in faith communities.
- To explore and describe the experiences and suggestions of church leaders with regards to disability and the inclusion of people with disabilities in faith communities
- To explore and describe the suggestions of people with disabilities and church leaders for practice guidelines aimed at the inclusion of people with disabilities in faith communities, in order to develop culture and context specific guidelines for their inclusion in South African churches. The latter will be an application of the knowledge gained and not part of the actual research.

The exploration of experiences of people with disabilities was done in **chapter three** of this report. Most of the participants utilised the interviews and group discussions to express their (often negative) feelings regarding their experiences in the church. Some of the interviews were quite long as some participants went into detail about how they live their daily lives with disability, which is also the context of their inclusion/exclusion by their faith community.

Achieving the objective of exploring the experiences of church leaders was more difficult. Some church leaders were rather reluctant to commit themselves to interviews because of their busy programmes, while others promised to participate in group discussions, but simply did not turn up for appointments. This is also presented in chapter three.

The objective of exploring suggestions for inclusion was achieved in the many substantial responses in this regard, as presented in **chapter four**. However, in emphasising their negative experiences, suggestions for inclusion were made

indirectly. All these suggestions contributed to an understanding of what guidelines are paramount in an inclusion process.

5.2.2 Conclusions on the appropriateness of the research approach and research design

The application of the **qualitative research approach** proved to be the correct choice for the study, as it focussed on the experiences of individuals with disability regarding their inclusion in the church. The qualitative approach allowed thick descriptions of meanings and perceptions of the participants, expressing their own voices. It therefore led to new knowledge of the topic for the South African context. The evolving and dynamic nature of the qualitative approach further contributed to the study. As explained in chapter two, discussions with the *disAbility ConneXion* core group members helped to open doors to the community of people with disabilities, and to grow in understanding of cultural perceptions of disability.

The chosen **research designs** were exploratory, descriptive and contextual. In exploring the phenomenon, a rough understanding of the inclusion/exclusion of people with disabilities in faith communities was developed. It showed that in spite of some participants being fairly well included in their churches, their experience is still predominantly negative regarding attitudes and accessibility. The descriptive study design helped to answer the “what” question of the study, namely the barriers and enablers to inclusion. Both the interest groups, namely people with disabilities and church leaders indicated that much still needs to be done to allow for the full inclusion of people with disabilities in churches.

Regarding the contextual design, the most significant benefit was spelling out the complexities of perceptions regarding disability in the African context. These perceptions included views on the causes of disability, ways of isolating a disabled family member and derogatory terminology in the isiZulu language. While disability is a topic rarely talked about in African churches, the study contributed to the beginning of a discussion amongst isiZulu speaking people.

Lastly, the participatory action design allowed for the involvement of the core group members of *disAbility ConneXion* who were involved in the sampling of

participants and data collection process. In this way the study had a grassroots characteristic which hopefully added value to the voice of people with disabilities.

Since the number of people with disabilities in the research area is unknown, snowball sampling was used for the **population and sampling** of the study. The only problem in the sampling process was the difficulty of achieving a balanced representation of churches among the participants (see chapter one, section 1.8.1 and chapter two, section 2.4). In the practical situation, I was dependent on those who were willing and available, with the result that the majority of participants were from mainline churches and few from the wide variety of African independent churches.

The **data collection instruments**, did not pose any problems. Semi-structured interview guides were used in individual and focus group interviews as presented in chapter one, section 1.8.2.4 and chapter two section 2.5.3. The only complication was that some participants talked great detail about their personal experiences in answer to the first question to people with disabilities (see appendices 4, 5, and 6).

Regarding the **data collection** process, no major problems were experienced, but **limitations** were as follows:

- My limited knowledge of the isiZulu language necessitated translations in all the focus groups. While the translator was efficient, I accept the possibility that some discussions may not have reached their full depth because of the language barrier. For financial reasons, the recorded isiZulu translations were not back-translated by an independent translator. This may be a limitation in assuring that the responses of the isiZulu-speaking participants were fully understood.
- Some perceptions of disability were not fully explored. An example was the perception that people with disabilities should not get married. Some church leaders in the group were non-responsive about the topic but resolved that they would discuss it among themselves.

- The cross-cultural situation of me as a white female researcher in the Zulu speaking context, may have added to the above-mentioned limitations.
- There is the possibility that some participants, for whom research is an unknown concept, may have expected personal benefits from taking part in the interviews. The purpose of research was explained as clearly as possible.
- The non-attendance of some church leaders from the isiZulu speaking churches who were invited to the focus groups was problematic, in the sense that less isiZulu speaking church leaders then participated and thus limited views were heard. It was difficult to actually explore the reasons for this (see chapter two, section 2.5.3.5). The fact remains that only a fairly small number of church leaders of the Zulu culture participated in the study.
- Not all racial groups were represented in the sample. Only a very few Indian and Coloured people were among the participants.
- Only a very few children with disability were represented by their parents. The inclusion of children with disabilities in faith communities may be a vast area of need.

The **analysis of the data**, done by myself, with co-coding by my study supervisor, and consultation with a qualitative research expert, enriched the process, although it was cumbersome, because of the large volume of data.

Comparing the findings with available literature revealed a paucity of applicable South Africa literature on the topic (chapter two, section 2.6).

5.3 CONCLUSIONS REGARDING THE FINDINGS OF THE RESEARCH

This section presents my conclusions on the research findings, firstly the conclusions about the experiences of participants (sections 5.3.1 – 5.3.4), and secondly the conclusions about suggestions for inclusion (sections 5.3.5 – 5.3.8).

5.3.1 Theme one: The lived experience of a person with disability: born with a disability or becoming disabled

The lived experiences of people with disabilities in coping with their disability included their emotional responses to the onset of the disability, trying to make meaning on the journey and facing daily challenges on a practical level.

Regarding the onset of disability, the participants reported emotional responses like shock and depression. Thus people with disabilities are often in a process of defining an alternative identity and renewed purpose in life, they fluctuate between hope and despair, deal with “why” questions and journey on a continuum of acceptance. Furthermore, their challenges of daily living may leave them vulnerable to being regarded as ‘different’ because of their limitations. However, these limitations do not mean a complete inability to do things, as is often the perception of others.

While this theme was not the focus of the study, all the experiences were confirmed by literature, with no new findings.

5.3.2 Theme two: The experiences of significant others in relation to living with a person with disability

Having a family member who is disabled, often determines household routines and roles of family members, and how the person is treated as a family member. These responses are influenced by cultural beliefs, family values and interactional patterns. Some families respond by hiding the disabled person and denying him/her a meaningful life with relationships with others. It is this situation of which the church should take cognisance, if it wants to be more inclusive and supportive of people with disabilities.

This theme was also not directly the focus of the study and the literature confirmed all the findings.

5.3.3 Theme three: The person with disability's experience of the physical environment of the faith community.

As is often the case in society, inaccessible transport and church buildings and - facilities, cause people with disabilities to be excluded.

In churches it is specifically the inaccessible procedures in worship services which do not take into consideration the needs of people with disabilities, which exacerbates their experience of exclusion (section 3.5.1). The lack of choice for wheelchair users of sitting in a comfortable place in church, as well as the needs of people with visual, hearing and intellectual impairments, causes them to feel excluded and not considered. Problems like transport to church also have a severe impact in the under-resourced African communities.

Furthermore, the experience that this is not a priority for church leadership leaves them to believe that they are actually not important enough for the church to make the necessary structural changes. For them, this confirms their experience of exclusion.

None of the above problems in worship services is addressed in South African literature. Concerning the church buildings, the National Building Regulations indicate requirements for accessibility for people with disabilities, but these are often not complied with by church authorities and not enforced by regulatory bodies.

While church leaders report that some churches are made accessible, the above-mentioned experiences make people with disabilities feel that the struggle for an accessible environment is ongoing.

5.3.4 Theme four: How people with disabilities in faith communities experience others' perceptions of disability and healing

Others' perceptions of disability have a severe impact on the lives of people with disabilities. In the church context, oppressive biblical interpretations are experienced. Some of these perceptions are expressed in practices like people with disabilities being coerced into prayers for healing, not given opportunities to

serve in the church and not being trusted for their abilities. These practices confirm to people with disabilities that they are not accepted, not respected, not understood, not regarded as autonomous human beings and actually not loved as friends.

5.3.5 Theme five: Suggested strategies for inclusion of people with disabilities in faith communities

Findings confirmed by literature were that strategies which will contribute directly to the inclusion of people with disabilities, have much to do with the relationships and interaction between them and non-disabled people in their faith community. This entails unconditional acceptance, which will liberate the person with disability to be his own person, allowing him to do whatever he is capable of doing; and giving practical support without being condescending.

In the wider context of the faith community, unconditional acceptance also means changes in beliefs about disability and changes in practices that will affirm him/her as an equal human being with the same needs as others, but also with potential to be of service in the church. With this interaction, people without disabilities may also experience liberation of their fears and feelings of not being respected. Findings that were very specific to the African isiZulu speaking context pointed to cultural beliefs about disability that were oppressive.

5.3.6 Theme six: Suggestions for accessibility of buildings and worship services

When churches consider how people with disabilities get to church and make facilities and buildings accessible, it is a demonstration of an attitude of inclusion, affirming to the person with disability that his presence and participation is important. Such inclusion becomes practical by having accessible parking, entrances, toilets as well as worship services where the liturgy is adapted to ensure the participation of people with, for example, visual impairment or hearing loss.

It is therefore suggested that churches are made aware of the National Building Regulations Part S: Regulations regarding people with disabilities, 2011, since it appears that this is not adhered to and not enforced by regulatory bodies

5.3.7 Theme seven: Suggestions for creating awareness about disability: models and content

Suggestions on the content of a disability awareness programme were confirmed in literature and disability organisations' materials. Information for understanding of different kinds of disability, terminology that affirms the dignity of people with disabilities and etiquette for interaction between disabled and non-disabled people would enhance the inclusion of people with disabilities in faith communities.

5.3.8 Theme eight: Suggestions of how people with disabilities can contribute to their inclusion.

People with disabilities suggest that they play an integral role in a disability awareness process in a faith community. By this, they would assume responsibility to make known their readiness to participate in such a programme. Their presence in the leadership of the church can add value to decisions which consider the needs of people with disabilities. Their willingness to also be accommodating, can indeed point to establishing a new approach in churches, where the aim of attitude change is for the common good of all in the faith community. Literature searches did not produce direct confirmation of these findings, but pointed to the necessity of enabling people with disabilities to grow beyond merely being present to playing active roles in all activities in the church.

5.3.9 Conclusions

The first two of the above themes, namely the lived experiences of persons with disability and the experiences of significant others of a disabled person, were not the focus of this study. However, they provided rich descriptions of the context of their experiences of inclusion or exclusion in faith communities. They described their emotions, process of making meaning in living with disability, their challenges of daily living, as well as the impact on the lives of their families. The findings in

these two themes also highlighted the context of the study, as was planned with the contextual design of the research. Emotional and family experiences may influence the readiness of people with disabilities to feel included in the church, but also provide indicators to which churches can respond. When churches understand the background realities of people with disabilities, it may help to develop a disability-friendly environment in the church.

The findings about experiences in the physical environment and worship services were significant in the sense that very little South African literature was found on the accessibility of church buildings and worship services. It appears that there is a need for information to help churches to be more aware of the accessibility of buildings and facilities and to develop inclusive worship services. This need has since been addressed. After the data collection, a task team of the Leprosy Mission started developing appropriate materials in cooperation of people with disabilities. These materials are now available on the website www.rampup.co.za.

Theme four on oppressive biblical interpretations and practices revealed severe experiences of exclusion and not being respected. As I look back on the data collection now, it appears that narrating these experiences evoked the strongest emotions in participants with disabilities. People with disabilities who were not healed from their disabilities after being coerced into prayers feel seriously hurt and misunderstood. This issue may have the most urgent need of attention.

Themes six to eight, confirmed and expanded on suggestions for inclusion originally made by *disAbility ConneXion* (chapter one, section 1.3). Immediately after the data collection and data analysis, through liaison between the Leprosy Mission, *disAbility ConneXion* and other disability experts, materials were compiled to address the exclusion of people with disabilities in faith communities and provide guidelines to churches for inclusion. Based on the findings of this research, these materials were written by disability experts (people with disabilities themselves) and published on the newly designed website www.rampup.co.za. The launch of the website in November 2011 was met with great excitement from the disability sector and at the time of writing this report, a campaign is underway to promote the website among all churches in South Africa. This emphasised the relevance and urgency of the study. The recommendations in section 5.4 therefore

also include implementing these suggestions through the materials as already published on the website.

A further indication of the relevance of the research was that the researcher was invited to present a paper, *The experiences of people with disabilities in faith communities: a social work perspective*, at a conference on *Theology, Disability and Human Dignity* at the University of Stellenbosch in May 2011.

Two articles on the research were accepted by two journals. Article one, *The experiences of people with disabilities in faith communities: A journey*, will appear in the *Journal of Religion, Disability and Health*. Article two, *The experiences of people with disabilities in faith communities and suggestions to enhance their inclusion*, will be included in a volume by the University of Stellenbosch in follow up to the above-mentioned conference.

In terms of liaising with the disability sector and the church, five workshops took place during the course of the study, initiated and/or facilitated by the researcher⁴.

5.4 RECOMMENDATIONS

The following recommendations are to be considered regarding the qualitative research process of this study, the practice of including people with disabilities in

⁴ Workshop on Theology and disability. Pietermaritzburg. 10 – 11 August 2010.

Workshop on the use of drama in social change. Pietermaritzburg. 18 September 2010.

Workshop on developing material for a resource pack on disability awareness in the church. Pretoria. 29 – 30 March 2011. At this workshop, a decision was taken to publish these materials on a website.

Workshop on experiences of healing practices in churches. Pietermaritzburg. 29 June 2011.

Workshop on disability and the church. Pietermaritzburg. 27 – 28 September 2011.

faith communities, the role of social workers in the process and future research of the topic.

5.4.1 Recommendations pertaining to the qualitative research process

- Based on the conclusion regarding contexts where research is unknown (section 5.2.2), it is recommended that more creative ways be pursued for doing qualitative research in contexts where research is not well known. A possibility could be having workshops with potential participants prior to data collection to discuss research processes and their role as participants.
- Based on the conclusion that translation between isiZulu and English may have limited the responses of isiZulu speaking participants, it is recommended that trained translators be used in trans-cultural qualitative research, as far as possible. Where not possible, the skills of local translators in qualitative research can be enhanced through in-service training by qualified translators. A researcher and translator working together in more than one research project could also enhance the translation skills.

5.4.2 Recommendations for practice from the findings

Recommendations derived from the research findings are divided into three categories, as per the following outline:

- Recommendations regarding areas of consideration for the reality of people with disabilities
- Recommendations regarding models for creating awareness
- Recommendations for the different role players in disability awareness programmes

Based on the findings on the lived reality and emotional experiences of people with disabilities, the following recommendations are presented:

For churches to become inclusive communities, they should take cognisance of the specific emotional experiences of being born with or becoming disabled, the

daily challenges of finding meaningful life amidst a disability and the experiences of families in adapting to having a disabled member, in order to position and equip themselves to be of appropriate support for people with disabilities and their families.

Based on the findings regarding accessibility of the physical environment and liturgy of the faith community, it is recommended that churches make their buildings, facilities and programmes fully accessible according to the needs of people with disabilities. The requirements and minimum standards for buildings as described in the National Building Regulations, Part S: people with disabilities should be implemented (SABS:2011). These standards include regulations for:

- Accessible parking
- Entrances and doorways
- Accessible toilets
- Notice boards / signage

It is furthermore recommended that church leaders consider making adaptations to the worship service and liturgy, according to the needs of wheelchair users, people with hearing loss, and people with visual impairments to ensure their participation in the liturgy.

All these regulations for buildings and adaptations to the liturgy in the worship service are fully described in appendix 16, which is based on the National Building Regulations (SABS:2011). For the full implementation of all these requirements, a newly developed website coordinated by the Leprosy Mission staff provides a comprehensive document that gives exact guidelines to churches (www.rampup.co.za).

Based on the findings that awareness about disability in faith communities should be raised, it is recommended that two models be considered:

The adult education model for social change through conscientisation of Freire (Hope and Timmel, 1996:17 and Schenck, Nel and Louw, 2010:70) and the community educational model (Weyers, 2001:174).

THE CONSCIENTISATION MODEL OF SOCIAL CHANGE

This model is a bottom-up approach that starts with a process of conscientisation through dialogue, in this case between disabled and non-disabled people in faith communities.

Paulo Freire's⁵ principles for change can be applied as follows (Schenck, et al. 2010:74):

- a) Dialogue is at the core of the process of change. This means critical discussion between equal partners who do not passively accept the oppressive situations of people with disabilities in churches. It aims at developing critical thinking, which motivates the partners to learn and act differently.
- b) The process aims for radical transformation by uncovering the roots of problems and values held by society and the church that cause suffering for people with disabilities. These problems include fears, uncertainties and cultural perceptions of disability and people with disabilities. The dialogue should therefore not be superficial.
- c) The process of dialogue and change needs to be relevant to the experience of people with disabilities. Relevant issues are “generative themes” that are raised and recur in the dialogue because people feel emotional about them. These strong emotions can generate energy for action for change.
- d) Such dialogue takes place in a group context. Groups would be comprised of church leaders, church members and people with disabilities, participating on equal footing, as in a learning circle. Collective action is a

⁵ Paulo Freire was a Brazilian pedagogue who revolutionised ideas regarding oppressed people, trusting them to critically explore, understand their world and then find their own solutions for their situation.

cyclical process where action is planned, implemented and reflected upon repeatedly. Participants who are dissatisfied with the status quo of disability exclusion in the church would reflect critically on the situation, plan and take action and repeat the process until change is experienced. Throughout the process, there is mutuality in the roles of learner and teacher, which implies that all stakeholders are to learn and teach, in an atmosphere of acceptance and trust. Figure 5.1 illustrates this cyclical process of action and reflection towards change (based on Schenck, et al. 2010:78).

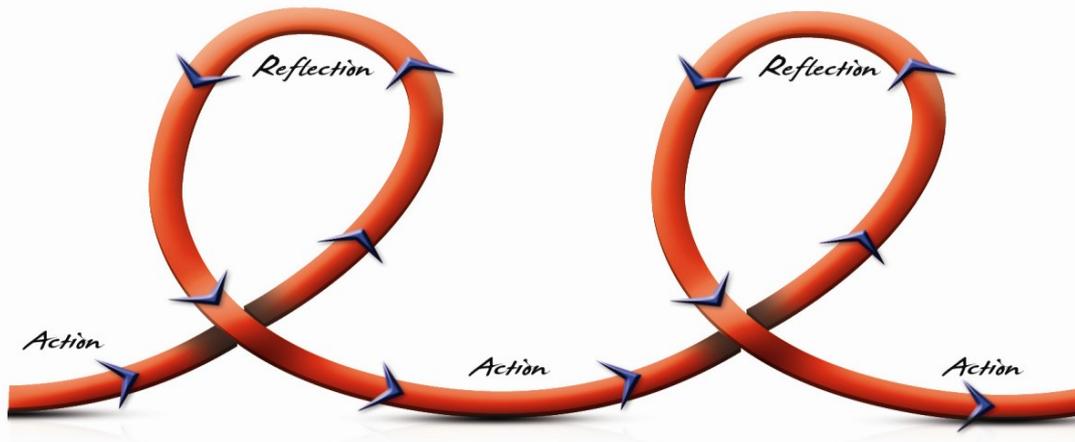


Figure 5-1: Action-reflection process

- e) The dialogue is a facilitated process. A facilitator presents the core problems of disability inclusion in the church to the participants through codes, using creative means like drama, music and storytelling⁶. Participants are stimulated to seek solutions and take action as described

⁶ Examples could be a drama of a wheelchair user confronted with a flight of steps that prevent him/her from getting into the church building; a song expressing the experiences of a person with intellectual disability; or a story about finding purpose in living with quadriplegia. Such creative means of presenting codes in the dialogue process need to be context specific, for example, for oral cultures where verbal interaction is preferred to written materials.

above. See section 5.4.3 on different role players who could initiate and facilitate this process.

THE COMMUNITY EDUCATIONAL MODEL

It is recommended that the educational model for community work (Weyers⁷, 2001:174) could also be applied to raise awareness of disability in churches where people are ready to receive new knowledge about disability. This model entails educating small groups where participants can internalise knowledge, master new skills and change behaviour regarding disability and people with disabilities.

A disability expert could cover the following topics (as suggested by participants in the study), by using techniques of group work, drama and visual materials.

- a) An overview of different disabilities, including physical, sensory and intellectual disabilities and some of their impact on people's lives, (see section 4.4.2.1).
- b) Terminology regarding disabilities that affirms the dignity of people with disabilities and that contributes to a different way of thinking about disability. Materials of the National Council for Persons with Physical disabilities could be used (see section 4.4.2.2).
- c) Etiquette for interacting with people with disabilities that set both people with disabilities and non-disabled people free of their uncertainties and that is conducive to rich relationships. Materials of the National Council for Persons with Physical disabilities (www.ncppdsa.org.za) could be used (see section 4.4.2.3).
- d) Practice examples of how people with disabilities and non-disabled people could interact and serve together in their faith community.

⁷ Prof. Mike Weyers is a lecturer in community work and community development at the Department of Social Work, North-West University, Potchefstroom campus, South Africa.

- e) Biblical interpretations that could help to develop liberating views and perceptions of disability (Orsmond, 2011).
- f) Organising an annual Disability Awareness Sunday could be part of the educational process. (Fourie, 2011).

In summary of this section, all materials to implement the two models for creating awareness, can be found on the newly designed South African website, www.rampup.co.za (see section 5.3.9).

5.4.3 Recommendations regarding the different role players in creating awareness

The above models for raising awareness are used in the field of social work. However, any person could take the initiative to apply these models to raise awareness in a faith community, for example, people with disabilities, social workers, church leaders or other concerned people.

a) Recommendations regarding the role of people with disabilities in their inclusion.

It is recommended that any disability awareness programme in a church should start with the direct involvement of people with disabilities. This could mean either finding those people with disabilities who are empowered to take such responsibility or position the programme in such a way that it is empowering for people with disabilities who participate.

In terms of the above-mentioned models, it is recommended that people with disabilities play an integral part in the conscientisation dialogue as equal partners in the teaching and learning process of each other. In the community education model, people with disabilities can play a specific role with regard to practice examples of serving together in the faith community.

It is recommended that people with disabilities be encouraged to make themselves and their gifts available for raising awareness of disability in faith communities.

b) **Recommendations regarding the role of social workers**

Referring to concepts in the definition of social work⁸, the following recommendations are made for the roles of social workers in raising awareness of disability in faith communities:

It is recommended that social workers in the disability field or those working in church welfare organisations take the initiative to liaise with churches to start disability awareness programmes.

It is recommended that social workers promote social change, social justice and human well-being for people with disabilities in faith communities by acting as networkers, facilitators and/or educators in accordance with the above-mentioned models to raise awareness as set out in section 5.4.2.

- As networkers, social workers could bring together all stakeholders to participate in awareness raising to the mutual benefit of people with disabilities, church leaders, church members and disability experts in becoming inclusive communities. Materials from the Ramp Up website (www.rampup.co.za) can be used.
- Social workers could act as facilitators, facilitating the dialogue process by using Freire's conscientisation model.
- Social workers could act as educators and conduct small group sessions using the community education process.

⁸ "The social work profession promotes social change, problem solving in human relationships and the empowerment and liberation of people to enhance well-being. Utilizing theories of human behaviour and social systems, social work intervenes at the points where people interact with their environments. Principles of human rights and social justice are fundamental to social work" (<http://www.ifsw.org> – accessed 10 April 2011).

- Social workers could do research, for example, on the social interaction between the Christian church and disability in a specific cultural group, for example, the Indian or Coloured community.

c) **Recommendations regarding the role of church leaders**

It is recommended that church leaders play various roles, applicable to local circumstances:

- Initiate disability awareness programmes by exploring the situation of people with disabilities in the local church as was done in this study. Materials from the Ramp Up website (www.rampup.co.za) could be used.
- Lobby with other church leaders about programmes and disability organisations to come on board and cooperate in creating awareness about the needs of people with disabilities in faith communities.
- Act as facilitators in the conscientisation dialogue processes, involving specific individuals with disabilities and those without in the dialogue, and move with the process of conscientisation in the local church.

5.4.4 Recommendations for further research

Further research could be:

- To monitor and research the implementation of the above two models in disability awareness programmes in faith communities to establish how they could be improved.
- To explore principles and ways of empowerment for people with disabilities in their inclusion in faith communities.
- The current research could be repeated in different areas of South Africa, with specific cultural groups like Indian and Coloured people with disabilities and with different denominations.
- To explore ways that children with disabilities can be included in faith communities and Sunday schools.

5.5 CONCLUSION

This chapter demonstrated how this research project achieved the research goal. Conclusions were drawn about the effectiveness of the research approach and – design, followed by conclusions on the research findings. These findings were divided into eight themes regarding the experiences of people with disabilities and church leaders about disability in faith communities, and their suggestions to improve the inclusion of the former. The themes spelled out the rather negative experiences of people with disabilities, followed by suggestions that are a rich resource for changing the situation to that of inclusive faith communities.

The chapter then presented recommendations pertaining to the research process and the implementation of the findings by different role players, namely people with disabilities, social workers and church leaders.

Lastly, there were recommendations for further research on the topic of including people with disabilities in faith communities.

In reviewing all the findings and recommendations, I am aware that the stories of the participants in the study inspired me to think differently about the interaction between people with disabilities and the church. I have come to see where breakdowns in relationships and interaction occur, resulting in people with disabilities feeling excluded and the church missing out on their enriching role. On both sides (and I am not promoting an “us” and “them” perspective), there is reservation and “holding back”, but also an awareness of wanting to grow for the greater good for all.

I have seen the possibility of a reciprocal perspective actually stimulating faith communities and people with disabilities to cultivate a **mutual vision of inclusion** (as formulated by myself, and endorsed by Barbara Watt, the leader of *disAbility ConneXion*):

“We want to be an inclusive community where everybody, including people with disabilities, is enabled and free to:

- *Participate in any activity – therefore our buildings and worship services should consider the needs and contributions of people with impairments.*
- *Serve with their gifts – therefore people with disabilities are an integral part of our programmes, taking leadership roles and making contributions to the enrichment of all members.*
- *Cultivate reciprocal relationships, friendships and “koinonia” – therefore people with disabilities are not merely the recipients of charity and ministry, but accepted as fellow believers who take full responsibility for their part in enriching relationships.*

We see our (faith) community as a creative space, where the diversity that people with disabilities bring is welcomed and enhanced. Therefore, we live, serve and worship in this space for the purpose of new and growing interaction amongst us all. We respect one another because of the image of God in each other which is not diminished by a different level of physical or intellectual functioning”.

6 REFERENCES AND BIBLIOGRAPHY

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APPENDICES

APPENDICES

1. People with disabilities: Invitation - English
2. People with disabilities: Uitnodiging – Afrikaans
3. People with disabilities: Invitation – isiZulu
4. People with disabilities: Interview guide - English
5. People with disabilities: Interview guide - Afrikaans
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7. Church leaders: Invitation – English
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13. Consent form: English
14. Consent form: Afrikaans
15. Consent form: isiZulu
16. Requirements for accessibility in church buildings for people with disabilities.

APPENDIX 1: INVITATION TO A PERSON WITH DISABILITY TO PARTICIPATE IN A RESEARCH PROJECT

PIETERMARITZBURG AREA - JULY 2009.

Research topic: *The inclusion of people with disabilities in faith communities: a social work perspective.*

Dear research participant,

I am Erna Möller, a social worker of the Leprosy Mission in Johannesburg and also a student of the Department of Social Work at the University of South Africa. As part of my studies I have to undertake a research project and for this reason I have decided to do an investigation about the experiences of people with disabilities in their churches (faith communities).

The aim of the research project is to gain knowledge about something of which very little is known. Since you have personal experience of this context, I would very much like you to participate and give your valuable input. Therefore I invite you to participate in a focus group meeting / individual interview where discussion will be around the following questions:

- Will you please tell us/me more of your involvement at church?
- What good experiences do you encounter at church?
- What makes it easy to be part of the church?
- What makes it difficult to be part of the church?
- Can you suggest how the church can include people with disabilities (PWD) as part of all their activities? What can the church do to make it easier for PWD?

I also ask your permission to record on tape the proceedings of the group discussion. This is to ensure that I can give my full attention to the discussion and not forget anything that is being said. The tape recording will be written out word-for-word, but all names of people in the group will be removed. This is to ensure

that nobody will confront you personally for what you said in the discussion. Although all the information given by participants will be written up in the research document, no participant will be identifiable.

Please note that your participation is completely voluntary, you are free to choose not to participate. Your decision will not affect you in any way, now or in the future. You are also free to change your decision and withdraw from the research project.

If I see that the information you have shared left you feeling emotionally upset, or anxious, I am required to refer you to a counselor for debriefing (should you agree to this).

You have the right to ask questions concerning the study at any time. I can be contacted at the following number: 011 440 6323.

If you agree to participate in the research project, I would like you to sign the consent form that follows.

Yours sincerely

Erna Moller (Researcher)

APPENDIX 2: PERSONE MET GESTREMDHEID: UITNODIGING OM DEEL TE NEEM AAN 'N NAVORSINGSPROJEK

PIETERMARITZBURG AREA JULIE NOVEMBER 2009.

Onderwerp: Die insluiting van persone met gestremdheid in kerke.

Beste deelnemer,

Ek is Erna Moller, 'n maatskaplike werker van die Sending aand die Melaatse in Johannesburg, asook 'n student by die departement van Maatskaplike Werk by Universiteit van Suid Afrika. Ek onderneem 'n navorsingstudie oor die insluiting van persone met gestremdheid in kerke.

Die doel van die studie is om inligting in te win oor 'n saak waaroor min bekend is, en moontlik die insluiting van persone met gestremdheid te bevorder. Aangesien u ondervinding in hierdie verband het, wil ek vriendelik vra vir u deelname. Ek vra dus u insette in 'n individuele onderhoud of 'n groep bespreking. Die volgende vrae sal bespreek word:

- Kan u my meer vertel van u betrokkenheid by die kerk?
- Watter positiewe ervarings het u t.o.v. die kerk?
- Wat maak dit maklik om deel van die kerk te wees?
- Wat maak dit moeilik om deel van die kerk te wees?
- Wat sou u voorstel wees, hoe kan die kerk meer persone met gestremdheid insluit in hul aktiwiteite?

Ek vra ook u toestemming om 'n klank opname te maak van die onderhoud. Dit is om te verseker dat ek my volle aandag kan gee aan wat u my vertel en nie

enigiets sal vergeet nie. Die klankopname word dan woord-vir-woord getranskribeer, maar alle name word daaruit verwyder sodat niemand se identiteit bekend sal wees nie. Dit is om te verseker dat niemand agterna u sal kan konfronteer oor wat u gesê het nie.

Let asb. daarop dat u deelname heeltemal vrywillig is. U kan ter enige tyd onttrek uit die onderhoud sonder dat u kwalik geneem sal word.

As ek waarneem dat die onderhoud u in enige opsig emosioneel benadeel het, sal ek reël dat u berading hiervoor ontvang, indien u natuurlik hiertoe instem.

U het die reg om ter enige tyd verdere vrae aan my te vra. Ek kan gekontak word by die volgende nommers: Kantoor: 011 440 6323 of selnommer: 082 731 9857.

Baie dankie

Erna Moller

MA navorsingstudent in Maatskaplike Werk.

APPENDIX 3: INVITATION LETTER TO PERSON WITH DISABILITY - ISIZULU

ISIMEMO KWABANOKUKHUBAZEKA SOKUZIBANDAKANYA OCWANINGWENI
ENDAWENI YASEPIETERMARITZBURG NGO JULAYI 2009

*Isihloko socwaningo: Ukubandakanywa kwabanokukhubazeka ezindaweni
zokukhonza: izeluleko zendlela yokukwenza lokhu.*

Kubo bonke abazozibandakanya,

Igama lami ngingu Erna wakwa Moller, ngingusonhlalakahle osebenzela inhlango ebizwa nge Leprosy Mission yase Goli futhi ngibuye ngibe umfundi kuphiko lezenhlalakahle kwi nyuvesi yase UNISA.

Njengexenye yezifundo zami, kumele ngenze ucwningo ngesihloko esithile, yingakho-ke ngikhethe ukwenza ucwaningo ngezinto abahlangabezana nazo abanokukhubazeka emasontweni. Inhloso-ke yalolucwaningo ukuthi ngithole lolulwazi ngoba kuncane ngempela okwaziwayo ngalo.

Njengabantu ababhekana nalezizimo nsukuzonke ngingajabula kakhulu uma ningaba yinxenye lalolucwaningo, nemibono yenu iyoba lusiso olukhulu.

Ngakho ngiyanimema nibe yinxenye yeqembu/noma ngabanye lapho sizobe sibuzana futhi sixoxe ngalemibuzo elandelayo:

- Ngicela ungitshale ngozibandakanya kukho esontweni?
- Yiziphi izinto ezinhle ohlangabezana nazo esontweni?
- Yini lena eyeza kubelula kuwe ukuba yingxenye yesonto?
- Yiziphi-ke lezozinto eziba yizinkinga kuwe esontweni?
- Yiziphi izindlela isonto elingabandakanya ngazo abantu abanokukhubazeka ezinhlelweni zalo?
- Yini isonto elingayenza ukwenza impilo ibelula kulabo abanokukhubazeka?

Ngicela nanemvume yokuqopha konke lokhu okuzobe kuxoxwa.

Lokhu kuzongisiza ukuthi ngigxile kulokhu okuyobe kuxoxwa futhi ngizikhumbuze lokhu engiyobe sengikukhohliwe. Konke okuqoshiwe ngenkathi sixoxa kuyobe sekubhalwa phansi izwi ngezwi kodwa amagama alabo abakushilo ayosuswa.

Lokhu siyokwenzela ukuvikela labo abakushilo ukuze kungabi bikho ohlukumezekayo ngakushilo sixoxisana. Nakuba lonke ulwazi oluyophuma ezingxoxweni luyosetshenziswa kulolucwaningo, kodwa akukho muntu oyodalulwa.

Ngiyacela futhi ukusho ukuthi ukubayinxenye yalolucwaningo kungokuzithandela-nje, akuphoqwa muntu.

Isinqumo sakho ngalesimemo siyohlonishwa futhi awukwehlelwa lutho ngaso.

Futhi-ke uvumelekile nokushitsha umqondo, ungabe usaba yingxenye yalolucwaningo.

Futhi uma ngibona ukuthi lokhu okushilo kukuphazamisile emoyeni, ngimele ngikuyise kubeluleki abangakusiza ukubhekana nakho ngendlela. (Uma nawe uvuma).

Uma usenemibuzo ngalolucwaningo ungangifonela lenombolo noma inini: 011 440 6323.

Uma uvuma ukuba yinxenye yalolucwaningo, uyocelwa ukusayina ifomu lesisivumelwano.

Owenu ngokuzithoba

Erna Moller (Umcwaningi)

APPENDIX 4: QUESTIONS TO A PERSON WITH DISABILITY

Research topic: The inclusion of people with disabilities in faith communities

1. I'm interested to know about your life, living with a disability? Will you tell me more?
2. How do you participate in the activities of the church? Tell me more about your involvement at the church.
3. What good experiences do you encounter in your church?
4. What makes it easy to be part of the church /faith community?
5. What makes it difficult to be part of the church /faith community?
6. Can you suggest how the church can include people with disabilities in all their activities? What can the church do to make it easier for people with disabilities? (to indicate criteria for inclusion in the church).

APPENDIX 5: VRAELYS: PERSONE MET GESTREMDHEID

Navorsingsonderwerp: Die insluiting van persone met gestremdheid in geloofsgemeenskappe

1. Ek stel belang in jou lewe met gestremdheid. Kan jy my meer vertel?
2. Hoe neem jy deel aan aktiwiteite in die kerk? Kan jy my meer vertel van jou betrokkenheid?
3. Watter positiewe ervarings het jy in die kerk?
4. Wat maak dit maklik om deel te wees van die kerk?
5. Wat maak dit moeilik?
6. Kan jy voorstelle maak hoe die kerk meer persone met gestremdheid kan insluit? Wat kan die kerk doen om dit makliker te maak vir persone met gestremdheid?

APPENDIX 6: PEOPLE WITH DISABILITIES: INTERVIEW GUIDE – ISIZULU

ISIMEMO KWABANOKUKHUBAZEKA SOKUZIBANDAKANYA OCWANINGWENI ENDAWENI YASEPIETERMARITZBURG NGO JULAYI 2009

*Isihloko socwaningo: Ukubandakanywa kwabanokukhubazeka ezindaweni
zokukhonza: izeluleko zendlela yokukwenza lokhu.*

Ngiyanimema nibe yinxenye yeqembu/noma ngabanye lapho sizobe sibuzana futhi sixoxe ngalemibuzo elandelayo:

- Ngicela ungitshele ngozibandakanya kukho esontweni?
- Yiziphi izinto ezinhle ohlangabezana nazo esontweni?
- Yini lena eyeza kubelula kuwe ukuba yinxenye yesonto?
- Yiziphi-ke lezozinto eziba yizinkinga kuwe esontweni?
- Yiziphi izindlela isonto elingabandakanya ngazo abantu abanokukhubazeka ezinhlelweni zalo?
- Yini isonto elingayenza ukwenza impilo ibelula kulabo abanokukhubazeka?

APPENDIX 7: INVITATION TO CHURCH LEADERS TO PARTICIPATE IN A RESEARCH PROJECT

PIETERMARITZBURG AREA – AUGUST 2009

Research topic: *The inclusion of people with disabilities in faith communities: a social work perspective*

Dear research participant,

I am Erna Moller, a social worker of the Leprosy Mission in Johannesburg and also a student of the Department of Social Work at the University of South Africa. As part of my studies I have to undertake a research project and for this reason I have decided to do an investigation about the experiences of people with disabilities in their churches (faith communities).

The aim of the research project is to gain knowledge about something of which very little is known. Since you have personal experience of this context, I would very much like to you to participate and give your valuable input. Therefore I invite you to participate in a focus group / individual interview where the following questions will be discussed:

- How do you understand the inclusion of people with disabilities (PWD) in churches? What does it entail?
- What kind of disabled people do you have in your church?
- From your perspective, how integrated do you think they feel in the church?
- What do you think helps the inclusion of PWD in your church?
- What do you think hinders the inclusion of PWD in your church?
- What do you think could be done in the church to make life easier for PWD?
- How would you accompany (“walk the road with”) a person with disability who wrestles with the question: Why am I like this?

I also ask your permission to record on tape the proceedings of the group discussion. This is to ensure that I can give my full attention to the discussion and not forget anything that is being said. The tape recording will be written out word-

for-word, but all names of people in the group will be removed. This is to ensure that nobody will confront you personally for what you said in the discussion. Although all the information given by participants will be written up in the research document, no participant will be identifiable.

Please note that your participation is completely voluntary, you are free to choose not to participate. Your decision will not affect you in any way, now or in the future. You are also free to change your decision and withdraw from the research project.

If I see that the information you have shared left you feeling emotionally upset, or anxious, I am required to refer you to a counselor for debriefing (should you agree to this).

You have the right to ask questions concerning the study at any time. I can be contacted at the following number: 011 440 6323.

If you agree to participate in the research project, I would like you to sign the consent form that follows.

Yours sincerely

Erna Moller (Researcher), August 2009.

APPENDIX 8: KERKLEIERS: UITNODIGING OM DEEL TE NEEM AAN 'N NAVORSINGSPROJEK

PIETERMARITZBURG AREA. JULIE - NOVEMBER 2009.

Onderwerp: Die insluiting van persone met gestremdheid in kerke.

Beste deelnemer,

Ek is Erna Moller, 'n maatskaplike werker van die Sending aand die Melaatse in Johannesburg, asook 'n student by die departement van Maatskaplike Werk by die Universiteit van Suid Afrika. Ek onderneem 'n navorsingstudie oor die insluiting van persone met gestremdheid in kerke.

Die doel van die studie is om inligting in te win oor 'n saak waaroor min bekend is, en moontlik die insluiting van persone met gestremdheid in kerke te bevorder. Aangesien u ondervinding in hierdie verband het, wil ek vriendelik vra vir u deelname. Ek vra dus u insette in 'n individuele onderhoud of 'n groep bespreking. Die volgende vrae sal bespreek word:

- Hoe sien u die insluiting van persone met gestremdheid by die kerk? Wat behels dit alles?
- Watter tipe persone met gestremdheid het u in u kerk?
- Vanuit u eie perspektief, hoe geïntegreerd dink u voel hulle in die kerk?
- Wat dink u bevorder hul insluiting in die kerk?
- Wat dink u verhinder hul insluiting in die kerk?
- Wat dink u kan die kerk doen om die lewe van gestremde persone makliker te maak?
- Hoe sal u geestelike begeleiding bied aan 'n persoon wat worstel met die vraag: Waarom is ek gestremd?

Ek vra ook u toestemming om 'n klank opname te maak van die onderhoud. Dit is om te verseker dat ek my volle aandag kan gee aan wat u my vertel en nie enigiets sal vergeet nie. Die klankopname word dan woord-vir-woord getranskribeer, maar alle name word daaruit verwyder sodat niemand se identiteit bekend sal wees nie. Dit is om te verseker dat niemand agterna u sal kan konfronteer oor wat u gesê het nie.

Let asb. daarop dat u deelname heeltemal vrywillig is. U kan ter enige tyd onttrek uit die onderhoud sonder dat u kwalik geneem sal word.

As ek waarneem dat die onderhoud u in enige opsig emosioneel benadeel het, sal ek reël dat u berading hiervoor ontvang, indien u natuurlik hiertoe instem.

U het die reg om ter enige tyd verdere vrae aan my te vra. Ek kan gekontak word by die volgende nommers: Kantoor: 011 440 6323 of selnommer: 082 731 9857.

Baie dankie

Erna Moller

APPENDIX 9: INVITATION TO A CHURCH LEADER TO PARTICIPATE IN A RESEARCH PROJECT – ISIZULU

PIETERMARITZBURG. JULY – NOVEMBER 2009

Research topic: *The inclusion of people with disabilities in faith communities:*

a social work perspective

Dear Pastor,

I am Erna Moller, a social worker of the Leprosy Mission in Johannesburg and also a student of the department of Social Work at the University of South Africa (Unisa). As part of my studies I am doing a research project regarding the inclusion of people with disabilities in churches in Pietermaritzburg.

The aim of the research project is to gain knowledge about the experiences of church leaders and people with disabilities in this regard, and what can be done to enhance the process.

I would very much like to you to participate and give your valuable input. Therefore I invite you to participate in a focus group where the following questions will be discussed:

- Uqondani ngokubandakanywa kwabantu abakhubazekile esontweni? Kunaqhaza lini?

How do you understand the inclusion of people with disabilities (PWD) in churches? What does it entail?

- Bakhubazeke ngandlelani noma kanjani abantu abakhubazekile abasesontweni lakho?

What kind of disabled people do you have in your church?

- Ngokubona kwakho bazizwa kanjani ngokuba sesontweni?

From your perspective, how integrated do you think they feel in the church?

- Ucabanga ukuthi yini engasiza ukuze kubandakanywe abantu abakhubazekile kusiza esontweni lakho?

What do you think helps the inclusion of PWD in your church?

- Ucabanga ukuthi yini engavimbela ukuzibandakanywa kwabantu abakhubazekile esontweni?

What do you think hinders the inclusion of PWD in your church?

- Ucabanga ukuthi yini engenziwa yisonto ukuze kube lula kubantu abakhubazekile?

What do you think could be done in the church to make life easier for PWD?

- Ungamcathulisa kanjani umuntu okhubazekile ohlushwa umbuzo othi kungani ngikhubazekile?

How would you accompany (“walk the road with”) a person with disability who wrestles with the question: Why am I like this?

I also ask your permission to record on tape the proceedings of the group discussion. This is to ensure that I can give my full attention to the discussion and not forget anything that is being said. The tape recording will be written out word-for-word, but all names of people in the group will be removed. This is to ensure that nobody will confront you personally for what you have said in the discussion. Although all the information given by participants will be written up in the research document, no participant will be identifiable.

Please note that your participation is voluntary, you are free to choose not to participate. Your decision will not affect you in any way, now or in the future. You are also free to change your decision and withdraw from the research project.

If I see that the information you have shared left you feeling emotionally upset, or anxious, I am required to refer you to a counselor for debriefing (should you agree on this). You have the right to ask questions concerning the study at any time. I can be contacted at the following number: 011 440 6323.

Yours sincerely,

Erna Moller (Researcher), August 2009

APPENDIX 10: INTERVIEW SCHEDULE FOR LEADERS OF FAITH
COMMUNITIES

RESEARCH PROJECT: THE INCLUSION OF PEOPLE WITH DISABILITIES IN
FAITH COMMUNITIES – PIETERMARITZBURG - 2009

1. How do you understand the inclusion of people with disabilities in churches?
(What does it entail?)

2. What kind of disabled people do you have in your church / community?
Mobility / Communication / Blind

3. From your perspective, how integrated do you think they feel in the church?
(What do you observe?)

4. What do you think helps the inclusion of PWD in your church?

5. What do you think hinders the inclusion of PWD in your church?

6. What do you think could be done in the church to make life easier for people with disabilities?

7. How would you accompany (walk the road with) a PWD who wrestles with the question: “Why am I like this, Why do I have to suffer like this?”

APPENDIX 11: ONDERHOUD MET LEIERS IN GELOOFSGEMEENSKAPPE

NAVORSINGSPROJEK: INSLUITING VAN PERSONE MET GESTREMDHEID IN KERKE – PIETERMARITZBURG – 2009

1. Hoe verstaan u die insluiting van persone met gestremdheid in kerke? Wat sluit dit alles in?
2. Watter soort persone met gestremdheid het u in u gemeente?
3. Vanuit u perspektief, hoe geïntegreerd is hulle in die gemeente?
4. Wat dink u bevorder hul insluiting?
5. Wat dink u belemmer die insluiting?
6. Wat dink u kan die kerk doen om die lewe vir persone met gestremdheid makliker te maak?
7. Hoe sal u 'n persoon met gestremdheid begelei wat worstel met die vraag: "Waarom is ek gestremd? Hoekom kry ek swaar?"

APPENDIX 12: INTERVIEW GUIDE FOR CHURCH LEADERS – ISIZULU

RESEARCH PROJECT: THE INCLUSION OF PEOPLE WITH DISABILITIES IN FAITH COMMUNITIES – PIETERMARITZBURG - 2009

- Uqondani ngokubandakanywa kwabantu abakhubazekile esontweni? Kunaqhaza lini?

How do you understand the inclusion of people with disabilities (PWD) in churches? What does it entail?

- Bakhubazeke ngandlelani noma kanjani abantu abakhubazekile abasesontweni lakho?

What kind of disabled people do you have in your church?

- Ngokubona kwakho bazizwa kanjani ngokuba sesontweni?

From your perspective, how integrated do you think they feel in the church?

- Ucabanga ukuthi yini engasiza ukuze kubandakanywe abantu abakhubazekile kusiza esontweni lakho?

What do you think helps the inclusion of PWD in your church?

- Ucabanga ukuthi yini engavimbela ukuzibandakanywa kwabantu abakhubazekile esontweni?

What do you think hinders the inclusion of PWD in your church?

- Ucabanga ukuthi yini engenziwa yisonto ukuze kube lula kubantu abakhubazekile?

What do you think could be done in the church to make life easier for PWD?

- Ungamcathulisa kanjani umuntu okhubazekile ohlushwa umbuzo othi kungani ngikhubazekile?

How would you accompany (“walk the road with”) a person with disability who wrestles with the question: Why am I like this?

APPENDIX 13: CONSENT FORM

Research topic: The inclusion of people with disabilities in their faith communities (churches).

I, _____ (name of participant) hereby agree of my free will to participate in this research project which focuses on the abovementioned topic.

I understand that the information that I will share will be used for research purposes only and that nowhere will my identity be made known in any research report. I am also aware of the fact that I can withdraw at any time during the study without incurring any penalty.

Signature of participant:

Date:

Church:

APPENDIX 14: TOESTEMMINGS BRIEF - AFRIKAANS

Navorsingstitel: Die insluiting van persone met gestremdheid in kerke.

Ek, _____ (naam van respondent)
gee hiermee my toestemming om vrywilliglik deel te neem aan hierdie
navorsingsprojek.

Ek verstaan dat die inligting wat ek sal gee, slegs vir die navorsing gebruik sal
word en dat my identiteit nêrens vermeld sal word nie.

Ek is ook bewus daarvan dat ek ter enige tyd van die projek kan onttrek, sonder
enige negatiewe gevolge vir myself.

Handtekening van respondent:

Datum:

Kerk:

Adres en telefoon nommer:

APPENDIX 15: CONSENT FORM - ISIZULU

Ukubandakanywa kwabantu abakhubazekile ezinkonzweni noma wemasontweni.

Mina, _____ (igama lakho),
ngiyavuma ukuzinikela ukubamba iqhaza kulolucwaningo mayelana
nokubandakanywa kwabantu abakhubazekile emasontweni.

Ngियाqonda ukuthi imininingwane nolwazi engizolunikeza luzosetshenziselwa
ucwaningo kuphela hhayi okunye. Kanjalo negama lami angeke lidalulwe uma
sekushicilelwa umbiko ngocwaningo. Ngियाqonda ukuthi futhi uma
ngingasathandi ukuqhubeka nocwaningo ngingayeka noma kunini ngaphandle
kokuhlawuliswa.

Sayina:

Usuku:

Masontweni:

APPENDIX 16: REQUIREMENTS FOR ACCESSIBILITY IN CHURCH BUILDINGS FOR PEOPLE WITH DISABILITIES

This information is based on the SOUTH AFRICAN NATIONAL STANDARD:

The application of NATIONAL BUILDING REGULATIONS:

PART S: FACILITIES FOR PEOPLE WITH DISABILITIES

For the full regulations, see

<http://www.rampup.co.za/index.php?page=buildingseveryone> and
www.sabs.co.za

1. Accessible parking

In order to supply suitable parking at all its venues, churches should comply with the National Building regulations, which details the following requirements:

- Parking bays reserved for drivers or passengers who use wheelchairs, walking frames or two crutches should be 3500 mm wide.
- Parking bays should be on firm level ground, close to the entrance of the building and under cover where possible.
- Right angle or fishbone parking is preferred, to allow for safety when the PWD accesses his vehicle.
- The bays should be clearly marked with the regulation blue reserved sign at the front of the vehicle, and the International Symbol of Accessibility painted on the ground to deter illegal use.

2. Entrances and doorways:

Ramps:

- A gradient less than 1:12 and width at least 1200 mm.
- Level landings at least every 1000 mm rise.
- A clear landing at the top and bottom of the ramp at least 1200 mm long.
- Handrails 900 mm above the ramp surface or stairway.

Doorways:

- Paths and floors should have firm, non-slip surfaces
- Clear door opening at least 750 mm wide.
- Passage ways at least 1200 mm wide, to allow space to negotiate corners

3. Wheelchair users in the worship service have the following requirements:

- Enough space to turn the wheelchair; 1500 x 1500 mm, according to regulations.
- A space which is level, not on a slope
- Electronic boards should be visible when others stand to sing
- A space to sit comfortably with family members or companions, and if possible not in an aisle where they “stick out” and be regarded as “different”.

4. People with hearing loss in the worship service:

The different categories of hearing loss need to be considered. Some suggestions for lip-readers are as follows:

- a. Allow for seating in a place where the speaker is clearly visible, usually in the front.
- b. Lighting should be sufficient to make lip-reading possible
- c. Lip readers need to see the face of the speaker at all times. Therefore, make preachers/speakers aware of not turning their backs on the audience (for example when looking at the electronic board) and not walking up and down while speaking.
- d. Train ushers and others who may relate to people with hearing loss to speak clearly without shouting.
- e. Ask people with hearing loss if they need help, for example, a person sitting next to them could help during the service, finding hymns in the hymnbook or scripture reading in the Bible.
- f. A written summary of the sermon could be of great help to a person with hearing loss.
- g. People who are Deaf, who use sign language have different needs. While this may be more difficult to respond to the following ideas could be considered:
- h. Try to find one church in a geographical area where a sign language interpreter can interpret for Deaf people, even if it is only occasionally like twice a month. Teachers at Schools for the Deaf may be willing to do this.

Bear in mind not to start a service for Deaf people which cannot be sustained. This causes great disappointment for them in a sometimes very lonely world.

5. People with visual impairment in the worship service

- Good lighting is helpful
- People using Braille hymnbooks or Bibles need enough time to look these up, in their Braille books

6. Install appropriate equipment

Requirements for people with **hearing loss**

- Provide Sign language interpreters or lip-reading practitioners where possible
- Ask if the person needs somebody to sit with him/her.
- Have a printed summary of the sermon available
- Install a loop system in the church into which all hearing aids can be tuned into.

Requirements for people with **visual impairments**

- Find alternatives for people who cannot read electronic boards by asking them what could work for them
- Large print material, for example, hymn books and Bibles can be helpful

7. Ensure accessible toilets / cloakrooms

Pathways and doorways to the toilets should comply with National Building Regulations as follows:

- a. Doorways and cubicles should comply with National Building Regulations, namely a minimum area of 1800 x 1800 mm and according to the standard layout as described in the Regulations (SABS 2011)
- b. Door opening outwards, or sliding, with lever-operated lock with emergency release from the outside

- c. A light switch not higher than 1200 mm above the floor level
- d. Clear space of at least 800 mm alongside the toilet pan to park a wheelchair while transferring
- e. Centreline of toilet pan should be 500 mm from the sidewall.
- f. An extended lever-type flush control, at least 150 mm long
- g. Grab rails 800 mm above floor level, as per SABS layout
- h. Hand basin with lever-operated taps
- i. 630 mm clear knee space under the basin, and maximum basin height 830 mm.
- j. A mirror above the basin, lower edge not higher than 900 mm above floor level
- k. Soap dispensing and hand drying facilities within reach when seated on the toilet and in a wheelchair.

8. Notice boards that help persons with disabilities to find their way independently

- Accessible facilities, wheelchair-friendly routes, lifts and toilets should be marked clearly. SABS standards should be used for the size and colouring of signage, and be symbolic where possible, i.e. not language specific.
- This information should be accessible to all, for example, tactile for people with visual impairments.