

**AN “INCLUSIVE CONGREGATIONAL MINISTRY”
PERSPECTIVE ON YOUTH AND CHILDREN WITH A
DISABILITY IN SOUTH AFRICA**

By

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DECLARATION

I, Anine Fischer, hereby declare that this research submitted to the University of Pretoria, is my original work, and has not been previously submitted to any University. Sources used or quoted have been acknowledged by means of complete references.

Signature (Student)



Date 30.04.2018

Signature (Supervisor)



Date 30.04.2018

DEDICATION

This thesis is dedicated to all people affected by disability. Regardless of their age, the type of disability or country of citizenship, life with a disability is challenging to the person affected as well as for their loved ones and caregivers. May the good Lord grant them the strength and perseverance to never give up, especially with regard to advocating for the rights of people with a disability. My ultimate wish for the disability sector is uncompromised inclusion and integration in all spheres of life.

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SUMMARY

The prevalence of children and youth living with a disability is a matter of concern on a national and international level. From a theological perspective the responsibility of faith communities toward children and youth with a disability is unquestionable. However, the question is whether this group of individuals benefit sufficiently from congregational ministry in South Africa. The father of a girl with Cerebral Palsy, Mr. H, made the following statement regarding the inclusion of children with a disability in faith communities: "It is not about putting up ramps. It is about breaking down walls ..." Mr. H.s' statement inspired this investigation. According to him structural accessibility is not the main reason for the experience of their child feeling excluded from the faith community. He suggests that the "barriers" to inclusion experienced by them are based on other excluding factors. This study aims to determine whether the parents of other children with a disability share Mr.H.'s concerns, what these barriers are and how they can be overcome.

The objectives of this study are the following:

- to determine whether youth ministry in a postmodern context adequately reaches, includes and serves children and youth with a disability, in relation to the national statistics of children and youth living with a disability;
- to determine the reasons why these children and youth with a disability experience exclusion from faith communities and youth ministry;
- to investigate youth ministry from an "inclusive congregational approach" as a possible model to facilitate the inclusion of children and youth with a disability in South African faith communities.

The first chapter is an introductory orientation of the situation of children and youth living with a disability nationally and internationally. The prevalent statistics of children and youth living with a disability indicate the scale of the challenge to faith communities to do effective ministry with this group of individuals in an inclusive way. The practical theological responsibility towards this group of individuals is discussed and the methodological positioning presented. From a postmodern perspective, the epistemological point of departure of this investigation is postfoundational and social constructionist. With regard to the latter especially the influence of social constructs with regard to disability is explored. The challenging topics of disability and disability

culture are investigated in Chapter 3. This thesis focuses specifically on four types of disabilities, based on the prevalent statistics in South Africa. These disabilities are Cerebral Palsy, Down Syndrome, Autism and Deafness. It is of the utmost importance that congregants and clergy have insight into these disabilities and their effect on the children and youth in order to better understand their limitations, needs and challenges. Inclusive ministry to this group of individuals can only become a reality if there is a sound understanding of their circumstances and challenges.

The empirical part of the investigation focuses on qualitative data gathered by means of structured interviews with the parents of five children and youth living with a disability and their experience as a family in various South African faith communities. By means of a quantitative survey data with regard to disability in congregations was procured. The results of the empirical investigation are brought into dialogue with the theoretical data regarding youth ministry and disability.

This study aims to contribute to consciousness raising with regard to the inclusion and integration of children and youth with a disability in South African faith communities. It aims to benefit both the disability community as well as faith communities so that a more effective and inclusive ministry to children and youth with a disability can become a reality in churches in the country.

KEY TERMS

Children	Disability
Youth	Postfoundational
Practical theology	Social constructionism
Youth ministry	Faith communities
“Inclusive congregational ministry” perspective	Barriers

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CHAPTER 1

INTRODUCTION

1.1 “It is about breaking down the walls ...”

In 2011 a situation analysis was done with regard to children with a disability in South Africa. The study was a combined effort of the Department of Social Development, the Department of Women, Children and People with Disabilities and UNICEF South Africa (2012). In conjunction with this study, Sue Philpott and Pam McLaren from the Disability Action Research Team (DART), focused specifically on gathering information from children with a disability and their caregivers and/or parents, in order to facilitate a better understanding of the children’s experience of living with disability in South Africa. They found the following (Philpott & McLaren 2011:3):

- that children and youth with a disability (physical, sensory, intellectual or mental health disabilities) are among the most excluded groups in the world;
- that children and youth with a disability enjoy only a limited measure of basic human rights;
- that children and youth with a disability often do not have access to educational and health services;
- that children and youth with a disability easily become victims of violence, abuse and exploitation;
- that children and youth with a disability are likely to be denied the right to grow up within a family structure.

These challenges are referred to as “barriers” in the literature. The barriers are frequently caused not by the disability itself, but rather by a combination of social, cultural, attitudinal and physical obstacles (World Health Organisation 2001:214). Many of the factors contributing to the high levels of impairment, such as congenital defects, malnutrition, childhood illnesses, lack of sanitation and clean water, as well as accidents, are preventable (Philpott & McLaren 2011:3).

One reason for taking action with regard to children and youth with a disability internationally and nationally is the disturbing world statistics. It is estimated that

globally 93 million children under the age of fourteen are living with some form of disability, be it moderate or severe (United Nations International Children's Emergency Fund 2013b:2). The prevalence of disability for young children is exceptionally high: 28% of children between 0 – 4 years and 10% of children between 5 – 9 years were classified as "children with a disability" (World Health Organisation 2012:8). The situation is no different locally: Census 2011 recorded 447 843 or 10.8% of South African children in the age group of 5 – 9 years as children living with a disability (Statistics South Africa 2011a:3). Given these statistics and the results of the situation analysis regarding children and youth with a disability that was done in 2011, it can be concluded that the prevalence of children and youth living with a disability is a cause for concern on national and international level. Children and youth living with a disability and their families are confronted with several, unique challenges on a daily basis.

This study investigates the situation and experiences of children and youth with a disability specifically in the context of Christian faith communities in South Africa. It aims to explore possibilities for the optimal inclusion of this group of individuals in the youth ministry of churches. Given the prevalence of children and youth with a disability, ministry to this group of people who have to deal with severe challenges and exclusion on a daily basis, should be a central concern of faith communities. However, a recent study in the US (Dingle 2016) found that more than half of parents with children with a disability reported that their child was largely excluded from church activities. The responsibility of faith communities towards children and youth with a disability and their families should to be recognised and taken up, also in South Africa. To aid in this, in-depth practical theological investigation regarding the status and situation of children and youth with a disability in faith communities is needed.

In 2009 I met Evah, a seven-year old girl diagnosed at birth with severe cerebral palsy. Evah cannot and will probably never be able to eat, sit, speak or walk by herself. Since both her parents had to work full time, Evah was placed in the care centre of which I was the manager. The other family members felt intimidated by and incapable of caring for Evah's, given her daunting special needs. Evah is the last-born of Mr. and Mrs. H who have three children. They live a simple life in a

disadvantaged community which forms part of the township of Mamelodi, near Pretoria in South Africa. They were devastated by Evah's disability. It was unexpected, since the pregnancy and birth were uncomplicated. For Mr. and Mrs. H the worst part of their journey with Evah was not the disability itself, but rather the discrimination and exclusion they experienced from family, friends and the community. They soon discovered that structural inaccessibility was a small problem in comparison to the hurtful attitudes of people. Their family soon became isolated. The stigmatisation of disability is a global phenomenon (see Martz 2004:139), but it is especially harsh in some African cultures, where a person with a disability can be perceived as cursed (see Eskay et al 2012:478). With regard to children living with a disability in Africa, Bjorn Franzen (1990:21-26) whose study focused on communities in Kenya and Zimbabwe, puts it as follows:

A child with a disability is a symbol of a curse befalling the whole family. Such a child is a "shame" to the whole family, hence their rejection by the family or the community. Children who are met by those beliefs and attitudes can hardly develop to their full potential: They get less attention, less stimulation, less education, less medical care, less upbringing and sometimes less nourishment than other children.

Only when Mr. H confronted me about the status and treatment of children with a disability in the congregation, did I realise to what extent the congregation was not accessible to children or youth with a disability. Mr. H further conscientised me with his poignant comment that it was "not about putting up ramps, but about breaking down walls." With this insight he pointed to the theological obligation to prioritise not only accessibility, but also ministry to children and youth with a disability.

An aim of this study is to ascertain whether parents of children and youth with a disability in a South African context experience similar challenges as those in the US study. The objectives of this study are:

- to investigate the church attendance of children and youth with a disability and establish the reasons for their attendance or non-attendance;

- to ascertain whether children and youth with a disability are included and ministered to effectively;
- to investigate the factors that contribute to the non-participation of children and youth with a disability in faith communities;
- to evaluate whether an “inclusive congregational approach” to youth ministry could provide new insights which could contribute possible solutions to the problem.

Raising a child with a disability, whichever disability it may be, truly is challenging and difficult. Parents have many questions and need the support, care and understanding of friends, family and the community. Unfortunately, parents of children and youth with a disability often find themselves being stared at and generally excluded from society. Such attitudes are often due to a lack of information on and understanding of disability in the broader community. Grose (2011:1) describes it as follows:

No one would claim that parenting is easy, but when you have a child with a disability, there is a whole new level of challenge involved. There are different issues with special needs kids depending on the kind of disability and their age, however there are also some issues common to all disabilities... Parents with children with special needs often comment on the level of misunderstanding there is about their child’s condition.

Where parents and their child with a disability experience exclusion from their faith communities, intervention is needed. Children and youth with a disability and their parents encounter extensive challenges on a daily basis. These include social, cultural, attitudinal and physical obstacles (see Philpott & McLaren 2011:3). Mr. H implied a general exclusion of people with a disability from the ministry activities of faith communities with his statement: “It is not about putting up ramps. It is about breaking down walls ...” This observation, meant to encourage the faith community to take action and remove the invisible barriers of exclusion, comes from the personal experience of having been misunderstood on many levels. Consequently, the inclusion or exclusion of and ministry to this group of individuals should be investigated. Despite an

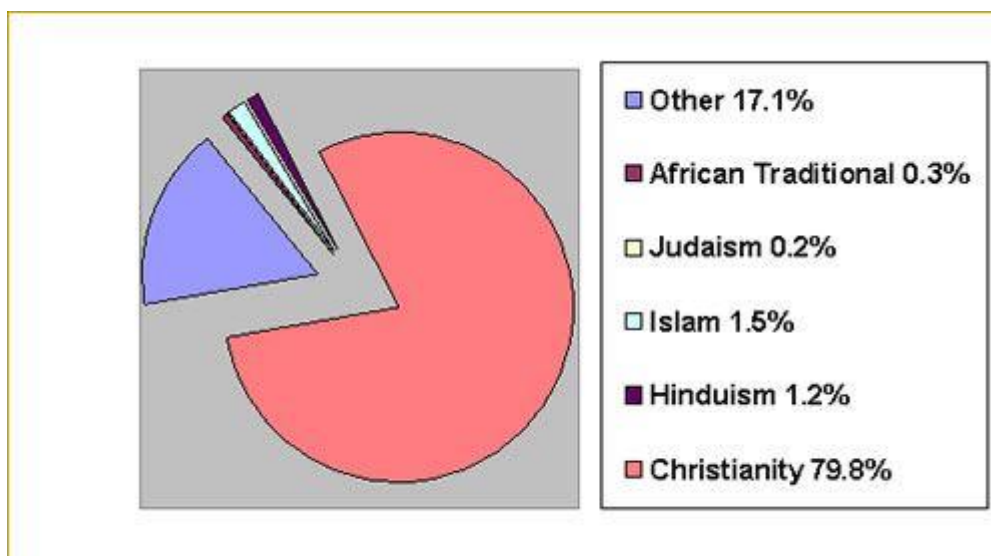
estimated two hundred million children or 10% of the global child population between 0 – 19 years born with or having acquired a disability (United Nations Convention on the Rights of the Child 2006:16), inadequate information and gaps with regard to services are an undeniable reality (see Philpott & McLaren 2011:4). This includes ignorance and a lack of meaningful support in faith communities.

Religious faith is an important aspect of the lives of many people with a disability and their families (National Organisation on Disability 2004). Faith can be a source of support to the parents and caregivers of children and youth with a disability (Boehm et al 2015). However, involvement in congregational activities is limited for people with a disability due to factors such as structural accessibility, lack of disability awareness and uninviting attitudes of faith communities towards this group of individuals and their families (Carter 2007:4). Despite a shared Christian perspective that people with a disability should be included unconditionally in faith communities and the various ministries they offer, the way in which children with a disability and their families are received and treated varies from congregation to congregation (see Jacober 2010:170). Inconsistencies in the support and services provided to people with a disability and their families in congregations were identified by Carter et al (2017:576). In her studies regarding the status of people with a disability in US churches, Shannon Dingle (2016) found that more than half of the parents of children with a disability felt excluded by their faith community. Melinda Jones Ault's 2010 study with 400 parents of children and youth with a disability, finds the following:

- 32.3% of the parents left at least one church because of the exclusion of their child with a disability;
- 46.6% of the parents refrained from participation in religious activities due to the exclusion of their child with a disability;
- more than 55% of the parents kept their child with a disability from participation in religious activities due to a lack of support from the church or the expectation of the church that they should stay with their child at all times in order to provide the support themselves;

- 86.5% of church attending parents of children with a disability reported that their congregation needed more education on disability;
- parents reported that the inclusion of their child with a disability was easier when the child was younger, but became increasingly difficult as the child grew older;
- despite a strong desire for a faith community, parents refrain from going to church, because of fatigue: "... we have not had the time or energy to seek-out and prepare (educate) a new spiritual home for ourselves. Therefore, we do not attend regular weekly services anywhere, as much as we could really use the support and spiritual community";
- children with a disability often make it difficult to attend church because of: being noisy, having complex needs, not being able to sit still, touching others, being overwhelmed by the noise and chaos, being loud, unpredictable and aggressive towards other people, not being able to understand religious education lessons, becoming over stimulated, which causes embarrassment;
- parents refrain from religious participation, or remove their child from activities, or attend activities with their child to provide assistance or are asked not to bring their child back to services or activities.

South Africa is a predominantly Christian country with almost 80% of the population adhering to the Christian faith. This is demonstrated by the following diagram (South African Embassy in the Netherlands 2013):



With more than 10% of South African children living with a disability (Statistics South Africa 2011a:3), local Christian pastors and faith communities should find an effective way of including and ministering to children and youth with a disability and their families. This study investigates the present situation with the aim of providing insights for an improved practice.

1.2 Research problem

With his sharp assessment of the problem, the parent of a child living with disability, Mr. H, distinguishes two aspects, namely physical accessibility (“building ramps”) and the much more insidious problem of breaking down relational, emotional and social barriers. Ramps are built to ensure accessibility to buildings or terrains for people who make use of a wheelchair. The issue of structural accessibility to churches for people with disabilities in South Africa has been investigated by Erna Moller and Barbara Watt (2011) in their study for Ramp Up, an organisation that focuses on accessibility to churches. Internationally and in South Africa, efforts are made to improve accessibility and services to people with a disability (Department of Social Development, Department of Women, Children and People with Disabilities and UNICEF 2012:5):

South Africa’s ratification of the UN Convention on the rights of the Child (UNCRC) in 1995 and the UN Convention on the Rights of People with Disabilities (UNCRPD) in 2007 has facilitated the implementation of programmes towards the fulfilment of the rights of children, and indeed people with disabilities in the country.

Despite these international and national efforts on behalf of people living with a disability, Mr. H pointed to a less visible and much more complex issue, namely “breaking down the walls.” Based on the findings of the American investigations regarding the exclusion of children and youth with a disability, this study aims to explore what Mr. H’s metaphor means in a South African context. It further investigates what “breaking down the walls,” would mean in youth ministry in a South African context. It aims to identify behavioural patterns and assess whether these can be traced across different sectors, institutions, cultures, religions and faith

communities. The question is whether these “walls” are a typical, general phenomenon encountered by the parents of children and youth living with a disability, or whether they are context specific. The contribution of this study is to ascertain from the perspective of practical theology and inclusive congregational ministry how these “walls” can be broken down.

1.3 Literature overview and research gap

Internationally, issues facing children and youth with a disability have increasingly received attention during the past two decades. South Africa is one of the leading countries when it comes to legislation and policies on the rights of these children (see Philpott & McLaren 2011:3). In South Africa, a person below the age of eighteen is regarded as a “child” (Children’s Act 38 of 2005:12). Youth are persons below the age of 35 (National Youth Policy 2015:10). The purpose of this study is to determine the extent to which persons under the age of 35 who live with a disability, are included in the life and activities of their faith community. Philpott and McLaren (2011:4) point out that awareness with regard to disability falls short in South Africa, despite much progress in policy making and legislation:

Despite the achievements in terms of policy and legislation, there has been limited impact on the lives of children with disabilities. While there is a political will to address the needs of people with disabilities, knowledge on disability is very fragmented, and many gaps in service delivery remain.

This insight from the field of social development can also be applied to other fields. Inadequate knowledge with regard to children and youth with a disability is a reality in all spheres of life (UNICEF 2013b:4). The contribution of this study is to investigate the challenges regarding disability among youth and children from a theological and specifically a youth ministry perspective. In Africa historical perceptions of disability play a significant role, but according to Munyi (2012) but limited literature on this aspect is available. Census 2011 provides statistics for children with a disability from five years and older. Below the age of five it is a challenge to differentiate between impairment and normal developmental processes (see Statistics South Africa 2009:89-92). According to the World Bank (Mont 2007:1), measuring the prevalence of disability in itself proves to be difficult, since there is no clear and general

description of disability or a globally accepted standard. The Washington Group Short Set of Questions was used to gather statistics on children and youth with disabilities in South Africa in the General Household Survey of 2008 (Statistics South Africa 2009:19). This survey focused on challenges regarding the following seven domains of functioning:

- seeing;
- hearing;
- walking;
- remembering;
- concentrating;
- self-care;
- communication.

According to the Washington Group Short Set of Questions, people are regarded as a person with a disability if they have “some difficulty” with two or more of the categories above or they experience “significant difficulty” with or are “fully unable” with regard to one specific category. By using the Washington Group Set of Short Questions in the General Household Survey 2009, 2.1 million South Africa children and youth were classified as living with a disability (Statistics South Africa 2010:89-92). The prevalence of disability among young children was excessive: 28% of children between 0 – 4 years and 10% of children between 5 – 9 years. The Household Survey statistics showed that statistics from Census 2011 regarding young children with disabilities grossly underestimated the prevalence of disability among children in South Africa (DSD, DWCPD & UNICEF 2012:11).

Though a practical theological study of people with a disability across all age groups would certainly be justified, this study focuses on the needs of children and youth with a disability from infancy to the age of to 35. The motivation for the selection of this particular age group is the following:

- Difficulties with data collection regarding children and youth with a disability resulted in gaps in the existing research. This is the case in various fields, including the field of practical theology and youth ministry (UNICEF 2013b:6).
- The reality of disability is a traumatic experience for parents and families. It presents specific challenges for their faith practice and is therefore a relevant topic for the academic field of practical theology and its sub-discipline of youth ministry. The discovery of disability often occurs during the early years of a person's life, depending on the type of disability and the cause. The needs of the child or youth with the disability and their family are particularly urgent in this time. This need constitutes a specific appeal to pastoral care and youth ministry.
- Ideally, when disability is discovered the affected person should benefit from all the available support services as soon possible. Early intervention is the key to ensuring optimal quality of life for the child or youth (see Mariano 2012). Parents and families will need support in this time of decision making.

Practical theological efforts to increase the congregational and ministerial inclusion of persons with a disability are taking place on international front, with a specific interest in the pastoral care of these individuals and their families. In England, a government-backed strategy to remove children with particular behavioural and learning problems from the special needs register by providing them with improved pastoral care in schools, was unveiled as part of improved disability provision (Vasagar 2011). Children are often diagnosed with a learning disability, while the cause for their behaviour could be other difficulties such as social problems at home. If adequate pastoral care is provided to these children, with the perceptive eye of an "outsider" in the equation, there could be a greater chance for the actual reason for their challenges to be identified. The result could be an improvement in their life and performance, and the child could be removed from the special needs register. Other theologically inspired institutional services to people with a disability have been established. One such service is provided by a department of The Archdiocese of Philadelphia. It has specialised in the pastoral care of persons with a disability since 1991. This department serves as a pastoral resource for parishes, institutions,

families and individuals. It provides access for and is welcoming to persons with a disability. Another institution of this kind is the Summer Institute for Theology and Disability which was established in Pennsylvania in 2009. The purpose of this institute was to provide practical resources such as videos and audio-files to empower faith communities to make their ministries inclusive to people with a disability.

Individual contributions that focus on the provision of inclusive and effective pastoral care services to persons with a disability in faith communities include the works of William Gaventa (2001, 2010 and 2013). Gaventa designed a sample module for seminary courses in pastoral care in order to empower pastoral counsellors and other theologians to provide more effective pastoral care to persons with a disability and their families. In his 2012 and 2014 works, Bill Gaventa also advocates for inclusive church communities and pastoral care to people with a disability. What distinguishes the contribution of Mindi Welton-Mitchell (2014) is the fact that she not only addresses inclusive pastoral care to people with a disability as a theologian, but also as the mother of a boy who is autistic. Having experienced the frustrations of the exclusion of her child from a multiple activities and ministries in faith communities, her insightful article on pastoral care to families of children with a disability is a valuable contribution to practical theology and also to clergy who are involved with children and youth living with a disability in practice.

Various quantitative studies with regard to the status and experiences of children and youth with a disability and their parents in faith communities have been done worldwide. One such study is that of Shannon Dingle (2016) study on churches in the US and disability, as well as the study of Mary Jane Ault (2010) who interviewed more than four hundred parents of children and youth with a disability. She provided theoretical guidelines for faith communities to make their ministries more accessible to people with a disability. Eric Carter's 2015 study which focuses on supporting the presence and participation of people with a disability and their families in their faith communities, is also referred to as "congregational inclusion" (Carter et al 2015:372-389). The needs and experiences of these families who live with a disability and the responses of the congregations were examined. The views and experiences of 433 parents were explored to ascertain how helpful and available the 14 support projects

of their congregations really were. Indicators of congregational inclusion were identified. Findings from this study inform efforts by congregations and professionals to effectively support the involvement of families and highlight potential areas for future research and improved practices at the intersection of faith and disability.

Erik Carter and his team (2017) conducted a study in Tennessee to determine how congregations can foster the improved inclusion of people with a disability and their families. They used “community conversations” as the method to collect the data. The participant pool consisted of 175 people, including people with a disability and other stakeholders in the local disability sector. A thousand suggestions to improve and facilitate inclusion were generated by this investigation. As a result of this study 23 categories were identified as well as five overarching themes. The themes and categories are the following (Carter et al 2017:582-583):

Theme	Category
Disability-specific efforts (congregational efforts that are designed for people with disabilities and their families).	<ul style="list-style-type: none"> • family support • individual support • awareness efforts • training • intentional training • focused reflection
Internal activities (activities and events specifically for congregation members, focused on growth and community development).	<ul style="list-style-type: none"> • Fellowship • serving and using their gifts • worship services • religious education • hospitality initiatives • general congregational activities • small group discipleship
External activities (cooperation with	<ul style="list-style-type: none"> • partnerships with other

organisations or individuals outside of the faith community)

congregations

- communication and dissemination
- outreach missions and social service
- partnerships with community organisations

Influencers (leadership and orientations directing actions of the faith community).

- congregational culture and climate
- leadership, staffing and governance
- doctrine and theology

Resources (practical attributes of the faith community).

- availability of transport
- structural accessibility
- financial assistance

In the South African context, Mercy Shumbamhini's 2008 study investigated *Narrative and participatory pastoral care and therapy with children at Mary Ward's Children's Home*, a facility for children with a disability. Shumbamhini's work focuses on individual pastoral care and therapy and not the role of faith communities. In his 2012 South African study, Patrick Mdluli investigated disability from a theological and socio-economic perspective. He finds that faith communities are experienced as liberating by some people with a disability, but not by others. He suggests awareness programmes in faith communities (Mdluli 2012:79). He also recommends that further research should be done on how to adequately and effectively provide pastoral support for families who raise children with a disability (Mdluli 2012:80). The contribution of this study is its focus on congregational inclusion of children or youth with a disability and their families, specifically from a youth ministry perspective.

1.4 Relevance of the study

Statistics of children and youth with a disability in South Africa is comparable to what is found internationally. The South African Census of 2011 provides the following statistics regarding disability, and also specifically children and youth with a disability that is relevant to this study (Statistics South Africa 2011a:3):

Age group	With disabilities		Without disabilities		Total	
	N	%	N	%	N	%
5–9	447 843	10,8	3 719 835	89,3	4 167 678	100,0
10–14	161 828	4,1	3 802 210	95,9	3 964 038	100,0
15–19	108 738	2,6	4 118 948	97,4	4 227 686	100,0
20–24	99 665	2,4	4 128 757	97,6	4 228 422	100,0
25–29	100 371	2,5	3 906 800	97,5	4 007 171	100,0
30–34	96 274	3,0	3 104 571	97,0	3 200 845	100,0
35–39	108 559	3,8	2 735 168	96,2	2 843 727	100,0
40–44	132 672	5,5	2 283 966	94,5	2 416 638	100,0
45–49	189 774	8,7	1 998 996	91,3	2 188 770	100,0
50–54	225 498	12,2	1 626 667	87,8	1 852 165	100,0
55–59	233 735	15,6	1 268 491	84,4	1 502 226	100,0
60–64	216 572	18,7	942 615	81,3	1 159 187	100,0
65–69	184 428	22,7	627 474	77,3	811 902	100,0
70–74	186 401	29,4	447 044	70,6	633 445	100,0
75–79	148 452	36,6	257 502	63,4	405 954	100,0
80–84	120 001	44,5	149 446	55,5	269 447	100,0
85+	109 319	53,2	96 256	46,8	205 575	100,0
Total	2 870 130	7,5	35 214 746	92,5	38 084 876	100,0

This indicates an increase in disability among children and youth. South African Census 2001 recorded 2.5% of children between the ages of 5 – 9 as children with a disability (DSD et al 2012:4). Ten years later, Census 2011 recorded 10.8% of children in this same age group as children living with a disability (see Statistics South Africa 2011a). Consequently, an increase in disability of 8.3% is indicated for children between 5 – 9 years within a decade. This increase in childhood disability

correlates with international estimations (UNICEF 2013a:2). However, despite the increase of childhood disability, the numbers (local and global) may be questioned. Investigations should rather consider them estimations than specific. To obtain correct information and data regarding children and youth with a disability is challenging, especially in a developing country such as South Africa (Mont 2007:4). Various reasons for this are given, including the following (Philpott & McLaren 2011:27):

- there is no universally accepted definition for disability, which makes it difficult to measure the prevalence of disability;
- stigmatisation and discrimination prevent people from reporting their child's disability;
- often, disability in a child or youth is identified by a family member (guardian) and not necessarily by a medical professional, which could lead to a misdiagnosis;
- social circumstances and environmental disadvantages can be the cause of disability in children or youth, rather than disability from birth.

Considering these national and international estimations with regard to children and youth with a disability, it is necessary that faith communities are informed with regard to the needs of this group of people and focus on inclusive activities and ministries to serve them effectively. Therefore this study is relevant to practical theology and church practice. The specific contribution is the youth ministry perspective.

1.5 Personal positioning

I have been working with children and teenagers in different settings over the past thirteen years. In 2005 I was appointed as deputy-director of a local non-profit organisation which specialises in disability services. I was tasked, among others, with managing a project for twenty pre-school children with various severe disabilities. These children were from previously disadvantaged communities. A great variety of cultures, races and religions were represented. I worked closely with various national departments and other stakeholders in the disability sector, including the Department of Mental Health, the Department of Social Development and the Department of

Education. Collaboration with other non-profit organisations in informal settlements for rendering services was required. I acquired extensive knowledge and experience working with multi-disciplinary professionals from organisations in a great variety of circumstances.

On my first day of work at the care facility, I was overwhelmed by the number of small wheelchairs everywhere; the cots filled with either oversized or exceptionally tiny children just lying there in their nappies, the eyes glazed, and mouths drooling uncontrollably. I was not prepared for the situation and had no skills to offer. Children are not supposed to suffer like this! I suddenly felt a tiny, shivering hand taking hold of mine. “Morning, Mam,” she said and I looked down to see the warmest, most inviting smile. I knelt down to look into her intriguing eyes. “Thank you for coming to help us,” she said. From that moment on I felt at home, though it took months to familiarise myself with disability and disability etiquette.

At first, I was uncomfortable with the most basic daily activities. I did not know whether to stand, bend or kneel down when talking to a child in a wheelchair, how to have a “normal” conversation with a deaf child or how to keep myself from crying when faced with severe disabilities, pain or disturbing deformities. With my ignorance, discomfort, and until then lack of interest and knowledge regarding disability and children and youth with a disability, I was not the exception to the rule. People tend to only take an interest in disability when they are personally affected by it. Even in the twenty-first century, in a developing country, the attitude towards, misunderstanding and stigmatisation of disability in general remains a matter of concern (UNICEF 2013:iii).

1.6 Research challenges

Because of the complexity of the subject matter a multi-disciplinary approach to the investigation is necessary (see Müller 2005:82) in order to facilitate an understanding not only of the primary focus area of youth ministry and pastoral care with people whose lives are touched by the reality of child disability, but also of related aspects such as childhood development, social development, and disability. In order to come

to an inclusive youth ministry for children and youth with a disability, some understanding of these aspects is essential.

South Africa consists of a minority of extremely rich people, a growing middle class and a large number of people who live in abject poverty (see World Bank 2012:viii). This economic inequality influences all levels of South African society and is also of international concern (World Bank 2012:vi). Economic status influences access to services. The challenges faced by parents who raise children and youth with a disability will vary depending on their financial position (World Bank 2007:1). Statistics South Africa's Community Survey 2007 indicates that living conditions for children and youth with a disability in South Africa are of particular concern and that these children are less likely to have access to adequate water, housing and sanitation (Statistics South African 2008:44–55). The reason for this is not necessarily because children with a disability live in poorer households than children without a disability (World Health Organisation & World Bank 2011:36). Poverty-stricken South Africans reside mostly in townships and rural areas where access to basic services (such as water and sanitation) is not readily available. Though these services are limited for all residents, it is even more challenging for people with a disability to gain access them due to their lack of physical mobility as well as the inaccessibility of some structures and terrains.

Unequal economic status means that a parent who raises a child with a disability can either be from a wealthy background or from a disadvantaged community. There is a relation between disability and poverty: there is a higher rate of disability prevalent in developing areas. However, disability manifests everywhere and is not restricted to particular socio-economic status, environments or residential areas. Consequently, the first practical research challenge of this study is to consider and familiarise oneself with the participants' socio-economic situation in order to ensure that interviews can be scheduled according to the situation of parents: matters such as the availability of basic services and the accessibility of infrastructure plays a role in setting up meetings. In cases where these basic services are not available, I will have to take measures to provide transport or meet people at their home.

Another challenging factor is the fact that my socio-economic status as a white, middle-class woman with permanent employment, might differ from the socio-economic background of some of the participants. All parties should be aware of these differences to avoid misunderstandings or wrong perceptions and interpretations. Since my own personal circumstances and socio-economic status will often be different to that of the respondents, I will have to be cautious not to make assumptions from my own life experiences. Exploring and attempting to understand what economical and social realities mean to the respondents will be a constant challenge in conducting the investigation.

The safety and security of participants will be prioritised. South Africa is one of the most violent and unsafe countries in the world (Writer 2015). When it comes to societal safety and security, South Africa ranks as the 15th worst country in the world, and the 8th most violent with a murder rate of 31 per 100,000 people. Acknowledging that one cannot guarantee the safety and security of participants in a country where crime statistics is of concern, it is important to not expose people unnecessarily to potentially dangerous areas and circumstances. Setting up interviews in a reasonably safe environment and providing security measures where necessary, are essential for the sake of all.

The designation of South Africa as the “Rainbow Nation,” in the words of Archbishop Desmond Tutu, captures the country's cultural and ethnic diversity (Buqa 2015:1). South African society is one of the most complex and diverse in the world. The cultural, ethnicity and language identity of the country is summarised as follows (Statistics South Africa 2012:21-24):

- of the 51.7 million South Africans, over 41 million are black, 4.5 million are white, and 4.6 million are coloured and about 1.3 million are Indian or Asian;
- 51.3% are female, and 48.7% male;
- there are eleven official languages in South Africa: English (9.6%), Afrikaans (13.5%), Ndebele (2.1%), Sepedi (9.1%), Xhosa (16%), Venda (2.4%), Tswana (8%), Southern Sotho (7.6%), Zulu 22.7%),

Swazi or SiSwati (2.5%) and Tsonga (4.5%), and some languages that are also spoken include Portuguese, Greek, Italian, French, Chinese and others.

As an Afrikaans-speaking white woman it will be a challenge to communicate with parents who speak other languages. In order to overcome this challenge, English will be used as communication language where possible. In cases where participants are not fluent in either English or Afrikaans, the services of an interpreter will be engaged.

Cultural differences constitute a significant challenge in this investigation. Cultures are constantly evolving. Culture can be described as a pattern of ideas, customs and behaviours shared by a particular community. The Canadian Paediatric Society endorsed a study on disability across cultures, confirming that cultural diversity in itself brings about many problems with regard to interpretation and understanding. This is escalated when it comes to the topic of disability (Baxter & Mahoney 2016). The cultures of the respondents differ in their approach to disability. This aspect will require extensive investigation in order to eliminate the possibility of erroneous interpretation. Culture influences how disability is understood. This includes their understanding of its etiology, whether to seek help or not, their consideration of treatment options and relations with health professionals.

Whereas Western cultures tend to prioritise autonomy, individualism and independence (Christman 2015), Eastern cultures value interdependence and role dedication (Markus & Kitayama 1991). With its vast variety of cultural ethnicities, South African society is influenced by Western, Eastern and African cultures. Some cultural groups have a more westernised lifestyle, whereas others' lifestyle is more traditional and hierarchical. Medical intervention is prioritised in Western cultures, whereas spiritual healers and traditional medicines are often the first port of call for some people of indigenous cultures (see Ross 2010:44-51). In South Africa, with its rich cultural diversity, this can complicate the understanding of and actions taken with regard to disability.

1.7 Clarification of terms

People who have little to no contact with the world of disability often do not understand the sub-culture. Brown (2003:5) explains disability culture as follows:

People with disabilities have forged a group identity. We share a common history of oppression and a common bond of resilience. We generate art, music, literature, and other expressions of our lives and our culture, infused from our experience of disability. Most importantly, we are proud of ourselves as people with disabilities. We claim our disabilities with pride as part of our identity.

People with a disability spontaneously form an exclusive group, based on their commonalities and interests. A basic guide on disability language and etiquette was published by the Barking & Dagenham Centre for Independent, Integrated, Inclusive Living Consortium in 2001. This publication distinguishes between appropriate and inappropriate (disability) language. The correct use of language is essential in order to communicate respect and avoid discrimination:

INAPPROPRIATE REFERENCES

APPROPRIATE REFERENCES

The disabled

People with a disability

Invalid

Person with disability

Severely disabled

Requires substantial or significant personal assistance

Suffers from

Living with or state actual medical condition

Mental illness

Living with mental health problem, but preferably diagnosis

Learning disability	People with learning difficulty
The deaf	Deaf people / hard of hearing people / hearing impaired people
The blind	Blind people / partially sighted people / visually impaired people
Care	Personal assistance / personal support
Paid caregivers	Personal assistants
Disabled toilet	Accessible toilet
Disabled parking	Accessible parking
Wheelchair accessible	Accessible for wheelchair users

Terms are specific to specific disabilities for practical reasons (Barking & Dagenham Centre for Independent, Integrated, Inclusive Living Consortium 2001). The general rule is that of common courtesy. It is about treating a person with a disability as one would any other person. The person should be addressed directly rather than speaking to or through the companion or assistant. People should not make assumptions about an individual's abilities and then treat them accordingly. Because disability etiquette relies on the type of disability, the etiquette discussed in Chapter 3 will be limited to the disabilities on which this study focuses.

1.8 Spirituality, religion and disability

This study is in the field of youth ministry and is conducted in the context of Christian faith communities. Various Christian churches articulate their perspective on disability and children with a disability differently. The following are some examples of declarations regarding people with a disability published by various denominations globally:

- The United States Catholic Conference (1978) was one of the first faith communities to compile a document titled *Pastoral Statement of U.S. Catholic Bishops on People with Disabilities* almost 40 years ago. This declaration calls for the unconditional integration of people with disabilities in the church (The United States Catholic Conference 1978:1):

As pastors of the Church in America, we are committed to working for a deeper understanding of both the pain and the potential of our neighbors who are blind, deaf, mentally retarded, emotionally impaired, who have special learning problems, or who suffer from single or multiple physical handicaps—all those whom disability may set apart. We call upon people of good will to re-examine their attitudes toward their brothers and sisters with disabilities and promote their well-being, acting with the sense of justice and the compassion that the Lord so clearly desires. Further, realizing the unique gifts individuals with disabilities have to offer the Church, we wish to address the need for their integration into the Christian community and their fuller participation in its life.

- In August 2000 the global General Presbytery of the Assemblies of God published a document titled *Ministry to People with Disabilities: A Biblical Perspective* in which it acknowledges the challenges of ministering to people who are permanently disabled and might not be healed by prayer. Congregations are encouraged to integrate persons with disabilities. They should be embraced fully by all church members (General Council of the Assemblies of God 2000:4):

People with disabilities are essential to the wholeness of the Christian community. In a culture that worships physical perfection, devalues human life, and takes pride in disposability, the church must protect the helpless, vulnerable, disenfranchised, including people with disabilities. They are people created in God's image, possessing dignity, value, and purpose. The church must extend open arms of invitation and fellowship. Those with mental disabilities can respond to the presence of the Holy Spirit. Paul reported the answer he received when he asked that his thorn in the flesh be removed: "[The Lord] said to me, 'My grace is sufficient for

you, for my power is made perfect in weakness” (2 Corinthians 12:9). We can trust God to reveal His power through the weakness of those with disabilities.

- Considering that internationally 1 in 10 members of the church lives with a disability and needs support, the Church of the Latter Day Saints also encourages the unconditional integration of people with a disability in the church (Dyches 2006:91-102). Considering the needs of others is seen as an integral part of support for congregation members with a disability, especially people with children with a disability (Dyches 2006:91). In a study with 97 sets of parents who are raising children with a disability with regard to support services, most indicated social services, schools and governmental organisations to be useful to them, whereas faith communities were rarely mentioned (Dyches 2006:96).

Despite differences in denominational orientations towards people with a disability, Christians are generally in agreement that people with a disability are to be treated with the same human dignity as all others. This conviction is based on the gospel message. However, the lack of appropriate language with reference to disability in these denominational statements once again indicates a lack of knowledge of and insight into the fields of disability and faith communities. An increased awareness of disability within faith communities is necessary. Faith practices are investigated in the discipline of practical theology, which is described as follows by Woodward & Pattison (1994:9):

Pastoral / practical theology is a place where religious belief, tradition and practice meets contemporary experiences, questions and actions and conducts a dialogue that is mutually enriching, intellectually critical, and practically transforming.

1.9 Methodology

A theological investigation of faith practices today requires a perusal of the source document of the Christian faith, the Bible (see Nel 1998:13). No direct “instructions” can be gleaned from Scripture with regard to God, believers and children with disabilities. However, from how Jesus interacted with people with a variety of illnesses and impairments and how he engaged with children throughout his earthly life, some principles can be deducted. The following Scriptural pericopes are pertinent with regard to disability (see Otieno 2009 and Bayes 2015):

- Matthew 18:10: “See that you do not despise one of these little ones. For I tell you that in heaven their angels always see the face of my Father who is in heaven.”
- Matthew 18:4-5: “Whoever humbles himself like this child is the greatest in the kingdom of heaven. Whoever receives one such child in my name receives me ...”
- Mark 2:1-12: “And they came, bringing to him a paralytic carried by four men... And when Jesus saw their faith, he said to the paralytic, “Son, your sins are forgiven.”
- Matthew 15:31: “So that the crowd wondered, when they saw the mute speaking, the crippled healthy, the lame walking, and the blind seeing. And they glorified the God of Israel.”
- Mark 8:22-35: “And they came to Bethsaida. And some people brought to him a blind man and begged him to touch him. And he took the blind man by the hand and led him out of the village, and when he had spit on his eyes and laid his hands on him, he asked him, “Do you see anything?” And he looked up and said, “I see men, but they look like trees, walking.” Then Jesus laid his hands on his eyes again; and he opened his eyes, his sight was restored, and he saw everything clearly. And he sent him to his home, saying, “Do not even enter the village.”

As followers and disciples of Jesus Christ, Christians have a responsibility towards children and youth with a disability. Heitink (1999:18) describes practical theology as a discipline that aims to transform empirical, theological theories into practices of the modern society by means of faith. Consequently, practical theology is dually

theological: Christian tradition is a primary resource for practical theology, and practical theology, in turn, contributes to Christian understandings and theology. An objective of this study is to determine *how* this responsibility can be taken up in practice by faith communities. This investigation aims to identify and engage with the needs and experiences of children and youth with a disability from a practical theology perspective. The needs will be identified according to how they are reported by their parents who participate in the study. The practical theological responsibility towards children and youth with a disability in the church as a theological integration between theory and praxis in a postmodern society should be investigated (see Müller 1996:1).

This study is done in a specific context. This means that personalisation and subjectivity will necessarily play a role. The personal background or history of the person who executes the study and the environment in which it is done have an influence on the investigation. Investigating the status and experience of children with a disability in South African faith communities in the 21st century, I choose to conduct this study from a postmodern perspective.

In order to implement the requirements of a postmodern approach in this investigation, it will be of value to briefly explore the development and paradigm of its precursor namely “modernism” first (Comstock 1989:196) in order to clarify the shift that has taken place. Prior to the era of enlightenment, philosophy was based on ontology (Lose 2003:8). People lived in times of ultimate authority and dictatorship and were left with minimal to no freedom of opinion or choice. Enlightenment liberated people from these dehumanising circumstances (van Huyssteen 1999:22). However, modernism was born from the era of enlightenment, which brought about change from an ontological philosophy to that of already defined epistemology (Lose 2003:8) and strived to encourage rationalisation and reasoning (van Huyssteen 1999:22-23). The era of modernism became known as the “Age of Reason” (Jun 2015:2). Modernism searched for absolute truths and categorised science as the single method of obtaining knowledge (see Comstock 1989:196; Van Huyssteen 1999:29). The world consisted of factual truths applicable to each and everybody, irrespective of any other influences (see Freedman & Combs 1996:20). Modernism strived to identify, develop and implement generalised rules and laws across all

scopes, manipulating operation according to an established order (Lose 2003:10). Despite people now having the right of contributing to accessibility of knowledge, obtained knowledge was immediately categorised (see Van Huyssteen 1999:23).

The pursuit of “absolute truths” in the modern era often had dehumanising consequences for people. This manifested, among others, in the relationship of therapeutic experts to non-contributing dependants (Freedman & Combs 1996:21). Therapists took a position of separation, objectivity and control over “patients,” their aim being to “fix” problems and behaviour by applying the same ineffective methods time and again (Freedman & Combs 1996:3 - 4). Whereas the epistemologies of modernism resulted in significant scientific contributions, the human obsession to structure and even control the world, became dangerous to the point of destruction of the same world and its people as modernistic inventions such as nuclear weapons and pollution show (see Pieterse 1993:19). With the increasingly evident failures of the modernistic paradigm, the realisation dawned that it was a paradigm with limitations (see Freedman & Combs 1996:21). Modernism stimulated the development of ideologies such as objectivity, value-freedom and absolute truth (Foster 2004:1-7). The mere existence of ideologies are once again limiting to all contributors and subjects. Hence, postmodernity emerged as modernists realised the shortcomings of their epistemology. Alternatives were discovered and explored. One such alternative epistemology is that of socially constructed truth (see Lose 2003:52).

Postmodern thought rejects the unrealistic notion of objectivity (Freedman & Combs 1996:5) as well as modernistic ideologies, rules and realities in order to focus on *meaning* (Freedman & Combs 1996:22). Postmodern thought rejects generalised knowledge and meta-narratives (Van Huyssteen 1999:28). The questioning of findings rather than designating authority to acquired “factual knowledge” becomes characteristic of postmodern epistemology (see Gergen 1992:57). Consequently, no truths are absolute (Goldenberg 2008:341). Barry Burke (2000) explains the postmodern era as follows:

... this new era has been characterised by a rejection of absolute truths and grand narratives explaining the progressive evolution of society. At the same time it has brought to the surface a multitude of different perspectives on society and an appreciation of different cultures. It has highlighted

globalisation on the one hand and localisation on the other, the celebration of difference and the search for commonality.

This study, in its search for meaning (Freedman & Combs 1996:6), also does not subscribe to ideologies, the notion of objectivity or absolutes of any sort (cf. Foster 2004:1-7). Therefore, a postmodern paradigm is chosen. The aim is to gain knowledge regarding the status and experience of children and youth with a disability in faith communities, rather than to stipulate facts and rules about this group of individuals (see Freedman & Combs 1996:22). A variety of realities and narratives as encountered by respondents will be considered (see Erickson & Rossi 1981:206). The non-generalised circumstances and responds of all participants are presented individually (see Van Huyssteen 1999:28). The findings of the investigation and the impacts thereof are considered in the last chapter of the study. True to this postmodernist view, no hypothesis is formulated, whereas facts will not have any authority above the circumstances or experiences of the respondents (see Gergen 1992:57).

Postmodern thought did not develop as modernism came to an end, but it emerged in the modernistic search for truth (Van Huyssteen 1999:59). Elements of modernist thought remained in postmodern thought which can be described as the selective departure from untenable values of modern thought. Jun (2015:4) summarises the interlinked relation between modernism and postmodern thought as follows:

... I believe that modernism and postmodernism, while being marked by conformism and pluralism, respectively, as their chief characteristics, can be linked to twins born from the same womb, i.e. humanism.

The main differences between modernism and postmodern thought can be summarised as follows (Freedman & Combs 1996:20-21):

Modernism	Postmodernity
Absolute truths	No absolute truths
Limited, prescribed approach	Multiple approaches
Concerned with facts & rules	Concerned with meaning

Precision	Interpretation
Universally applicable	Contextual
One dimensional	Multi dimensional
Objective	Subjective
Value-free knowledge	All knowledge has value
Generalisation	Individualisation
Action based on ideologies and theories	Regards rationality & reason as personal
Foundational & primitive	Hermeneutical & liberal
Embraces similarity	Embraces difference
Supports rationality & reason within particular frameworks	Regards rationality & reason as personal

Despite the contra-paradigms of modernism and the postmodern paradigm, both represent progress in human thought. This study opts for a postmodern approach because such an epistemology values the contribution, potential, freedom of life, choice and thoughts of all people. Each participant in the study contributes valuable knowledge for better understanding of children and youth with disabilities in the context of youth ministry in the faith community.

The field of specialisation of this study in practical theology is youth ministry. In the discipline of practical theology, youth ministry specifically focuses on the understanding of and ministry to children and youth (see Nel 1982:121). In this field youth is generally understood from a theological perspective as people in the adolescent phase of their lives (see Dean, Clark & Rahn 2001:21-22). Congregations are seen holistically and youth ministry is not deemed separate from other ministries (Martinson 1988:12). People of all ages are involved in and responsible for youth ministry, directly or indirectly. Children and youth are called upon to participate in the practices of Christian ministries, seeing that all God's children form part of his salvation (see Dean, Clark & Rahn 2001:19 - 20). The result is that youth ministry is categorised under practical theology because Christian actions are reflected on

theologically. For the purposes of this study the Christian actions with regard to children and youth with disabilities is established from a youth ministry point of view.

An integral element of effective youth ministry is the family and its influence on the formation of children and youth (Nel 1998:19 - 22). This no different in the lives of children and youth with disabilities. Therefore this investigation focused t includea great extent on the family (see Strommen & Hardel 1989:7). Due to strict child protection policies, especially with regard to investigations concerning vulnerable children such as children with a disability, interviews will be conducted with the parents of children and youth with a disability rather than the children themselves. The impact of the family in a support and care capacity to the child or youth, is an essential element in this study.

Inclusive Congregational Youth Ministry as an approach, aims to reveal God's presence and engagement with children and youth through all the activities in the faith community (see Nel 1998:96). In essence this means that all ministries and activities in faith communities should be accessible to children and the youth, including those with a disability. In the postmodern era, *inclusion* is a key term in the field of disability. This is attested to, for example, by the policies of the *National Center on Birth Defects and Developmental Disabilities (2016)*. Consequently, with an *inclusive focus*, Malan Nel's (1998) *inclusive congregational approach to youth ministry* is proposed by this study as a way to facilitate the inclusion of children and youth with disabilities in their churches. This is worked out in Chapter 7. The degree of the inclusion of children and youth with a disability in their faith communities will be evaluated in correlation with the six aspects of Nel's (1998:96) creteria for an inclusive youth ministry. An in-depth understanding of the inclusion of peole with a disability and the *inclusive congregational approach to youth ministry* can also be of value to youth workers and faith communities who aim to serve children and youth with disabilities effectively. This investigation is therefore approached from a postfoundational practical theological, "Inclusive Congregational Ministry" and youth ministry perspective. Chapter 7 addresses Müller's (2005:82) call to propose alternative understandings in the broader community. It is here that youth ministry and the most suitable model to facilitate effective youth ministry to children and youth living with disabilities will be discussed.

In a postmodern paradigm it is acknowledged that people's realities and narratives are influenced by social convictions and expectations (see Lose 2003:53). The term "social constructionism" refers to how people collectively arrive at assumptions about reality and truths that are generally not questioned (Lose 2003:13). This development of perceptions about reality is reached by means of interaction with others. The social input affects how people allocate meaning to their lives and events in their lives (Freedman & Combs 1996:1). Social constructs are generated when notions or meanings are assigned to particular environmental objects and events during people's interactions with these objects (*The International Encyclopedia of the Social Sciences* 2008). Although these social constructs appear to be "natural" or "obvious" to the people who believe and accept them, they do not necessarily correlate with "reality" and therefore remain the inventions of a particular society.

Societies hold specific norms, beliefs and standards to which people are expected to comply. Despite the postmodern acknowledgement of a variety of knowledges that provide valuable perspectives, specific "social constructs" with regard to reality and truth are unavoidably part of all societies and cultures. According to Freedman & Combs (1996:16) people's lives are formed by the realities of the society in which they have lived since birth. Their realities and truths are constructed by social convictions (Freedman & Combs 1996:16). These social realities influence beliefs, values, institutions, customs, labels, laws and the division of labour. Social constructs exist and will continue to exist in their local and extended cultures (Freedman & Combs 1996:17). People share these "constructs" instinctively with their immediate communities (Müller 1996:33).

Social constructs are formed in societal communities where people interact with one another and share common norms and beliefs. Hence, social constructs are investigated from a relational perspective and are not limited to individual realities (Freedman & Combs 1996:27). An aim of this study is to identify the social constructs encountered by the parents of children and youth living with a disability in their different societies and faith communities. A study by UNICEF (2013b:5) on children and young people with a disability describes their situation as follows:

Children with disabilities are one of the most marginalised and excluded groups of children, experiencing widespread violations of their rights. Discrimination arises not as a result of the intrinsic nature of children's disability, but rather as a consequence of lack of understanding and knowledge of its causes and implications, fear of difference, fear of contagion or contamination or negative religious or cultural views of disability. It is further compounded by poverty and social isolation, humanitarian emergencies, lack of services and support, and a hostile and inaccessible environment. Too often, children with disabilities are defined and judged by what they lack than what they have. Their exclusion and invisibility serves to render them uniquely vulnerable, denying them respect for their dignity, their individuality, even their right to life itself.

In this quote, various social constructs regarding children with a disability that lead to discrimination against and exclusion of this group of individuals, can be identified. This study aims to identify such social constructs in the narratives of parents who raise a child with a disability.

The epistemological point of departure of this study is postfoundational. Van Huyssteen (1999) accentuates three traits of the postfoundational thought which are implemented throughout this study. Firstly, the value of a multi-disciplinary approach is taken into account. In order to ensure that the best interest of children and youth with disabilities in South African faith communities are represented throughout, investigation cannot be limited to the field of theology. Inputs and contributions from various fields are required to add value to the quality of the study. A concept such as disability is complex and therefore insights from the health and social development sectors are utilised in this study. Secondly, the influence of contextual and tradition specificity on knowledge and perspectives is respected in this study. The influence of factors such as contexts and traditions on the lives and narratives of people is also unique and specifically experienced by parents who raise a child with a disability. A basic knowledge of such influences is therefore essential to the theoretical foundation of this study. Lastly, correspondence between the individual and his or her world, as well as between environments and experienced emotions is validated in the study. People naturally exist in relation to others, but also to their surroundings, the objects in it and their experiences of it. People's own interpretation of their world

is a key element in the search to facilitate a better understanding of people and their experiences in a specific situation.

From a postfoundational point of departure this study will make use of practical theologian Julian Müller's (2005:82) research model which consists of seven movements:

- working within a specific context;
- describing experiences within this specific context;
- respecting and applying interpretation traditions in the field;
- acknowledging God's presence and guidance during the research process;
- consulting interdisciplinary contributions;
- evaluating experiences after multi-professional inputs;
- proposing alternative understandings within a broader community.

Although this is not a narrative therapy study, the seven movements of practical theological remain relevant as research method of this thesis (see Müller 2004). Müller (2004:301-304) distinguishes between seven movements as basic requirements for performing quality, postfoundational practical theology. These seven movements of practical theology have been designed in correlation with Wentzel van Huyssteen's five basic requirements of postfoundational practical theology, expecting practical theology to always be (van Huyssteen 1997:4) relevant in and for the local context, considerate of social constructs within the context, directed by tradition and beliefs, investigative of multi-disciplinary contributions and influences and directive beyond the point of the local community.

Whereas Van Huyssteen's (1997:4) five basic requirements for practical theology is implemented, six of the seven movements of practical theology apply throughout this thesis and are to be discussed categorically to determine the relevancy of every movement in the lives of children and youth living with disabilities. Movement 1 focuses on the description of the specific context. The context of focus of this study is the lives and experiences of children and youth with disabilities in faith communities in South Africa. Children and youth with disabilities encounter unique challenges on a daily basis, one of which is exclusion from various services and institutes (Philpott &

McLaren 2011:3). Despite a theological responsibility towards children and youth living with a disability, exclusion of this group of individuals from church has been indicated on international front (see Dingle 2016). To obtain information of the contexts and statuses of children and youth with a disability in faith communities, the following methods will be used:

- Consultation of literature contributions with regard to children and youth with a disability in South African faith communities.
- Distribution of a structured questionnaire regarding the status of children and youth with a disability in faith communities. Five church leaders from various denominations are to complete the document.
- Consultation of literature regarding the status of children and youth with a disability in faith communities on international level. The purpose is to compare the South African investigation with these findings, while knowledge and insight regarding the target group is extensive.
- The narratives of five parents of children and youth with a disability in the context of faith communities will be shared. Each participant's inputs and contributions are unique, seeing that their contexts differ and adds value to the search for meaning in this study.

Movement 2 requires the investigator to listen to and describe the experiences of the people in the specified context. This study is not conducted from a narrative therapy perspective and interaction with the parents of children and youth with a disability is limited to the structured interviews in the empirical investigation. Interviewees will thus not have the opportunity to retell and reconstruct their narratives. The facilitation of transformed identities and realities is therefore eliminated (Demasure & Müller 2006:413). The purpose of this study is rather to collect data related to the situation of children and youth with a disability in faith communities and ministries. Listening to the narratives and stories of the parents of children and youth with a disability in faith communities remain relevant, with the focus on the narrative aspect and not the therapy component. The following methods will be used to listen to and describe the experiences of the target group in the specified context:

- the narratives of children and youth with a disability as encountered in a professional capacity, for example the narrative of Evah and her father, Mr. H, in Chapter 1 will be shared;
- the narratives of parents of children and youth with a disability as published in open letters and articles will be shared, especially in Chapter 3 where the focus of the investigation is on disability;
- literature about the narratives of children and youth with a disability will be consulted;
- interviews will be conducted with the parents or guardians of five children or youth with a disability;
- the four elements of postmodern perspective of reality will be considered throughout these interviews, namely social constructs, language, the metaphor of narratives and the rejection of “essential truths” (Freedman & Combs 1996:22). Interpretation and correct usage of these four elements seems to be very relevant and complex in the disability sector (UNICEF 2013:5).

In Movement 3 the investigator interprets, describes and develops the experiences of the people in the specified context with their input and cooperation. Due to this study not following a narrative therapy approach, the experiences of children and youth with a disability within faith communities will not be interpreted, described or developed with neither their input nor that of their guardians or parents. Interaction with participants is limited to a once-off interview in order to determine their experience as parents who are raising a child or youth with a disability, from the perspective of South African faith communities and specifically youth ministry. Transformation or development of identities and realities is not the aim of this investigation. The aim is transformation of faith community structures and activities in order to be more accessible to children and youth with a disability, should it be found inadequately inclusive of this group of individuals. The result is that the third of Müller’s seven movements (Müller 2004:302) is not applicable to this study.

Movement 4 requires the investigator to analyse and describe the experiences of participants as continually influenced by traditions of interpretations or discourses. Particular traditions, beliefs and discourses within the specified context can impact

the perceptions, actions and orientations towards children and youth with a disability (Müller 2004:302). In order to form a better understanding of the situation within South African faith communities, the following methods will be applied:

- common, global discourses (or social constructs) regarding disabilities and children and youth living with a disability will be identified;
- discourses applicable to the context of this study, including that of cultural influences will be investigated, determined and analysed;
- literary contributions with regard to discourses identified in the context of this study will be consulted.

Movement 5 reflects on the spiritual and religious aspects of the people involved, especially their experience of the presence of God within the specific situation. Although Movement 5 does not force incorporation of the presence of God in any investigative situation (Müller 2004:303), the fact is that this study is concerned with the status of children and youth within the context of Christian faith communities specifically. Consequently, this movement is a realistic practical theology requirement and the influence and interpretation of the experiences of God's presence in the narratives of the parents of children and youth with a disability is to be expected. Methods used in this movement include:

- analysis of the interpretation of God's presence from the interviews conducted with the parents of children and youth with a disability;
- establishment of the theological orientations of the faith communities towards children and youth with a disability, as presented in structured interviews with pastors from various churches;
- literature studies, with the Bible as primary source.

In Movement 6 I will consider and describe these in-context experiences at the hand of multidisciplinary contributions. A multidisciplinary research approach is complex, though fundamental in the field of practical theology (Müller 2004:303). Conversing with other disciplines is essential to form an understanding of the experiences of children and youth with disabilities in faith communities. For the purpose of this study, contributions from the social sciences, psychology, early childhood

development and health sciences (with specific reference to disability), will be considered. The research method for the sixth movement is restricted to literature studies.

In the seventh and final movement, alternative interpretations of experiences beyond the limitations of the local society are developed. Müller (2004:304) explains the final movement as follows:

Practical theological research is not only about description and interpretation of experiences. “Alternative interpretations” mean that this way of doing theology is also about deconstruction and emancipation. The bold move should be taken to allow all the different stories of the research to develop into a new story of understanding that points beyond the local community, not in an effort to generalise, but to deconstruct negative discourses. According to the narrative approach, this will not happen on the basis of structured and rigid methods, by means of which stories are analysed and interpreted. It rather happens on the basis of a holistic understanding and as a social-constructionist process in which all the co-researchers are invited and engaged in the creation of new meaning.

At the end of the day the purpose is to make a difference in the lives of children and youth living with a disability from a youth ministry perspective. By having gained insight into the narratives of these individuals, valuable information is obtained in order to enhance inclusivity and accessibility of youth ministries in future. Although this is not a narrative therapy study, six of the seven movements of practical theology remain relative and are incorporated. Movement 7 will be addressed in the final chapter, with specific reference to Malan Nel’s (see Nel 2008) “inclusive congregational ministry” perspective to youth ministry. After careful analysis of the contributions from the parents of children and youth with disabilities and the questionnaire to pastors in the empirical research chapter, alternative approaches will be considered to facilitate improved inclusion of this group of individuals in their churches. It is to be determined whether the inclusive focus of Nel’s (2008) approach to youth ministry will serve as an effective alternative to increase the inclusion of children and youth with a disability at their churches. At the end of the day, this study is not aimed at the transformation or development of the personalities of the

participants, but at the transformation of faith community ministries (especially youth ministry), to be effectively inclusive of children and youth with a disability.

A situation analysis of children and youth with a disability in faith communities will be done. This will include a practical theological approach, specifically from the sub-discipline youth ministry, as well as insights from relevant disciplines such as the health sciences (with specific focus on disability) and social psychology (as part of Movement Five). The processing of parents' narratives of their experiences will form part of Movement 6. Chapter 3 specifically focuses on disability. Insights from the health and social development sectors are utilised here. Finally, alternative understandings within the field of youth ministry from an "inclusive congregational ministry" perspective will be discussed in Chapter 7.

When it comes to the gathering of data, this study follows a qualitative approach (see Patton & Cochran 2002:1-11). The relevant literature from practical theology, youth ministry and disability theories will be utilised to construct the theoretical framework of the study. Empirical data will be attained by means of qualitative interviews with parents of children or youth with a disability. The results of the empirical investigation will be brought into dialogue with the theoretical insights in Chapter 6 in order to establish whether and how children with a disability are excluded from the activities of faith communities and whether an inclusive congregational youth ministry approach could present a solution. I will schedule structured interviews with the parents of five children and/or youth with a disability. Structured interviews with the parents of five children and/or youth with a disability will be conducted. These children or youth are 35 years or younger. Both sexes and various disabilities will be represented. A quantitative approach (see Murray 2003:2) will also be used to collect data. Five spiritual leaders will be requested to complete a questionnaire in order to investigate the situation regarding children and youth with a disability in the churches. Various denominations, cultures and regions in South Africa will be represented.

1.10 Chapter outline

In Chapter 2 youth ministry which focuses on children and youth with a disability and the families affected by the disability of one of its members, will be discussed from the perspective of a practical theological responsibility. Christian faith communities have a responsibility towards people with a disability. This will function as a theoretical lense to explore the development of youth ministry, what the ministry entails and the challenges it presents. Various approaches will be evaluated. Insights from various disciplines will be utilised to clarify concepts such as “children” and “youth.”

In Chapter 3 the focus is on disability. Different descriptions and approaches are discussed. A historical overview of the understanding of disability is presented. Perspectives from the various sectors of society on this matter will be included. A practical theological approach to people with a disability will be developed with a specific focus on the context of faith communities in the South Africa. The four types of disabilities that are the focus of this study are Cerebral Palsy, Down Syndrome, Autism and Deafness. Data gathered from parents who are raising a child with a disability and their experiences are presented.

In Chapter 4 the focus is on youth ministry. The development of youth ministry from its origin to its currents postmodern status is investigated. This chapter overviews what youth ministry entails, as well as who the term “youth” refers to. The youth sub-culture is investigated, as well as the various challenges experienced by the youth and youth ministry in the 21st century. Four different models of youth ministry are introduces, with focus on the “Inclusive congregational youth ministry” model of Malan Nel.

Chapter 5 presents the empirical investigation of the study. Data is gathered firstly by means of qualitative methods, including a literature overview on the topics in various fields and structured interviews with five parents who are raising a child or youth with a disability. A quantitative survey will also be done to gather statistical data with regard to disability in congregations.

Chapter 6 facilitates a dialogue between the theoretical and empirical data in the study. The processing and interpretation of data is presented in this chapter.

Chapter 7 presents the findings of the study. These findings will be discussed in relation to the theoretical data with regard to youth ministry and disability.

CHAPTER 2

EPISTEMOLOGICAL AND PRACTICAL THEOLOGICAL APPROACH

2.1 Epistemology

This study is done from a postmodern paradigm. As an investigation of the status and experiences of children and youth with a disability in South African faith communities in the 21st century, the search for insight in the matter is context-specific. Influences such as personalisation and subjectivity are acknowledged, whereas the unrealistic notion of objectivity (see Freedman & Combs 1996:5) is disregarded. Objectivity is simply not possible for the human mind, seeing that the combination of experience, personality and culture is unique to each person. Background, history, belief and environment are but a few examples of internalised factors that cannot be separated from the existence, orientation or character of any person. Being familiar with these influences and continuously considering them throughout the study is the only way to present findings as true and honest as possible. The theological positioning of this study is determined by my personal understanding of reality and truth. This investigation was approached from a postmodern worldview, because such an epistemology values the contribution, potential and freedom of life, choice and thoughts of all people irrespective of their status and abilities. Each contributor in the study adds valuable knowledge to understanding the experiences of children and youth with a disability in the context of youth ministry in South African faith communities.

Reflecting on a postmodern worldview is easier said than done. Firstly, a brief description of “modernism” is necessary, before the paradigm of postmodernism can be introduced (Comstock 1989:196). Prior to the era of enlightenment, people lived in times of non-negotiable authority and dictatorship and were left with minimal to no freedom of opinion, speech or choice (Lose 2003:8). Enlightenment liberated people from these circumstances (Van Huyssteen 1999:22) and led to modernism. Modernism brought about the change from ontological notions to that of epistemology (Lose 2003:8). During this time rationalisation and reasoning were

encouraged (Van Huyssteen 1999:22-23). In fact, the era of modernism became known as the “Age of Reason” (see Jun 2015:2). Modernism searched for “absolute truths” (Comstock 1989:196) and categorised science as the single method to obtain knowledge (Van Huyssteen 1999:29). The world consisted of factual truths applicable to each and everybody, irrespective of any other influences (Freedman & Combs 1996:20). Modernism aimed to identify, develop and implement generalised rules and laws across all scopes, manipulating operation according to an established order (Lose 2003:10). People now had the right to contribute to the accessibility of knowledge, whereas obtained knowledge was immediately categorised (Van Huyssteen 1999:23). Characteristics of modernism include “naturalism,” “humanism,” “scientific methods,” “reductionism,” “progressivism,” “view of nature,” “certainty,” “determinism,” “individualism,” and “antiauthoritarianism” (Jun 2014:3).

Under the impression that they had all the answers, the impact of the notion of “absolute truths” in therapeutic efforts was nothing less than dehumanising (Freedman & Combs 1996:21). Therapists took a role of separation, objectivity and control over “patients,” trying to “fix” problems and behaviour by applying the same ineffective methods time and again (Freedman & Combs 1996:3-4). The epistemological philosophy of modernism gave birth to significant scientific contributions. However, the human obsession to structure and even control the world became dangerous to the point of destroying this same world and its people, considering modernistic inventions such as nuclear weapons and pollution (Pieterse 1993:19). As failures increased, modernists realised that this paradigm was limited in its rigid, precise and prescribed paradigms (Freedman & Combs 1996:21). Modernism also stimulated the development of ideologies (Foster 2004:1-7). Foster (2004:1-7) identifies at least three of these ideologies: *objectivity*, *value-freedom* and *absolute truth*. The modernistic reply of freedom of thinking and dictating ideologies once again did not satisfy an inquisitive and evolving world. To encourage notions such as these ideologies do not do away with the fact that the mere existence thereof are limiting to all contributors and subjects. Hence, postmodern thought emerged as modernists realised the shortcomings of their epistemological thinking and declared that there could be other alternatives to discover, explore and reveal the truths of the world. Postmodern influences regard these truths as socially constructed (Lose

2003:52). No consensus exists on a global definition for a postmodern paradigm for the following reasons (Vanhoozer 2003:3):

- the notion of a neutral definition of any sorts is rejected;
- tightly bound terms that totalise concepts is refused;
- David Tracey argues that “postmodernity” does not exist, only postmodernities. Phrasing this paradigm in the plural form excludes an insinuation of a generalised concept.

Despite modernism and postmodern thought being in direct contrast with each other, postmodern paradigms emerged from modernity and have to be understood in relation to it (Shrag 1992:7). Postmodern thought did not develop as modernism came to an end, but in truth emerged in answer to modernistic searches (Van Huyssteen 1999:59). Elements of modernism remained applicable in these postmodern times. Jun (2015:4) summarises the interlinked relation between modernism and postmodern thought as follows:

...I believe that modernism and postmodernism, while being marked by conformism and pluralism, respectively, as their chief characteristics, can be linked to twins born from the same womb, i.e. humanism.

It is clear that rigid modernistic concepts such as unity, totality, sameness and certainty, are rejected by postmodern personalities and replaced with interpretive categories of pluralism, diversity and multiplicity (Schrag 1992:8). Despite the contra-paradigms of modernism and postmodernism, both eras were a step towards the progress of humankind. Postmodern thought do not object the search for truth and reality, but only that of an authoritative truth that is not to be questioned (Gergen 1992:57). The modernist search for certainty is rejected in an attempt to find knowledgeable meaning (Lose 2003:12). The main differences between modernism and postmodern thought can be summarised as follows (Freedman & Combs 1996:20-21):

Modernism	Postmodernism
Absolute truths	No absolute truths
Limited, prescribed approach	Multiple approaches
Concerned with facts & rules	Concerned with meaning
Precision	Interpretation
Universally applicable	Contextual
One dimensional	Multi dimensional
Objective	Subjective
Value-free knowledge	All knowledge has value
Generalisation	Individualisation
Action based on ideologies and theories	Regards rationality & reason as personal
Foundational & primitive	Hermeneutical & liberal
Embraces similarity	Embraces difference
Supports rationality & reason within particular frameworks	Regards rationality & reason as personal

Postmodern investigations rather focus on the exploration of *meaning* (Freedman & Combs 1996:22) and specifically with regard to the experiences of children and youth with a disability in South African faith communities in this study. The contributions of all participants provide knowledge and insight in the matter, without generalising their circumstances or forming meta-narratives (Van Huyssteen 1999:28). It is about questioning findings instead of designating authority to facts (Gergen 1992:57). No truths are regarded as absolute truths (Goldenberg & Goldenberg 2008:341). The notion of a universal rationality is rejected (Vanhoozer 2003:10) and does not feature throughout this investigation. Reason is understood as a contextual and relative affair always situated within specific narratives, histories, traditions, practices and institutions (Vanhoozer 2003:10). This study is conducted from a postmodern paradigm (evolving from modernistic views) and investigates a variety of realities and narratives (see Erickson & Rossi 1981:206) encountered by the parents of children and youth living with a disability in the context of faith communities and ministries.

2.2 Views of reality from a postmodern perspective

The transformation from pre-modern to postmodern paradigms resulted in the views of reality being changed. Reality, prior to the Enlightenment (or the pre-modern era), was perceived as “metaphysical” (see Anderson 2001:15). The theological and philosophical interpretation of reality was primarily mediated by means of sacraments and myths. An appeal to abstract, well defined concepts ensured universal standards that prioritised the acquirement of moral virtues. Therefore reality remained partially mysterious and was only indirectly accessible through signs, symbols and natural phenomena. This meant that theistic revelation had more authority in determining reality than any other influences, such as through traditions and history (cf. Anderson 2001:15).

The view of reality during the modern era was primarily focused on “truth” (see Townsley 2002). The search for truth was founded in describable, explainable realities, which resulted in the development of empirical research. The understanding of God was influenced mainly by developments such as deism and fundamentalism, suggesting that God created the world, but was not involved with the creation any longer. Scripture was interpreted literally and had to correlate with logic, explainable science.

This study is conducted from a postmodern view of reality and my interpretation and experiences of it. Four notions identified within a postmodern perspective of reality include social constructionism, the value of language, narratives sustaining realities and essential truths (Freedman & Combs 1996:22).

- **Social constructionism**

Firstly, realities are socially constructed within the postmodern paradigm. People who live together spontaneously develop shared activities, languages, laws, social customs and diets for example. People “... construct their realities as they live them” (Freeman & Combs 1996:23). Social interaction over time leads to the instinctive sharing of these beliefs or constructs within the interpreting community (see Müller 1996:33). It is these constructs that determine truth and reality in the postmodern era. Postmodern philosophers are of the belief that people’s realities and narratives today are influenced by social convictions and expectations (Lose 2003:53). The

term “social constructionism” is explained as appropriate societal assumptions that the human races are not to question (Lose 2003:13). Social constructionism is explained as follows (Freedman & Combs 1996:1):

Using the metaphor of social constructionism leads us to consider the ways in which every person’s social, interpersonal reality has been constructed through interaction with other human beings and human institutions and to focus on the influence of social realities on the meaning of people’s lives.

In other words, society holds specific norms, beliefs and standards, expected to be complied with by all. There is no single universal definition for social constructionism as a multidisciplinary science. However, social constructionists share a common understanding of the social realities and the analyses thereof (Sremac 2010:9). Although the postmodern vision regards all knowledge as valuable, or is interested in the varying perspectives of inhabitants, “social constructs” are unavoidable and a natural way of living for all societies and cultures. People’s lives are formed by the realities of the society they live in since birth, which influences beliefs, values, institutions, customs, labels, laws and labour divisions (Freedman & Combs 1996:16). Social constructs exist and will continue to exist for as long as people live within their local and extended cultures (Freedman & Combs 1996:17). Social interaction over time determines all disciplines of life (Freedman & Combs 1996:23). Our realities and truth is constructed by these societal orientations (Freedman & Combs 1996:16). People’s social interactions should be studied in order to identify and admit these truths or social constructs within the community and cannot be limited to individual realities (Freedman & Combs 1996:27). Therefore, the social constructs experienced by the parents of children and youth with a disability in faith communities are investigated in this study. Kenneth Gergen (1994:24) summarised five suppositions central to social constructionist analyses:

- The conditions by which the world and its people are accounted for are not determined by the stipulated objects of such accounts. This means that no principles can be assumed or taken for granted. The experiences or statuses of children and youth with a disability can therefore not be generalised, not from the perspective of the affected families, nor from that of the faith communities.

- The understanding of the universe and its people are socially derived results of historical and cultural human interactions. They are not mere factual understandings, especially with regard to linguistic influences. Traditions and beliefs regarding disability is context-specific, based on social interactions and orientations, and should be considered as such.
- The extent to which a given account of world or self is established over a period of time is not primarily dependent on the objective validity thereof. It is rather reliant on the continuous social processes taking place on a daily basis. This study disregards objectivity and investigates the situations of children and youth with a disability within their developing contexts.
- The significance of language is derived from human relations, interactive patterns and communication. It is the sharing of collective interpretations that leads to the formation of understandings, not individual, mental concepts. Although the experiences of the participants in this study are unique, it is true that the social constructs with regard to disability developed from communal beliefs and orientations in a specific society.
- None of the elements of the social constructionist matrix qualifies as “truth.” What is regarded as true is a product of inter-social behaviour and not objective observations of the world. The narratives of the participants are unique, individual contributions and not generalisations of any sort.

Social constructionism disregards objectivity entirely, whereas realities are formed through people’s interactions with one another (Goldenberg & Goldenberg 2008:342). Disregarding the notion of objectivity, this study is based on realities formed through social constructionism. Social constructionism is further divided in two categories, namely micro social constructionism and macro social constructionism (Burr 2015:24-25). Micro social constructionism refers to the occurrence of social constructionism when people interact with one another, whereas macro social constructionism acknowledges the constructive power of

language that derives from expanded social structures, relations and institutionalised practices (Burr 2015:26). These two categories should not be viewed mutually exclusive, but rather as interrelated. Four processes essential to socially constructed realities are distinguished (see Berger & Luckmann 1966):

- Typification: the process of categorising perceptions into types or classes. Examples in this study include faith communities and cultures with regard to disability.
- Institutionalisation: the process through which sets of typifications produce institutions. The institutionalisation of people with a disability remains a reality in this era.
- Legitimation: the process that gives legitimacy to these various typifications and institutes, such as that of people with a disability.
- Reification: the process through which humankind is capable of distancing or separating themselves from the cosmos as if they are not a part of it. An example of reification is an attitude of ignorance towards disability by some that can result in these individuals withdrawing and distancing themselves from the general society.

The science of people's interactions in the process of construction of these norms should be taken into consideration (Freedman & Combs 1996:27). A study by UNICEF (2013b:5) regarding the facts of children and young people with a disability introduces the experience of affected individuals as follows:

Children with disabilities are one of the most marginalised and excluded groups of children, experiencing widespread violations of their rights. Discrimination arises not as a result of the intrinsic nature of children's disability, but rather as a consequence of lack of understanding and knowledge of its causes and implications, fear of difference, fear of contagion or contamination or negative religious or cultural views of disability. It is further compounded by poverty and social isolation, humanitarian emergencies, lack of services and support, and a hostile and inaccessible environment. Too often, children with disabilities are defined and judged by what they lack than

what they have. Their exclusion and invisibility serves to render them uniquely vulnerable, denying them respect for their dignity, their individuality, even their right to life itself.

Social constructionism is pertinent in the disability community. From the earliest times people with a disability were misunderstood, which resulted in severe discrimination, stigmatisation, exclusion and sometimes even death (see Martz 2004). It is this combination of social, cultural and attitudinal social constructs regarding people with a disability that often cause more challenges to the affected group of people than the disability itself (Philpott & McLaren 2011:3). In the African context persons with a disability are often perceived as *cursed* and should not be alive or living within the community (Eskay et al 2012:478). Social constructs are revealed by listening to people's narratives within their contexts and cultures (Freedman & Combs 1996:33). General social constructs regarding people with a disability include that they do not feel and think as others do, that they are charitable and always in need of assistance, that they cannot function independently and that they should be pitied. However, these social constructs are often related to a specific type of disability and will be discussed in more detail in Chapters 3 and 6 of this study.

- **The role of language**

Secondly, the realities of the participants of this study are communicated through speech, and in essence language. Language plays a major role in the constitution, reflection and interpretation of people's narratives and should be considered as an influential factor (Freedman & Combs 1996:27). The value of language is described by Freedman & Combs (1996:28) as follows:

Language is capable of becoming an objective repository of vast accumulations of meaning and experience, which it can then preserve in time and transmit to following generations... Language is capable of "making present" a variety of objects that are spatially, temporally, and socially absent from the "here and now." ...Through language an entire world can be actualised at any moment.

Living in a language rich world and country, language should be appreciated as one of the single most valued communication mediums. South Africa has eleven official languages (Statistics South Africa 2011:21-24), a fact that can also cause challenges in conducting this study (See Point 1.6). Doing a study in such a language rich country calls for communication in a language that both parties are fluent in, such as English or Afrikaans. However, chances are that participants might not be fluent in either of these languages, in which the services of an interpreter will be engaged. Languages as the only tool people have to share their realities and truth with others is indicative of an inadequate communication method: the story told and the story heard might differ. Each person has a unique frame of reference that influences their perspective on reality. Therefore, the formation of meaning of a message or narrative will always be determined by the people participating in the conversation; or between the text and its reader(s) (Freedman & Combs 1996:29). A new reality is created every time people communicate with each other (Freedman & Combs 1996:29). Humankind is simply not capable of grasping truth and reality completely. When realities are shared by means of language, the meaning of the story or message is instinctively impacted upon. The intended message and the interpreted version thereof will never be exactly the same, due to different views of reality, experiences and the interpretations of words and phrases.

Lindbeck (1984) proposes a “cultural-linguistic” approach to religion that emphasises the aspects in which religions resemble languages together with their correlative forms of life, similar to culture. Regulative theories of church doctrines are understood as communally authoritative rules of discourse, attitude, and action, not as truth claims or expressive symbols. He found that people perceived God differently in different communities, due to the meaning of the term “God” as constituted by language (1984:114). Consequently, these rules can have different meanings in different contexts, meaning that doctrines can be regulatory or reconciled without any change in themselves, depending on the situation. This study follows the cultural-linguistic model as a theoretical point of departure because, with the Bible used as primary source, it explores the narratives of parents raising a child with a disability in Christian faith communities, as impacted by their own histories, culture and social environments. The same is to be expected with the meaning of key terms such as “disability” in different communities, as well as people’s understanding

of the term and the effects thereof, with regard to the experience of their children with a disability within their specific societies and faith communities.

In fact, the influence of language on reality is unique when it comes to people living with a disability. People with a disability spontaneously formed a sub-culture, based on their commonalities and interests (Brown 2003:5):

People with disabilities have forged a group identity. We share a common history of oppression and a common bond of resilience. We generate art, music, literature, and other expressions of our lives and our culture, infused from our experience of disability. Most importantly, we are proud of ourselves as people with disabilities. We claim our disabilities with pride as part of our identity.

The disability sub-culture resulted in various rules and regulations with regard to language and etiquette (See Point 1.7). The purpose of the classification of these terms and etiquettes is to be respectful to people with a disability and to treat them like one would any other person. It is of the utmost importance to familiarise myself with these terms before I conduct the empirical investigations. Disability-appropriate language differs between communities, whereas a specific society's view of disability will also affect the use of correct language. It is a reality that most people, including the families of people with a disability, as well as the pastoral personnel of faith communities, are not aware of this code of language and etiquette and its correct use. During the interviews with participants who live with children with a disability whom are often non-verbal and not able to express themselves through language, the value of language once again became clear. Although the meaning of a message from its presentation to its interpretation can differ, language remains the *only* tool to transfer the ideas and thoughts of one person to another. Language is a valuable tool in exploring the realities of families raising a child with a disability within the context of South African faith communities.

- **Metaphor of the narrative**

Thirdly, stories organise and maintain realities, as explained by Freedman & Combs 1996:29-30: "If the realities we inhabit are brought forth in the language we use, they are kept alive and passed along in the stories that we live and tell." In other words, the only reason people are aware of historical occurrences and figures, world

shaping events and news, is the fact that these stories were told and retold repeatedly, both orally and in writing. In the postmodern era and in this study, narratives are to be distinguished from storytelling. Whereas a narrative refers to narrators sharing their experiences with others, storytelling is the repeated telling of a story by a person other than the narrator (Fried et al 2000:695). Narratives are not shared without purpose, but rather to reflect the essence of human life (Müller 2000:9-10). Narratives and the sharing thereof become the platform that shapes and provides meaning to a person's life when put into perspective (Ricoeur 1991:73):

After all, do not human lives become more readable [*lisibles*] when they are interpreted in function of the stories people tell about themselves? And these "life stories," are they not rendered more intelligible when they are applied to narrative models – plots – borrowed from history and fiction (drama or novels)? The epistemological status of autobiography seems to confirm this institution.

The narratives encountered in this investigation provide insight in the lives of families raising children with a disability, with specific reference to their experience in the context of faith communities. The telling and retelling of personal stories provide a person the opportunity to create and transform their identity, through the selection and connection of life events and facts (Demasure and Müller 2006:412). However, this is not a therapy investigation and participants did not get the opportunity to retell their narratives in search of transformed realities and identities. The purpose of listening to the narratives of the affected families is to make a difference in the lives of these children and youth with a disability from a practical theology point of view, based on the knowledge gained from interviews with the participants.

The content of a story is not organised from beginning to end and can be constructed in multiple ways depending on the storytelling choices of the narrator. For narrators, it is important to be selective of what the audience is told when in order to ensure that the story or message is conveyed in such a manner that their ideas or thoughts are communicated clearly. The way in which the story is narrated influence the perceptions of the listeners. Because of this constructive characteristic of stories, narratives reveal concepts about narrators, as well as about the discourses specific to their society and context (Demasure & Müller 2006:412). The listeners get insight

into the life of the narrators and the world they live in. In effect the narrators construct and develop a “narrative identity” (Ricoeur 1991:73). Elements of the world they live in with its various role players are also revealed and called the “social narrative” (Demasure & Müller 2006:412). Therefore, in practice, the concept of a narrative identity is not only applicable to a person, but also to a social group. The social narrative refers to the various people who interact in the co-construction of a narrative identity. The meaning of a narrative is also influenced by the audience and their contexts and perspectives (Gerkin 1991:20). Due to the variability of the construction of narratives, multiple meanings and interpretations become a possibility. No narrative identity is set in gold, which leaves the narrator and the audience with various interpretative and understanding options. This liberating development ensures the transformation of the lives and experiences of the narrator and the listener(s) (Demasure & Müller 2006:413).

For the purpose of this study, the narrative identities and social narratives of all participants need to be interpreted in an attempt to improve the inclusivity of youth ministry to children and youth living with a disability. The narratives of families raising a child with a disability will be explored by means of structured interviews. As these narratives develop during the interviews, key influences such as social constructs and cultural orientations will be revealed with regard to disability. Commonalities identified during these interviews will indicate shared frustrations and experiences regarding disability in faith communities. These findings will be used to guide faith communities in the required transformation and developments of effective ministering to children and youth with a disability.

- **No “essential truths”**

The fourth and last element identified with a postmodern perspective on reality is the rejection of “essential truths” (Freedman & Combs 1996:33). In the light of the discussions above (namely social constructionism, the influence of language and the sharing of narratives), it is clear that this study is in search of meaning and not of truth. Considering the variables and influences, the study opts for the multiple possibilities and interpretations of the narratives and realities of families raising a child or youth with a disability within the contexts of local faith communities. Ultimately, interpretations of these narratives from different points of views create different meanings (Freedman & Combs 1996:33). The result is that there is no one

single truth. What is perceived as “true” is somewhat fluid and negotiable, depending on the narrative and social identities of a person. The conclusion is that “essential truths” do not exist. However, people tend to accentuate a particular version of themselves, depending on their experienced social constructs, known as a “preferred self” (Freedman & Combs 1996:35). The “preferred self” is reliant on how people constitute themselves through interaction with others. From multiple options, people prefer a particular version of themselves. Irrespective of the preference of a particular self, an “essential truth” or true self does not exist. People’s understanding of themselves change as the world around them develops and changes. Different selves come forward in different contexts, with no one self truer or more real than another.

This extended approach to reality is not an isolated attempt in order to explain the methodological positioning of this study, but rather a lifestyle. Interactions with the various participants are unique (Erickson & Rossi 1979:233) and each an exploration in search of knowledge and meaning for ministering to children and youth living with a disability. The true effects of social realities cannot be underestimated (Freedman & Combs 1996:36). Throughout this study the various social constructions, language, stories and the absence of essential truths will be considered as a basis for interpretation of the experiences of participants.

2.3 Postfoundationalism

In order to understand postfoundationalism in itself, it is important to familiarise oneself with the establishment and development of this notion. As postmodern thought stepped forward in reaction to modernism, so did postfoundationalism develop in reaction to the discourses of foundationalism, antifoundationalism and nonfoundationalism. In fact, postfoundationalism is positioned within the broader discourse of foundationalism (see Müller 2011) and is easier to understand by firstly describing what it is not. Hence, a short description of each of these models is a justified introduction to postfoundationalism.

In search of platforms for the claims of knowledge, modernity found identity in the model of foundationalism (Van Huyssteen 1999:61). During the era of modernity, knowledge was based on fixed foundations that were not allowed to be questioned

(Van Huyssteen 1999:64). The theological consequence of foundationalism was biblical literalism (literal interpretation of the Scripture), whereas religious experiences on the other hand were personal and unique, that resulted in a distinguished discipline. Theology was isolated from all other sciences (Van Huyssteen 1999:62). Foundationalism is generalised, global understandings that do not allow for individualism, opinions or alternatives. The world evolved around authoritative truths and eliminated a democracy of any sorts (Van Huyssteen 1999:62). Due to these rigid, factual orientations, limited opportunity exists for cross disciplinary dialogues leading to minimal collaboration of investigations and research (Müller 2009:202). Müller (2011) summarises the epistemological paradigm of foundationalism as follows:

The foundationalist approach takes it for granted that absolute truth is available to all of us. This would be a perspective faithful to the true foundation and which therefore would provide us with the 'God's eye view'. A theory built on such a presumption could be referred to as a 'universal rationality'. This rationality is based on the idea of a universe of knowledge that functions as an overarching frame of reference. Accordingly, there is only one theoretical truth and that must be pursued.

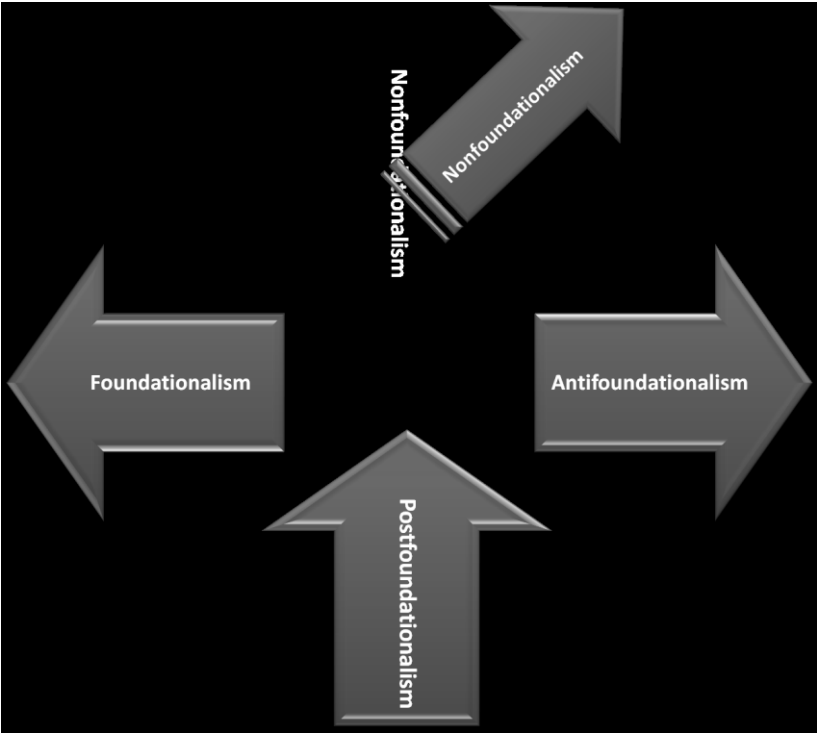
On the other hand, antifoundationalism aims to remove the superiority of science in society through recognition of the impact of dogmatism and science's exclusive interest in particular communities (Van Huyssteen 1999:28). The result is that scientific formalities are easily replaceable by developments more relevant to the context of its time, by means of modular structures and restrictive language (cf. Van Huyssteen 1999:28). Therefore, in antifoundationalism foundations do exist, but are only useful when it can be practically implemented in specific contexts and timeframes.

Non-foundationalism developed in strong reaction against the modernistic notion of a universal reality and acknowledges the distinct realities of historical cultures and contexts (Van Huyssteen 1999:63). Non-foundationalism (or the "diverse perspective") opposes foundationalism and claims that "...fundamentals do not exist and that we only have a diversity of opinion" (see Müller 2011). Human knowledge revolves around social phenomenon constructed by the practical impacts of ideas in a matrix of beliefs (Van Huyssteen 1999:64). Nonfoundationalism focuses on local

contexts and personal understandings of reality from a theological perspective (Van Huyssteen 1999:63). Nonfoundationalism results in many complexities, including people to be unguided, lack of stability, security or a frame of reference (Van Huyssteen1999:65-66). The consequence is radical relativism and justification of reality (Van Huyssteen 1999:80). Interdisciplinary dialogue also becomes challenging: “...constructive discussions are difficult in a situation where everything is relative and subjective” Müller (2009:203). Müller (2011) criticises the pastoral value of the nonfoundational and antifoundational paradigms as follows:

The non-foundational or anti-foundational position makes a pastoral understanding and intervention even more difficult, because there is skepticism about any effort to create mutual understanding. Understanding or knowledge according to this approach is always diverse. Such an approach will create more tolerance, which is always helpful for an effective pastoral ministry, but on the other hand, a non-foundational approach tends to be relativistic and therefore without any direction. This can easily create a helpless situation where stories are heard, but where there is a lack of development into alternative options.

The following figure demonstrates the polarity of the concepts of postfoundationalism, in an attempt to make the explanation of these elements and the relations between them more visual (see Meyer 2015:60):



Postfoundationalism is a notion of reality that mediates a better understanding of challenging epistemological and hermeneutical concepts by means of informed and considered discernments (Van Huyssteen 1999:33). Theologically, postfoundationalism advocates for a holistic approach to knowledge. Interpretation and understanding is mediated "...not through foundationalist notions of revelation, tradition, or inspired texts, but through responsible judgements about the explanatory role of those beliefs that are part of our interpreted religious experience" (Van Huyssteen 1999:115).

Postfoundationalism has an inclusive nature and considers various disciplines from a non-judgemental point of view (see Meyer 2015). Müller (2011) accentuates the interdisciplinary characteristic of postfoundationalism as follows: "The postfoundational understanding of theology puts *inter alia* the interdisciplinary aspect of research very much in the focus." Theological knowledge is enriched by learning from and considering other fields when busy with investigations such as this one. The conversation between these disciplines and contexts (or interdisciplinary dialogue) occurs through transversal reasoning and is explained as follows (Müller 2005:76-77):

... promotes different but equally legitimate ways of viewing specific topics, problems, traditions, or disciplines, and creates the kind of space where different voices need not always be in contradiction, or in danger of assimilating one another, but are in fact dynamically interactive with one another.

A second key concept of postfoundationalism is contextuality (see Müller 2011). Knowledge embedded in local contexts contains discourses of tradition which contributes to the formation of society's epistemologies (Demasure & Müller 2006: 418). People's contexts directly impact on their narratives and realities. Van Huyssteen (2006:25) explains this as follows: "Because of our irrevocable contextuality and the embeddedness of all belief and action in networks of social and cultural traditions, beliefs, meaning, and action arise out of our embedded lifeworlds." This means that the narrative and social identity of a person is a product of personal experiences and realities, in relation to that of others. Without social interactions

between people, all narratives would be meaningless and pointless. In effect, postfoundationalism is an interactionist model of reality, moving beyond the models of foundationalist objectivity and nonfoundationalist relativism (van Huyssteen 1999:130). Additional narratives are generated within such contexts where people can interact rationally and with other disciplines, while the influences of tradition on knowledge are also considered. Therefore, postfoundationalism is a model of transaction. This so called transaction occurs during the interdisciplinary and cross-contextual conversations that determine a relational view of knowledge and reality (Van Huyssteen 1999:174). In other words, meaning derives from dialogue between these different disciplines and contexts and only that. Without this interaction, it would be difficult to gain any knowledge in the first place, or make sense of it in any way. Postfoundationalism therefore lacks an epistemological point of departure, however, people can still trust in their ability to make informed choices (Van Huyssteen 1999:131). The notion of rationality can only be formed when the contextual and interdisciplinary approach of postfoundationalism is applied in real-life contexts and narratives (Müller 2009:204). In this study, the postfoundational approach is followed and applied in the lives and narratives of families who raise a child or youth with disability, with regard to their experiences and statuses in their faith communities. The meaning and impact of the model of postfoundationalism can be summarised as follows (Müller 2011):

The postfoundationalist approach is sensitive for both the danger of relativity and subjectivity in a multiverse rationality and of the rigidity and false claims of the universal rationality. Therefore, it consists of an effort to move beyond both foundationalist and nonfoundationalist claims. For that reason, it is called *post*-foundationalism and not anti-foundationalism or non-foundationalism.

Van Huyssteen (1999) describes the requirements of postfoundational theologians as follows:

- they acknowledge all intellectual work as inevitably contextual and interpreted by personal epistemological experiences;
- they are aware of the imperative to attain an epistemology that moves beyond the boundaries of their personal backgrounds, namely disciplines,

communities, groups, or cultures (cf. Müller 2005:76-77) toward credible ways to engage in interdisciplinary conversations;

- they acknowledge that it is specifically shared traditional resources which are the motivating force that enables interdisciplinary dialogue.

The contributions of all the participants of this study provide insight and knowledge in the statuses and experiences of children and youth with disabilities within faith communities. Understanding that the perspectives of the participants are influenced and determined by their personal contexts and experiences does not reduce the value of their inputs; it only provides an extended perspective into their lives and narratives. In the collaborated search for meaning in this investigation multiple disciplines are consulted, including that of psychology, social development and the health sciences. Lastly, interaction with these various disciplines were made possible by working from familiar histories and backgrounds of the participants, as well as from a theoretical and literature perspective. According to these requirements as stipulated by Van Huyssteen (1999), the departure point of this study is postfoundationalism and specifically postfoundational theology.

2.4 A practical theological approach

As a systematic reflection on the status and experience of children and youth with a disability in Christian faith communities in South Africa, this study is first and foremost a theological investigation. Although various disciplines are consulted throughout this study, it is the common element of Christianity that binds these inputs and findings together as a theological unit (see Schleiermacher 2011:1). Scripture, or the Bible, is used as a primary reference to investigate the responsibility of Christian faith communities towards children and youth with a disability, which is a basic requirement for the purposes of practical theology and youth ministry in particular (Nel 1998:13). Biblical text does not specifically “instruct” Christians with regard to children and youth with a disability, but indicates repeatedly that Jesus interacted with children, as well as with people living with disabilities throughout his earthly ministry. The following Biblical texts are pertinent with regard to disability (see Otieno 2009 and Bayes 2015):

- Matthew 19:13-14: "Then some children were brought to Him so that He might lay His hands on them and pray; and the disciples rebuked them. But Jesus said, "Let the children alone, and do not hinder them from coming to Me; for the kingdom of heaven belongs to such as these;"
- Matthew 18:4-5: "Whoever humbles himself like this child is the greatest in the kingdom of heaven. Whoever receives one such child in my name receives me;..."
- Luke 18:15-17: "And they were bringing even their babies to Him so that He would touch them, but when the disciples saw it, they began rebuking them. But Jesus called for them, saying, "Permit the children to come to Me, and do not hinder them, for the kingdom of God belongs to such as these."Truly I say to you, whoever does not receive the kingdom of God like a child will not enter it at all;"
- Mark 9:36-37: "Taking a child, He set him before them, and taking him in His arms, He said to them, ""Whoever receives one child like this in My name receives Me; and whoever receives Me does not receive Me, but Him who sent Me;"
- Luke 9:47-48: "But Jesus, knowing what they were thinking in their heart, took a child and stood him by His side, and said to them, "Whoever receives this child in My name receives Me, and whoever receives Me receives Him who sent Me; for the one who is least among all of you, this is the one who is great;"
- Matthew 18:10: "See that you do not despise one of these little ones, for I say to you that their angels in heaven continually see the face of My Father who is in heaven;
- Matthew 18:14: "So it is not the will of your Father who is in heaven that one of these little ones perish;"
- Mark 2:1-12: "And they came, bringing to him a paralytic carried by four men. And when they could not get near him because of the crowd, they removed the roof above him, and when they had made an opening, they let down the bed on which the paralytic lay. And when Jesus saw their faith, he said to the paralytic, "Son, your sins are forgiven;"

- Matthew 15:31: “So that the crowd wondered, when they saw the mute speaking, the crippled healthy, the lame walking, and the blind seeing. And they glorified the God of Israel;”
- Mark 8:22-35: “And they came to Bethsaida. And some people brought to him a blind man and begged him to touch him. And he took the blind man by the hand and led him out of the village, and when he had spit on his eyes and laid his hands on him, he asked him, “Do you see anything?” And he looked up and said, “I see men, but they look like trees, walking.” Then Jesus laid his hands on his eyes again; and he opened his eyes, his sight was restored, and he saw everything clearly.”

Based on Jesus’ interaction with children and people with a disability throughout his earthly life, Christians who are followers of Christ and strive to be and act like Jesus did, *do* have an obligation towards both these groups from a Scriptural and theological point of view. Although Biblical authority is preserved, the relevance of tradition and the historical conscience of disability cannot be ignored (see Browning 1991). At the hand of the Gospel, questions are answered with regard to what should be done and how Christians should act toward children and youth living with a disability (see Browning 1991:10). With regard to disability in Christian faith communities and Scripture used as primary reference, this action-reflection practical theology study considers four interrelated and interactive elements, namely interpretive paradigms, experiences, history and the community of memory (see Browning 1991:11). The potential influences of faith and pneumatology regarding the interpretation of these texts are also considered (Heitink 1999:18). Although this is an academic investigation, the relation between tradition, theory and the interpretation of these texts through the work of the Holy Spirit is an actuality (Heitink 1999:192-193).

This study consists of practical theology developments over centuries. Practical theology is not stagnant and remains a developing discipline influenced by various role players, methods and challenges (Woodward & Pattison 2000:4). An overview of the development of practical theology is required in order to understand this investigation and its contribution to the field better. Practical theology was founded in the eighteenth century by Friedrich Schleiermacher who emphasised the theological value of practical theology. He divided the science of theology into three sections,

namely philosophical theology, historical theology and practical theology (see Schleiermacher 2011). It is this theological emphasis of the discipline that is discussed in section 2.2, in order to determine the theological responsibility towards children and youth with disabilities in South African faith communities. Practical theology was mainly regarded as the practice of leadership within the church until the twentieth century in Europe (Dingemans 1996:82). Although practical theology does not exclusively refer to the leadership of the church anymore, leadership remains an integral component in this field. The study aims to question five leaders of faith communities about the status of children and youth with a disability in their congregations. An objective of the study is to increase awareness of disability and the effects thereof among church leaders in order to facilitate more accessible ministries. Increased inclusivity can only be implemented once traditional orientations towards disability in the faith community are understood and challenged. Woodward & Pattison (1994:9) describes practical theology as follows:

Pastoral / practical theology is a place where religious belief, tradition and practice meets contemporary experiences, questions and actions and conducts a dialogue that is mutually enriching, intellectually critical, and practically transforming.

Based on the common ground of ministerial practices practical theology refers to the classification of various disciplines together. It has developed to become a theology of action, closely linked to the social sciences (Heitink 1991:1). From a postfoundational point of departure (see Van Huyssteen 1999:33), a multi-disciplinary approach is followed in this investigation and includes contributions from social development, psychology, education and the health sciences. This multi-disciplinary component is presented in accordance with Müller's (2005:82) fifth of his seven movements that is required for quality practical theology investigations. In order to increase the accessibility of faith communities to children and youth with a disability, the theological relation of theory to practice is considered carefully. It is understood that the prioritisation of theory will result in an unsubstantial practice preoccupied with methods, techniques and ministerial strategies. However, the accentuation of practice above theory will lead to pragmatic results, rather than prophetic revelation and involvement (Anderson 2001:14). The purpose of this study

is to motivate actions in faith communities to provide improved, inclusive ministries and actions to children and youth with a disability, especially from the perspective of youth ministry.

Practical theology is set apart from dogmatic theology and Christian ethics based on three elements (Osmer 1999:126):

- the performance orientation of practical theology that aims to determine the best performance for a particular practice in concrete circumstances;
- the implementation of a theory of transformation guiding the praxis of Christian life over a period of time;
- a practical theological hermeneutic of the field in which praxis occur, identifying the participants involved in moral time and space.

These three elements clearly manifest in this study, seeing that the aim is firstly to enhance the performances of youth ministry by advocating for more effective and inclusive practices to children and youth with a disability in the context of their faith communities. Secondly, the findings of the investigation can lead to the transformation of faith communities and leaders with regard to theories about people with a disability in their congregations. Lastly, an investigation of the experiences of parents with children and youth with a disability in faith communities can lead to the facilitation of cooperative relations between these parties in order to optimise effective youth ministry to this group of individuals. At the end of the day, it is the sincere presence and interest in the lives of these children and youth with a disability that will grow into transformed understanding of and practices for disability within faith communities (see Osmer 2008:34):

It is a matter of what is going on in the lives of individuals, families and communities... It is a matter of opening ourselves to the forming and transforming Spirit of God who remakes us in the image of Christ within his body. Unless we first learn to attend to, we cannot really lead.

The ultimate objective of this study is to bring about change in the lives of children and youth living with a disability from a practical theology point of view. Transformation is mediated on five different levels (see Browning 1991:105-108):

- visional: to suggest a new understanding of children and youth living with a disability;
- obligational: to form new interpretations of traditions and practices with regard to disability;
- tendency-need: to allow families raising a child or youth with a disability to deal with their needs in a more conscious and intentional manner;
- environmental-social: to transform society's perspectives of disability by increasing intentional reflection on and awareness of theological orientations regarding the matter;
- rules and roles: to change concrete patterns of living for families raising a child with a disability.

Therefore, this study is dually theological: Christian tradition approaches to disability are primary resources, whereas practical theologically the objective is to continuously contribute to the Christian understandings with regard to children and youth living with a disability in local faith communities. A practical theological perspective is followed to determine the approach of faith communities to implement Scriptural theories regarding children and youth with a disability into a postmodern praxis under pastoral leadership (see Müller 1996:1).

Truthful practical theology entails a cycle of responsible research with context as the starting point, followed by theoretical consultation and back to context again (Browning 1991:34). Being a theology of action that requires a spirit of presence in the lives of the identified participants (Osmer 2008:34), the purpose of this study should not be understood as a form of therapeutic investigation or intervention with the families of children and youth living with a disability. It rather is a combined qualitative and quantitative investigation to facilitate understanding of the contexts of this group of individuals in order to facilitate an enhanced inclusion in the ministries of their faith communities. The purpose is to investigate the existing statuses and experiences of the target group within the context of faith communities, followed by the consultation of theories and literature regarding this matter. In the final chapter the knowledge gained from both the empirical and theoretical investigations will be used to guide these same faith communities (contexts) to make youth ministries

more accessible and inclusive to children and youth with disabilities. Hence, the full cycle of responsible practical theological investigation is completed.

This study aims to investigate the inclusion of children and youth with a disability in their faith communities, to evaluate the presence of faith communities in the lives of these young people and their families and to establish ways to increase and secure their rightful place in the church and youth ministry specifically.

2.5 Biblical and theological perspectives on disability

In a study in Kenya it was found that one of the most important causes of stigmatisation, prejudice of and discrimination against people with a disability is ironically religion related (see Otieno 2009). Various theological themes created obstacles for people with disabilities in the past (Eiesland 1994:73-74), including:

- disability often being regarded as punishment for sin;
- disability regarded as suffering that must be endured in order to purify the righteous;
- people with a disability is perceived as “charitable,” a stigma preventing them from full social, economic, and political participation;
- the healing narratives in the Gospels have been viewed as controversial, as the healing stories of Jesus was perceived as denoting a moral imperfection of people with disabilities (see Chae 2002).

It is interesting to see how the Bible contributed to these misunderstandings of disability. Disability is attributed to God. The general view of the Old Testament writers is that God brings disability as punishment for transgressions for sin or as an expression of God's wrath for people's disobedience. It is seen as a curse and as a result of unbelief and ignorance (see Otieno 2009). Examples of texts and Biblical narratives which views disability as a punishment inflicted upon an individual or family by God as a result of sin include (see Chae 2002):

- Leviticus 26:14-16: “I will bring upon you sudden terror, wasting diseases and fever that will destroy your sight and drain away your life.” This text forms part of God’s punishment of the Israelites’ disobedience;

- in Judges 14 – 16 Samson’s eyes is his downfall when he sees a Philistine woman, desires her and demands that she is brought to him. These same eyes that caused his sinfulness, is gorged out by the Philistines to punish him;
- Proverbs 30:17 warns that eyes being used to disrespect parents will be plucked out by birds of prey;
- God inflicts disability on the unfaithful King Jeroboam in 1 Kings 13:4;
- In John 9:1-3 the disciples also connect between disability and sin: "Rabbi, who sinned, this man or his parents, that he was born blind?" This question implies that disability was the punishment meant for some unspecified sin;
- John 5:14: When a man is healed from his paralysis by Jesus at the pool of Bethesda, He said to him: "See, you are well again. Stop sinning or something worse will happen to you." These words of Jesus unquestionably a connection between the man's disability and his sin(s);
- When Jesus healed the paralytic man lowered through the roof in Mark 2:1-12, He said to him: "Son, your sins are forgiven" before the miracle of healing was performed. Once again the connection between disability and sin is accentuated.

Throughout the Bible, the metaphoric use of disability reinforces the opinion that disability is caused by disobedience to God (see Chae 2002). For example, deafness symbolises spiritual stubbornness or wilful refusal to hear and obey the Scripture, visual impairment is viewed as a symbol of ignorance, sin, and unbelief. There is also a connection between physical disability, perfection of the body, and moral impurity in the Bible. In fact, physical imperfection was regarded as an impediment to exercise priesthood. The theological meaning of perfection has historically included physical flawlessness, and many religious orientations make a direct connection between physical perfection and spiritual beauty (see Eiesland 1994). The perfection of the body is a symbol of the perfection of the soul (see Melcher 1998). Based on these Biblical perspectives of disability, ancient Greece and Rome believed in the idea of the “beautiful body” and promoted the disposal of any deformed human being. Beautiful was “good,” whereas deformity and impairment was “bad” (see Shafer 2016).

The influence of Scripture on this antagonistic attitude towards people with a disability is summarised as follows (Chae 2002):

There are more than seventy (70) passages where Jesus cures an illness, raises a person from the dead, or takes away a disability. Of these, approximately twenty-six (26) scripture passages and stories about people with disabilities such as the paralyzed, the blind, the lame and the deaf are in the gospels. With the exception of Bartimaeus, the other disabled people in the gospels are nameless. Most people of disability are poor, unemployed, beggars, or servants. They are usually patronized, treated with contempt, publicly rebuked and humiliated, screamed at and spoken at, instead of spoken to.

Otieno (2009) states that the Bible also plays a role in the postmodern, inclusive view of disability and argues that the inclusion of people with a disability is seen in God's plan for the Israelites and in His salvation plan. In fact, God promises to reward people who endured hardship on earth, including people with a disability. God's eternal kingdom will favour the weak, the lame, and the outcasts. God did not leave people with a disability behind when he liberated the Israelites and neither should Christians. Otieno (2009) refers to the Parable of the Great Banquet in Luke 14 which accentuates the inclusion of people with disabilities in God's salvation plan. The invitation of this group of individuals to the Banquet is accentuated, implying the inclusion of people with a disability in God's kingdom.

According to Rayan (1991:28) the narrative of Mephibosheth in 2 Samuel 9 also illustrates the restoration of a person with a disability to normal life. Mephibosheth (the son of Jonathan, King David's great friend), was lame in both feet, following an accident he had as a child. Due to his disability, he was rejected and excluded by society, who regarded him as useless. However, King David did not share society's opinion on the matter and took care of Mephibosheth for the rest of his life. This act of kindness is regarded as a reflection of Jesus Christ's compassion and an example of a narrative of inclusion of a person with a disability in normal life. This inclusion restored Mephibosheth's self-worth, identity and societal image.

By coming close to people with a disability, healing them, and even touching them, Jesus challenged and transformed the negative perspective of people living with disabilities in the Biblical society (see Chae 2002):

In this respect Jesus was a real healer, not just a medical doctor or a miracle maker. Jesus says clearly, "It is not the healthy who need a doctor, but the sick... I have not come to call the righteous, but the sinners" (Mt. 9:12-13). That is the real healing art. To Jesus there is no sharp difference between the righteous and the sinners, between the healthy and the sick. This principle is applied to people with disability, too. To him there is no difference between people with disability and people with ability in religious terms. He was willing to come close to the sick and people with disability because they needed him.

The perception that the healing narratives of Jesus are denoting a moral imperfection of people with disabilities is changed. A clear distinction between "healing" and "curing" brought about this change in perspective: whereas "healing" refers to the removal of oppressive systems (social constructs), "curing" refers to the physiological reconstruction of the physical body. Jesus' ministry was one of healing and not of curing (Ecumenical Disability Advocates Network 2006:4):

In this kind of theology, disability is a social construct and healing is the removal of social barriers. From these perspectives, the healing stories in the gospels are primarily concerned with restoration of persons to their communities, not the cure of their physiological conditions. The healing acts of Jesus, for example, the healing of the blind man in John 9 or the man with leprosy in Mark 1:40-45, who asks Jesus to make him clean, suggest the ways in which Jesus restores people to their community. In like manner, in Mark 2:1-12, Jesus met the paralytic and forgave him his sins. Forgiving sins here means removing the stigma imposed on him by a culture in which disability is associated with sin or where someone is ostracized as sinful and unworthy of his society's acceptance.

In postmodern times, theology tends to collaborate with human rights movements, recognising a person's dignity, regardless of religion, race, gender or religion. Discrimination against people with a disability is criticised, whereas the social inclusivity of this group of individuals is motivated and advocated for. Accordingly,

Eiesland (1994) developed a liberating theology by exploring the concept of the "Disabled God," to make sense of the relationship between disability and theology. Social constructs regarding people with a disability are challenged, whereas the divine body image is presented as imperfect. Eiesland connects Jesus' resurrected, injured body (see Luke 24:36-39) with disability and proposes the concept of the "Disabled God." If God is seen as having a disability, the negative views of people with a disability would change dramatically. The concept is explained as follows (Eiesland 1994:45): "The resurrected Christ making good on the promise that God would be with us, embodied, as we are, disabled and divine." Eiesland advocates that disability is more than often experienced as socially constructed and consequently transformable.

These Biblical and theological perspectives on disability provide an insight into the postmodern attitude of society towards people living with a disability. The result is that it is to be expected that these perspectives will feature in the narratives shared by the parents of children and youth living with a disability as encountered in the empirical investigations of the study.

CHAPTER 3

DISABILITIES

3.1 Introduction

Disability is a vast and complex topic which is investigated in a variety of academic fields. This chapter presents a brief overview of what disability entails and how the disability sector operates. This basic information is necessary in order to understand the types of disabilities and the effect of a specific disability on a person, whether it is a physical and or mental impairment. Living with a disability constitutes a unique situation for the affected child or youth, as well as for the family and care givers (Philpott & McLaren 2011:3). As a practical theological youth ministry study, the approach is interdisciplinary and postfoundational (see Chapter 2). Practical theology requires cross-contextual investigation (see Van Huyssteen 1999:61). Although interdisciplinary investigation is complex, it is essential for remaining true to the notions of social constructionism and postfoundationalism (see Müller 2005:85).

The objective of this study is to determine the accessibility of faith communities, specifically youth ministries, to children and youth living with a disability. Along with practical theology and youth ministry, this chapter makes use of insights also from the following disciplines:

- health sciences: insights regarding disabilities, the types of disabilities and the services provided by the health sector;
- sociology: insights with regard to social awareness and the orientation of children and youth living with a disability;
- developmental psychology: insights regarding educational efforts and interventions with children and youth living with a disability;
- legal studies: insights regarding legislative progress and the social and political responsibility towards children and youth living with a disability.

3.2 Defining disability

Generally, disability is understood as impairment, “defect,” “abnormality” or condition. However, explanation of disability is simplistic in contradiction to what is regarded as socially accepted disability terminology in the postmodern era. The World Health Organisation (2001:3) established the International Classification of Functioning, Disability and Health (ICF) in 2001, in which “disability” is described as follows:

A disability is a condition or function judged to be significantly impaired relative to the usual standard of an individual or group. The term is used to refer to individual functioning, including physical impairment, sensory impairment, cognitive impairment, intellectual impairment mental illness, and various types of chronic disease.

Disability is conceptualised as a multidimensional experience for the person involved (World Health Organisation 2001:16). The condition can have an effect on the organs or body parts. It can also affect the person's possibilities of participating in various areas of life. Three dimensions of disability are recognized in the ICF: body structure and functioning (or the impairment thereof), activity (or the restriction of activity) and participation (or restrictions with regard to participation) (World Health Organisation 2001:12-17). The classification recognises the role of factors such as the physical and social environment and highlights three factors specifically: physicality, the severity of the condition and environmental influences, and the execution of daily living activities and participation (World Health Organisation 2001:3). According to the World Report on Disability (2011:5) it is understood as conditions that affect the functioning of people on three levels:

- impairment: when a person experiences problems regarding body functioning or alteration in body structure, such as deafness and paralysis;
- limitations to activity: when a person finds it difficult or impossible to execute activities, like with eating and walking;
- restrictions of participation: when a person is restricted in or excluded from various facets of life, for example, access to transport.

Describing disability is a complex matter. People who live with disability see the notion of “disability” as a social construct. From this point of view the British Council

of Organisations of Disabled People and Manchester City Council, describes disability based on the social model as follows (The Disability Equality Scheme and Action Plan 2009 – 2012:7):

Disability is the disadvantage or restriction of activity caused by a society that takes little or no account of people who have impairments, and thus excludes them from mainstream activity. Impairment is certain individual appearance or certain functional limitations of the mind, body or senses.

The different approaches to disability are worked out further and discussed in section 3.2. In practice there is no single, universal legal definition of disability. This brings about challenges for gathering international disability statistics and refining laws against discrimination (see Degener 2006). South Africa legislation prohibits discrimination against people with a disability, but it does not define disability (see Bick 2011). Since there is no single, legal definition of disability in the South African context, in practice disability is defined differently by various entities and departments:

- **Employment Equity Act (Act No. 55 of 1998:3-5)**

People with a disability mean "people who have a long-term or recurring physical or mental impairment which substantially limits their prospects of entry into, or advancement in, employment."

- **Social Assistance Act (The Social Assistance Act No. 13 of 2004:8)**

A person with a disability is someone who is "owing to a physical or mental disability, unfit to obtain by virtue of any service, employment or profession the means needed to enable him or her to provide for his or her maintenance."

- **Section 18(3) of the Income Tax Act No. 58 of 1962**

Disability is defined as: "...a moderate to severe limitation of a person's ability to function or perform daily activities as a result of physical, sensory, communication, intellectual or mental impairment, if the limitation has lasted or has a prognosis of lasting more than a year; and is diagnosed by a duly registered medical practitioner in accordance with criteria prescribed by the Commissioner." The criteria of the Commissioner as set out in the Form ITR-DD Confirmation of Diagnosis of Disability for the purposes of the Income Tax Act, include disability in the areas of vision,

hearing, communication/speech, and physical, intellectual or mental capacity and a description of what “disability” is considered to be in each area.

- **The Mental Health Care Act (The Mental Health Care Act No. 17 of 2002:8)**

According to the Mental Health Care Act people with "severe to profound disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (UNCRPD 2007:7).

- **White Paper on the Rights of Persons with Disabilities (WPRPD 2015:17)**

The White Paper discusses the complexity of defining disability in detail. The various definitions emerged from specific historical contexts (namely Apartheid versus democracy) and discursive formations need to be considered throughout. No unified definition of disability is to be found either globally or locally. The challenge to define disability is described as follows: “The struggle to define disability which accurately and realistically encompasses the lived experience of persons with a disability is a historical one, characteristic of power dynamics, prejudice and social exclusion of those who do not ‘belong’” (WPRPD 2015:17).

Despite the differences in definitions of disability, some common elements can be identified. The following commonalities form the basis of the understanding of disability in this study:

- the presence of impairment;
- internal and external barriers prohibiting full and equal participation;
- a focus on the abilities of the person with a disability;
- loss or lack of access to opportunities due to environmental limitations and/or negative orientations of society;
- disabilities can be permanent, temporary or episodic.

3.2.1 Approaches to defining disability

An article in which definitions and terminology with regard to disability as used over the years were described, was released by the Government of the Western Cape (GWC) in 2014 (see GWC 2014). The following models identified:

- *the biomedical definition*: the disability is regarded as an illness and a “condition” that is to be cured if possible; if the condition is not curable the person is removed from society;
- *the philanthropic definition*: disability is regarded as a charitable cause, and people with disabilities are pitied and admitted to care institutions;
- *the sociological definition*: disability is regarded as a deviation from societal norms and performance;
- *the economic definition*: due to limited work productivity and additional costs related to disability, people with a disability constitute a financial and economic burden;
- *the socio-political definition*: this approach sees disability within context and limits stigmatization, classification and discrimination rather than emphasise people’s limitations and inabilities; disability is seen as a social construct; the effects of the disability on a person is more likely to be inflicted by the social environment than the disability itself.

The socio-political definition is the most “politically correct” and fits best is a postmodern paradigm. However, even in the 21st century, the two generally accepted approaches are the medical and social models of disability. These two models will now be discussed and compared:

The point of departure of the medical model is that disability has historically been seen predominantly as a health and welfare issue (see The Integrated National Disability Strategy White Paper 1997). Governmental intervention was restricted to welfare institutionalisation, whereas civil society was to provide care for people with a disability. Organisations were usually controlled by non-disabled people who provided services to people with a disability. The objective was firstly to provide treatment. Secondly, alternatives were sought to a life of dependence on charity or a life of people with a disability being hidden from society by their families. The

emphasis was on their dependence and impairments. Interventions were based on assessment, diagnosis and labelling. Therapy programmes developed separately and through alternative services. General needs were not taken into consideration. This notion of disability as a health and welfare issue permeated all areas of society and resulted in the isolation of people with a disability and their families. State dependency disempowered people with a disability and reduced their potential to contribute equally to society. The medical model of disability led to limited access to fundamental social, political and economic rights for people with a disability. The disadvantages of the medical model of disability include (see The New Health Guide 2014):

- emphasis of the limitations of individuals with a disability;
- the social degradation of people with a disability;
- excessive focus on expensive (and often inaccessible) medical care;
- contributing to the notion that people with a disability are pitiful, which results in a negative, disempowering perception of this group of individuals.

On the positive side the medical model of disability is beneficial to persons with a disability who experience pain and discomfort (see Sullivan 2001) since in such cases medical intervention is a basic requirement that can improve the quality of life for both the persons affected and for their caregivers.

The Integrated National Disability Strategy White Paper (1997:15) describes the social model of disability as the collective disadvantage of people with a disability caused by a complex form of institutional discrimination. This discrimination is fundamental to the way in which society thinks and operates. The social model is based on the idea that the social construction of discrimination against people with a disability leaves them in a worse position than their physical impairments alone would have. The disability rights movement sees the solution in the education and restructuring of society's attitude and view of disability. This requires a paradigm shift with regard to how disability is constructed. Examples of this approach are the following ideas: that it is the stairway that disables the wheelchair user rather than the wheelchair, and that the defects in the design of everyday equipment are what cause the difficulties, not the ability of the people who use it. The social model

emphasises the abilities and capabilities of people with a disability. Shakespeare (2013:215) puts it as follows: “The Social Model, therefore, implies that the reconstruction and development of our society involves a recognition of and intention to address the developmental needs of disabled people within a framework of inclusive development.” The strengths of the social model of disability are summarised as follows (Shakespeare 2013:216-217):

- it has positively influenced the political perspective on disability on an international level;
- it was and is instrumental in the removal of social barriers in the lives of people with a disability and contributes to the progressive liberation of this group of people;
- psychologically it led to the improvement of the self-esteem of people with a disability who are now seen as people collectively disabled by society, rather than individuals with an impairment.

The weaknesses of the social model of disability are summarised as follows (Shakespeare 2013:218-219):

- it implies that impairment is not problematic, denying the struggles, discomfort or pain that a person with a disability might be experiencing;
- it assumes that people with disabilities are oppressed, rather than proving that they are;
- the radical distinction between “impairment” (according to the medical model) and “disability” is unrealistic since in practice it is almost impossible to distinguish between the impact of impairment and that of social barriers;
- it conceptualises a barrier-free utopia, suggesting a fully transformed societal attitude and perspective on people living with a disability.

The differences between the medical and social models can be outlined as follows (The New Health Guide 2014):

Medical Model	Social Model
A disability is a deficiency or abnormality.	A disability is a difference.
Being disabled is considered to be negative.	Being disabled is considered neutral.
The disability resides within the individual.	The disability stems from an interaction between this individual and society.
Cures that will allow for the normalization of the individual are used to remedy the disability.	Altering the way society interacts with these individuals is used to remedy the problems associated with a disability.
A professional acts as the agent of the remedy.	The individual with the disability, an advocate or anyone that can affect the arrangements between society and the individual can act as an advocate of the remedy.

For the purpose of this study, a combination of these two models of disability is proposed because, while social constructs regarding disability are undoubtedly a reality and are discussed in various sections of the investigation, on the other hand the treatment and medical support of children and youth with a disability cannot be ignored when considering options for inclusive youth ministry to this group of individuals.

3.2.2 An overview of the understandings of disability

A brief overview of a development of the global and local understandings of disability will now be presented in order to provide insights for how to understand this matter in the postmodern era of today. Munyi (2012) laments the limited literature available about disability and how it was understood over the ages. This poses challenges to researchers in the field. He also points out that societal perceptions of disability differ across cultures and change over time.

In ancient times, the perspectives on disability were predominantly influenced by Greek and Roman thought (see *The History of Attitudes to Disabled People* 2007). In ancient Greek and Roman thought the idea of the “beautiful body” led to a negative view of and even the disposal of deformed human beings. Beautiful was regarded as “good,” whereas impairments and disabilities were regarded as “bad.” Giving birth to a child with a disability was considered as punishment by the gods, and magic and demonic interference were to blame for having an “imperfect” child (see Shafer 2016). The disposal or death of a child with a disability was not only regarded as in the best interest of the child and the society into which he or she was born in, but was a legal requirement enforced by the state. From the second century C.E. people with disabilities were often used to entertain crowds and were restrained in secured buildings where tourists would pay to peer at the strange ways of persons with a mental disability in their cells. In 1497 people with a disability were expected to be confined by their families. The state only intervened when this was not done sufficiently by the families.

The National Consortium on Leadership and Disability for Youth 2007 compiled a timeline of the development of perspectives and understandings of disability. The most significant developments will be summarised briefly. The 1700’s marks early progress in the field of disability, with founding father Stephen Hopkins from the USA, who had cerebral palsy, being one of the people who signed of the Declaration of Independence. Other highlights in this area include improved amputation procedures, the institutionalisation of blind people and the unchaining of people with a mental disability (some of whom had been chained to walls for more than thirty years). During the 1800’s there was even more progress in the US. Mental disabilities were classified as a medical matter, education for deaf people and people with a mental disability was started, Louis Braille invented the raised point alphabet to enable blind people to read, whereas Sigmund Freud, qualified as a medical doctor, established the fields of psychiatry and psychology and developed his theories of psychoanalysis. In the 1900’s there were many advancements, also with regard to civil rights. A historical event such as World War II resulted in improved care and opportunities for soldiers returning from the battle fields with injuries and amputations. Increased criticism of discrimination against people with a disability led to the development of equal rights and opportunities for this group of individuals.

Examples of the progressive inclusion of people with a disability can be seen on all levels of life, including education, job creation, medical care and sport. The first international Special Olympic Games took place in 1962. On a political level, legislation and policies were adopted internationally, whereas technology was developed to assist people with a disability and improve their lives. The 21st century paves the way further for people with a disability. Advocacy for the rights of people with a disability is increasing globally and discrimination is prohibited by courts. The disability sector also benefits from increased funding to further research and improves the lives of people with a disability.

Currently disability is viewed fairly positively. Progress is made with efforts to empower people with a disability. Great contributions have been made to this sector by the United Nations (UN). The Global Status Report on Disability and Development (2015:16) regards persons with a disability as both beneficiaries and agents of change in society. They are actively participating leading in their societies, and are establishing new stakeholder communities that focus on the inclusion and integration of people with a disability. These developments regarding people with a disability were the result of factors such as the following:

- international norms, policies and legislation relating to disability were adopted;
- an increasing international focus on the situation of persons with a disability led to successful mainstreaming;
- developments with regard to the rights of persons with a disability globally are given momentum by an increased awareness and enforcement thereof;
- commitment to include the issue of disability in the global development agenda over the past decade, led to a call for urgent action toward inclusive, accessible and sustainable society.

3.3 Language and culture

Disability remains a sensitive topic globally and therefore it is of the utmost importance to ensure usage of correct and preferred terminology. Incorrect usage of disability terminology comes across as offensive and may lead to persons with a disability feeling excluded (see Kids As Self Advocates 2006). The Barking and Dagenham Centre for Independent, Integrated, Inclusive Living Consortium (2001:6-

7) distinguishes between appropriate and inappropriate disability language as follows:

INAPPROPRIATE REFERENCES

APPROPRIATE REFERENCES

The disabled

People with disabilities

Invalid

Person with disability

Severely disabled

Requires substantial or significant personal assistance

Suffers from

Living with or state actual medical condition

Mental illness

Living with mental health problem, but preferably diagnosis

Learning disability

People with learning difficulty

The deaf

Deaf people / hard of hearing people / hearing impaired people

The blind

Blind people / partially sighted people / visually impaired people

Care

Personal assistance / personal support

Paid caregivers

Personal assistants

Disabled toilet

Accessible toilet

Disabled parking

Accessible parking

Wheelchair accessible

Accessible for wheelchair users

As important as appropriate language, is proper disability etiquette. It does not come naturally to interact with a person with a disability if one is not exposed to a person with a specific disability regularly. Being familiar with disability etiquette is helpful, but also complex as etiquette is specific to different types of disabilities. Basic rules of disability etiquette include the following (Cohen 2015:2-4):

- Ask a person with a disability if they require assistance before helping them. Persons with a disability want to be treated as independent people and often get around find. Offer assistance only if the person appears to need it and ask how to help them before taking action.
- Be sensitive about physical contact. Some people with a disability are dependent on their arms for balance. They can easily be knocked off balance when grabbed and held by their arms. Avoid touching a person with a disability by patting them or touching their equipment such as wheelchairs, scooters or canes. People with a disability consider their equipment part of their personal space.
- Thinking before speaking. A person with a disability should be directly spoken to and not through their companions, aides or sign language interpreters. They should be conversed with like all other people. Their privacy should be respected. Inquiring about their disability can make them feel dehumanised.
- Respond graciously to requests. Queries about the accessibility or accommodation of a disability should not be regarded as complaints. Individuals with a disability should feel comfortable to ask for what they need.
- No assumptions. People with a disability are the best judges of their abilities and inabilities. Decisions should not be made on their behalf.

Disability etiquette is particular to a type of disability. Examples of disability specific etiquettes include the following (see Cohen 2015:1-52):

Disability description or category	Etiquette
People who use wheelchairs or have mobility impairments	<ul style="list-style-type: none"> • do not lean over a person who uses a wheelchair; • do not push or touch a person who uses a wheelchair without their permission or request; • sit down in order to be on their level or stand at a distance comfortable to them to make eye contact; • consider the reach limits of a person using a wheelchair; • ensure signs are visible to direct people using wheelchairs to the most accessible routes.
People who are blind or visually impaired	<ul style="list-style-type: none"> • when conversing with a person who is blind, identification is required so that the individual knows who they are talking to; • offer a tour if a blind person is on the premises or in a building for the first time; • remain on the opposite side of the person's guide dog or cane; • do not touch a person's guide dog or cane as it is regarded as their personal space; • offer to read written information.
People who are deaf or hard of hearing	<ul style="list-style-type: none"> • talk to and keep eye contact with the deaf person directly, whether they are making use of an interpreter or not; • before speaking to a deaf person first get their attention by touching them or waving at them; • face the person who is deaf when speaking to them; • speak clearly, but do not shout; • make use of the deaf person's preference of communication as far as possible, such as a sign-language interpreter or writing back and forth.

<p>People with a speech disability</p>	<ul style="list-style-type: none"> • give the person your full attention when talking to them; • do not interrupt the person or complete their sentences; • do not indicate that you understand what they are trying to communicate if it is not the case; • if it is difficult to understand the person, request them to write down what they want to say; • it is easier to understand a person with a speech disability when conversing in a quiet environment.
<p>Persons of short stature</p>	<ul style="list-style-type: none"> • be considerate of the person's reach limits; • ensure that equipment required by a person of short stature is available and accessible; • never pet or kiss a person of short stature on the head; • be on the same level as the person as far as possible by sitting, kneeling down or standing at a slight distance.
<p>Invisible disabilities Not all disabilities are apparent.</p>	<ul style="list-style-type: none"> • be aware of the fact that "strange" behaviours can be disability related, such as psychiatric and mental disabilities; • do not scold a person acting different from societal norms; • do not stare; • be of assistance if requested by the person's caregivers; • remain calm and try to understand what the person wants.

Though "disability culture" is a broad and complex term to define and describe, also for the purposes of this study, it does exist and should be better understood (Brown 2002:34-50). Peters (2015) describes disability culture as follows: "... the sum total of

behaviours, beliefs, ways of living, and material artefacts that are unique to persons affected by disability.” For the purposes of this study an in depth knowledge of the history and development of the disability culture is not necessary. What is needed is an understanding of how people with a disability have formed an exclusive group based on what they have in common. Brown (2002:34) describes it as follows:

People with disabilities have forged a group identity. We share a common history of oppression and a common bond of resilience. We generate art, music, literature, and other expressions of our lives and our culture, infused from our experience of disability. ... We claim our disabilities with pride as part of our identity.

Brown (2002:34-50) points out that descriptions of disability culture vary depending on influences such as geography, ethnicity, race and gender. Disability culture can therefore be considered as a movement by people with a disability who aim to raise awareness and create for themselves a sense of global, societal belonging. In his speech at The Celebration of Disability Awards on 25 November 2000 in Durban, the Minister of Arts, Culture, Science and Technology, Dr Ben Ngubane, identified disability culture from a South African perspective as follows:

The struggle for inclusion is going to be a long one as the evolution of "disability culture" is still in an infant stage in our country. A key function of "disability culture" is the celebration of the uniqueness of disability. It is my belief however that it will blossom as people with disabilities increasingly identify with each other and begin to express themselves more artistically and participate in the cultural life of society as a whole.

Disability culture is a global phenomenon in the 21st century. People who live with a disability find and develop their identity as persons who partially belong to a worldwide group of individuals who share their unique though familiar narratives of living with disabilities on a global platform. This is also the case on in the South African context. This so called “disability culture” is relevant to this investigation of children and youth living with a disability from a youth ministry perspective.

3.4 Classification

The International Classification of Functioning, Disability and Health is a classification of the health components of functioning and disability (see World Health Organisation [WHO] 2001). The ICF is structured and classifies disability on three levels (WHO 2001:12-16):

- body function and structure;
- additional information on severity and contextual factors;
- activities (related to tasks and actions by an individual) and participation (involvement in a life situation).

Firstly, *mobility and physical impairments* can be present at birth or be acquired with age. There are various types of physical disabilities, including upper limb(s) disability, lower limb(s) disability, manual dexterity, and disabilities affecting organs or disability inflicted by broken bones. Physical disabilities include *spinal cord injuries* that may or may not be a lifelong condition. They can be due to a birth defect, but are mostly caused by severe accidents. The injury may be “complete” or “incomplete.” “Complete” injuries indicate the total collapse of the sensory organs, whereas an “incomplete” injury suggests partial dysfunction. *Head injuries* can cause brain disabilities. The severity of the injury is classified as mild, moderate or severe. Brain disability is categorised as “Acquired Brain Injury” (post natal degeneration of the brain and its functions) or “Traumatic Brain Injury,” (brain injuries leading to emotional and behavioral disruption). *Vision disability* refers to limited sight, ranging from minor to severe vision impairments and may lead to serious conditions such as blindness. *Hearing disability* refers to deafness and this can be partial or complete. A person can be deaf from birth or become deaf later on in life, due to sickness or trauma.

Secondly, *cognitive or learning disabilities* are diagnosed when a person experience challenges with learning, concentration and speech, including dyslexia and ADHD. Psychological disorders include *affective disorders* which impact on a person’s mood and emotional wellbeing, either on a short or long-term basis. An example is depression. *Mental health conditions* include psychiatric conditions such as personality disorders (peculiar patterns of thought or behaviour affecting a person’s

activities of daily life) and schizophrenia (a mental condition that affects an individual's thinking, mood and behavior). *Invisible disabilities* are conditions that are not immediately noticed by others, such as autism. Although their impairments are often not clearly noticeable, such people struggle with social interaction, anxiety and communication on different levels.

Disabilities affect people in different ways, though the diagnosis might be the same. The classification of disabilities is of importance in this study because it shed light on the likely impact a specific condition can have on a person's life. A person can be affected on various levels, such as vision, hearing, learning ability, movement, mental health, memory, communication, sensory ability or social interaction.

3.5 Types of disabilities

3.5.1 Introduction

Disability is a broad, complex and technical field, which makes it impossible to simply list the types of disabilities and then gain insight into the challenges of parents. Faith communities and youth workers need an understanding of the limitations experienced by children and youth living with a particular disability in the South African context if they are to make a difference in their lives of both the young people and their families.

This study will employ the first two of Julian Müller's (2005:82) seven movements, namely focusing on a specific context and describing experiences within this specific context. In order to simplify a complex field for the purposes of this investigation, the study will focus on the four most prevalent disabilities that are encountered nationally. The four types of disabilities with which the children of interviewees in this study have been diagnosed are Cerebral Palsy, Down syndrome, Autism Spectrum Disorder and Autism, as well as deafness. They will now be briefly discussed.

3.5.2 Cerebral Palsy

Cerebral Palsy is the most common motor disability in childhood globally (Centers for Disease Control and Prevention 2016). The high prevalence statistics of Cerebral Palsy justifies an introduction to this disability in order for faith communities and pastors to have a better understanding thereof. Novak (2014:1142) describes Cerebral Palsy as follows (Novak 2014:1143):

Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems.

Novak (2014:1141-1156) describes Cerebral Palsy as the loss or impairment of motor function, which is caused by brain damage. Injury during the development of the brain (before, during or after birth) or the abnormal development of the brain, causes brain damage of which Cerebral Palsy can be an outcome. Cerebral Palsy affects body movement, muscle control, muscle coordination, muscle tone, reflexes, posture and balance. Fine motor skills, gross motor skills and oral motor functioning can also be affected. Individuals with Cerebral Palsy were most likely born with the condition, although it can be acquired later on in life. Research indicates that the majority of Cerebral Palsy cases result from abnormal brain development or brain injury prior to or during the birth process. Cerebral Palsy can also be caused by accident, abuse, medical negligence, bacterial or viral infections and injuries. It is important for the pastor to note at what stage the family was informed of the diagnosis, because accepting the diagnosis is a lengthy, traumatic experience. It is during this time that adequate and effective pastoral care and support are especially needed.

The effects of Cerebral Palsy on the functioning and development of the person are many and varied. With regard to physical impairment, the type of motor dysfunction, the location, number of limbs involved, and the extent of the impairment will differ from one person to another. The functioning of the arms, legs, and even the face can be affected. Motor function and a person's ability to control his or her muscles can be affected. Limbs can be stiff and forced into painful, awkward position. Fluctuating muscle contractions can make limbs tremble, shake, cramp or writhe. Balance,

posture and coordination can also be affected. This can result in simple tasks such as walking, sitting, grasping objects or tying shoes being difficult or even impossible. Other complications, such as intellectual impairment, seizures, blindness and deafness can also be caused.

Since every case of Cerebral Palsy is unique to the individual, the severity of the disability will determine the degree of care that is required. This will depend on the extent of the paralysis, movement tremors, and muscle contractions. Cerebral Palsy is considered a non-life-threatening condition and children with Cerebral Palsy are expected to live well into their adulthood. However, it is a permanent, incurable and irreversible condition. The impact of Cerebral Palsy on the quality of life of the person affected, can be managed by means of treatment, therapy, surgery, medication and assistive devices. Though Cerebral Palsy is a non-progressive condition and brain function is not expected to improve or regress with time, secondary and co-mitigating conditions can cause additional problems, such as learning difficulties, seizures, and vision or hearing loss.

3.5.3 Down Syndrome

Down Syndrome is the most common chromosomal condition and the leading cause of intellectual and developmental impediments globally (see Global Down Syndrome Foundation 2015). The following is a summary of an explanation of Down Syndrome (see National Down Syndrome Society 2012): every human body consists of cells, each containing a nucleus that stores genetic material in the form of genes. Genes determine a person's inherited features and are categorised along rod-like structures named chromosomes. The nucleus contains 46 chromosomes, divided into 23 pairs, half of which are inherited from each parent. Down Syndrome occurs when a person has a full or partial extra copy of chromosome 21. The consequence of this extra genetic material has an impact on the development of the person and causes the features identified with Down Syndrome, "...like low muscle tone, small stature, an upward slant to the eyes, and a single deep crease across the centre of the palm - although each person with Down Syndrome is a unique individual and may possess these characteristics to different degrees, or not at all." Many individuals with Down Syndrome also suffer from secondary health conditions, such as hearing loss, heart disease, intestinal abnormalities, poor sight and nutritional challenges (see Kim 2015).

Though it is not possible to determine a single cause for Down Syndrome, medical research indicates that there is a greater risk for a mother over the age of 35 having a child with Down Syndrome (see Crosta 2016). The World Health Organisation (2017) estimates that 1 in 1000 to 1 in 1100 babies are born with Down Syndrome internationally. This brings the number of children born with Down Syndrome annually to between 3000 – 5000. The Global Down Syndrome Foundation (2015) warns against the misconceptions about Down Syndrome. From the point of departure of this study such misconceptions are seen as social constructs (see discussion in Chapter 2). Misconceptions include:

- that only older parents have children with Down Syndrome;
- that children with Down Syndrome will ruin a marriage;
- that children with Down Syndrome impact their siblings negatively;
- that children with Down Syndrome die young;
- that children with Down Syndrome cannot participate in sport;
- that children with Down Syndrome are illiterate;
- that children with Down Syndrome do not experience pain;
- that children with Down Syndrome cannot attend mainstream educational facilities;
- that people with Down Syndrome all look similar;
- that all people with Down Syndrome are overweight;
- that all people with Down Syndrome develop Alzheimers later on in life;
- that people with Down Syndrome cannot have children of their own;
- that people with Down Syndrome are always happy;
- that adults with Down Syndrome cannot function independently or have jobs;
- that people with Down Syndrome have no memory;
- that Down Syndrome is the result of incest.

These misconceptions about Down Syndrome can cause pain and challenges to children or youth with Down Syndrome and their families. Pastors need to be informed of these challenges, as it directly impacts on the pastoral care plan and journey with the family. The misconceptions listed above are typical social constructs that can lead to exclusion of children and youth with Down Syndrome, also with regard to faith communities. Unfair and judgemental labelling of these individuals impact their lives on various levels, including emotionally and spiritually, whereas

people's perceptions of them are formed based on these beliefs. Though social constructionism is not the only consideration for pastors working with children and youth with Down Syndrome, it is an integral factor for understanding these individuals and their narratives better.

3.5.4 Autism Spectrum Disorder and Autism

Autism Spectrum Disorder (ASD) and Autism are terms referring to a group of complex neurodevelopment disorders that are characterised by impaired social interactions, difficulty to communicate, as well as restricted and repetitive behaviors and interests (Matson 2011:3). Autism Spectrum Disorder (ASD) is now regarded by the American Psychiatric Association in their Diagnosis and Statistical Manual of Mental Disorders (DSM-5) as a single disorder that includes disorders previously seen as separate conditions, namely Autism, Asperger's Syndrome, Childhood Disintegrative Disorder and Pervasive Developmental Disorder (see [Mayo Clinic 2014](#)). The prevalence of children with ASD is high: an estimated 1 in 68 children in the United States (see Autism Society 2016). Autism is the fastest growing developmental disorder internationally with an increase of almost 120% from 2000 to 2010 in the US. It is more prevalent among boys and in developed countries. It is an incurable, lifelong disorder. However, an early diagnosis and intervention are integral to ensuring the optimal development of children with Autism (Robins et al 2001:131-144). It is difficult to diagnose this condition at an early age because too few developmental indicators are present before the age of two. Regression of any sort, such as the loss or lack of speech, babbling, gesturing, or social are typical indicators of Autism Spectrum Disorder (Smith et al 2016:2). Early signs of Autism can be observed when a baby or toddler does not (Smith et al 2016:4-5):

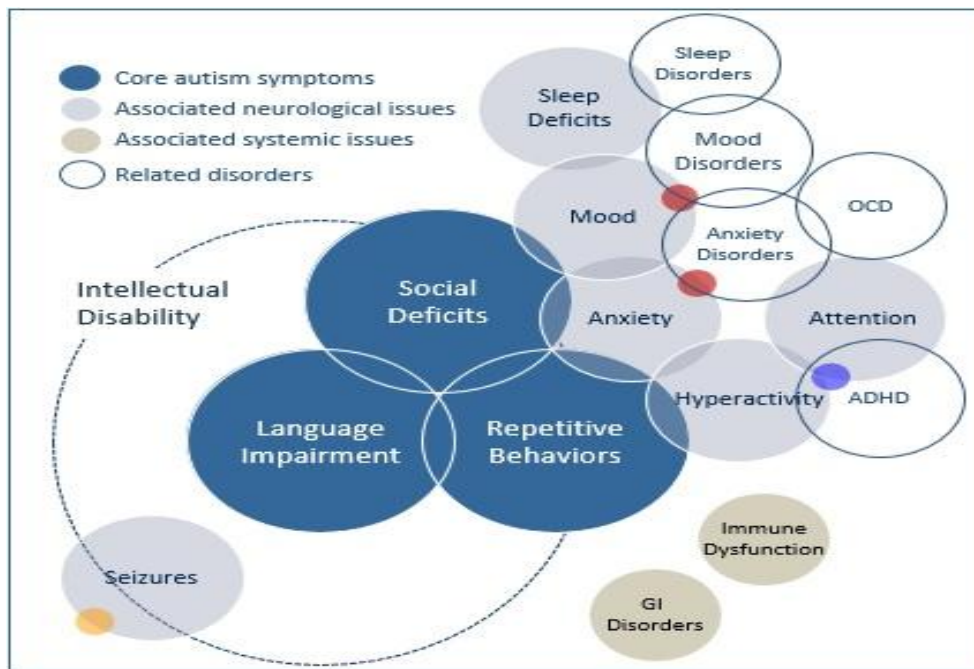
- make eye contact during feeding times or does not respond to a smile;
- respond to his or her name or to familiar voices;
- follow objects or gestures with their eyes;
- point, wave or use other communication gestures;
- make noises to get attention;
- initiate or respond to cuddling or reach out to be picked up;
- imitate movements and facial expressions;

- play with others or share interests and enjoyment;
- notice or care if he or she or others are hurt or experience discomfort.

Children on the Autism Spectrum Disorder experience challenges on various levels (Smith 2016:5-7). They find it difficult to interact with other people on a social level and might typically not want to be touched physically, do not connect or talk to others and struggle to understand emotions and feelings. They struggle to communicate – language and speech are challenging to them and they typically speak in strange tones or rhythms, repeat meaningless phrases over and over, or not speak at all. They also do not understand figurative speech, non-verbal communication and body language. They are often restricted, inflexible, and even obsessive in their behaviour, activities, and interests. They are rigid in their ways and routines and do not like changes of any sort. Examples of this type of behavior include flapping of hands, rocking, focusing on particular movements or staring at items such as ceiling fans or the wheels of a vehicle. According to the National Autistic Society (2016), children with ASD often struggle to process daily sensory information: any of their senses might be over- or under sensitive or even both. One can imagine the impact of an over- or underdeveloped sense of sight, hearing, smell and touch. This might lead to sensory overload, resulting in anxiety, stress or even physical pain. The result is withdrawal, behaviour challenges or meltdown.

Though no single cause for Autism has been identified thus far (O’Callaghan 2002:263), what has been identified as a possible cause is a combination of unknown genetic, biological and/or environmental factors. Some of these can include chemical imbalance, a virus and a lack of oxygen at birth. The manifestation of Autism has also been linked with diseases such as Rubella while the mother is pregnant, Tuberos Sclerosis, Fragile X Syndrome, brain inflammation and inadequate metabolism enzymes (Szatmari 2003:173-175).

The US based Autism advocacy organisation, Autism Speaks (2017) illustrates the core symptoms of autism, the associated neurological and systemic challenges, as well as disorders related to Autism as follows:



During the course of my investigation, I discovered a letter by Mr. Bob Cornelius on Facebook. He is the father of an eleven year old boy with Autism, named Christopher. Mr. Cornelius recently discovered the extent of the exclusion and judgement that his son with a mental disability is experiencing on a daily basis. The letter illustrates the social constructs with which children with Autism have to deal. On 19 September 2016 Mr. Bob Cornelius posted the letter on Facebook, urging other parents to speak to their children about children with a disability. He hopes that if parents have this conversation with their children it can result in less judgement, exclusion and heartache of children with Autism, but disability in general. Mr. Cornelius wrote the letter after Christopher asked to also have a sleepover like his brother. However, he could not tell his dad who he wanted to come over, because he does not have any friends. Christopher has never had a friend in his eleven years of existence. Mr. Cornelius made the following statement:

The reality is that I have to rely on the compassion of others to be incredibly understanding in order just to sit next to him, attempt to engage him, and make him feel included. ... As far as I know, (save for one time), Christopher's classmates have never been overtly cruel to him. What they have done, however, on some level, is to exclude him.

Mr. Cornelius urges parents to make their children aware of children with disabilities and their “differences.” If children could understand that those different from them also has a need to be included, to belong and to have friends, Christopher’s life will be much different. Mr. Cornelius’ letter is a desperate call for the inclusion of his son who has Autism and is excluded from basic interaction with his peers.

The study of Autism and Autism Spectrum Disorders is a complex field of investigation. This study focuses on the effect of this and other disabilities on the social experience and behaviour of the child. Since these children’s behavior differs from what society sees as “a well-behaved child” they will be treated accordingly. The impact of social constructs regarding this disability as well as the misunderstandings surrounding the condition is severe. This in turn has an impact on the development of their social skills, their adaptation and inclusion in society (see this illustrated by the letter of Christopher’s father). The question should be asked whether the faith community and youth ministry contribute to the exclusion of this group of individuals or to the alleviation of their misery.

3.5.5 Hearing impairment

Hearing impairment is the most prevalent disability globally. According to the World Health Organisation (2017), 328 million adults and 32 million children suffer from disabling hearing loss. Disabling hearing loss is when an adult experiences hearing loss greater than 40 decibels (dB) and children a hearing loss greater than 30 dB in the better hearing ear. Hearing loss is categorised as mild, moderate, severe or profound. One ear or both ears can be affected. Hearing loss can make it difficult or impossible for a person to hear sounds or volume (Disabled World 2011). Three types of hearing loss are distinguished (Mroz 2017):

- **Sensorineural hearing loss**

The most common type of permanent hearing loss occurs when either the tiny hair-like cells of the inner ear or the auditory nerve itself gets damaged and consequently prevents or weakens the transfer of nerve signals to the brain.

- **Conductive hearing loss**

Temporary or permanent hearing loss occurs when an obstruction or damage to the outer or middle ear prevents sound from being conducted to the inner ear.

- **Mixed hearing loss**

A combination of sensorineural and conductive hearing loss caused by trauma to the ear can happen gradually. It can be a temporary or permanent condition. Hearing loss or deafness can be due to either congenital or acquired causes (American Speech-Language-Hearing Association 2015). *Congenital causes* refers to hearing loss being present at or acquired soon after birth, due to hereditary and non-hereditary genetic factors or complications during pregnancy or childbirth. This can include maternal rubella, syphilis or other infections during pregnancy; low birth weight; a lack of oxygen at the time of birth; inappropriate use of particular drugs during pregnancy; severe jaundice in the neonatal period. *Acquired causes* of hearing loss or deafness refers to when the disability was acquired later in life due to infectious disease such as meningitis, measles or mumps; chronic ear infection; chronic fluid in the ear; the use of particular drugs such as certain antibiotic and anti-malarial medicines; injury to the head or ear; excessive noise; ageing; wax or a foreign body that blocks the ear canal. The effect of hearing loss on a person manifests on three levels: functional, social and emotional, as well as economic (Bess et al 1998:339-354):

- On a *functional* level people suffering from hearing loss or deafness experience challenges in communication, speech and language. Their academic performance can be influenced negatively.
- On the *social and emotional* level the person's daily life is affected severely when they are excluded from communication and social interaction. Consequences are loneliness, isolation and frustration.
- On an *economic* level children with hearing loss and deafness rarely have access to educational opportunities. Adults with hearing loss have fewer employment opportunities, especially in developing countries.

Early diagnoses and intervention are essential in order to minimise the impact of hearing loss or deafness on the life and development of a child (Störbeck & Pittman 2008:36-43). A person with hearing loss or deafness can benefit from the use of assistive hearing devices such as hearing aids or cochlear implants. Speech therapy, aural rehabilitation, and training in lip reading, literacy, sign language and other related services will also make a difference in the person's life. Cochlear implants can make it possible some to hear perfectly (World Health Organisation 2017). However, the global production of hearing aids meets less than 10% of the world's need and less than 3% of developing countries' needs. The lack of availability of services for fitting and maintaining these devices and the lack of batteries are also a problem in low-income settings. Making properly-fitted, affordable hearing aids and cochlear implants and providing accessible follow-up services available in all parts of the world will benefit many people with hearing loss. Primary prevention can reduce hearing loss and deafness with up to 50%. Primary prevention includes scheduled immunization of children and reproductive females, reduced exposure to loud noises, responsible and monitored use of particular prescription drugs and following healthy ear care practices.

3.6 Disability in South Africa

Since there is no generally accepted definition or measuring instrument available (World Bank 2007:1) it is difficult to describe the prevalence of disability in South Africa. However, in June 2001 the United Nations International Seminar on the Measurement of Disability requested that principles and standard forms for indicators of disability be developed for use in censuses (Centers for Disease Control and Prevention 2010). Such a measurement instrument to determine disability statistics was needed in order to measure and compare international statistics, especially in developing countries where such information was scarce and often of poor quality. The Washington Group on Disability Statistics was formed to address the need for high quality, comparable statistics on disability (Centers for Disease Control and Prevention 2010). The instrument, the Washington Group Short Set of Questions inquires about challenges experienced in seven domains of functioning, namely seeing, hearing, walking, remembering, concentrating, self-care, and communication.

The Profile of Persons with Disabilities in South Africa (Statistics South Africa 2011a:25-36) categorised disability in the following six activity domains, based on the Washington Group Short Set of Questions measuring tool:

- the degree of difficulty in seeing;
- the degree of difficulty in hearing;
- the degree of difficulty in communicating;
- the degree of difficulty in walking or climbing stairs;
- the degree of difficulty in remembering or concentrating;
- the degree of difficulty in self-care.

The South African Department of Social Development and the Department of Women, Children and People with Disabilities conducted a study in 2012 in order to do a situation analysis of children living with disabilities in the country (DSD, DWCPD and UNICEF 2012). In the course of this investigation it became clear that these statistics can only be regarded as guidelines. They do not provide an accurate reflection of situation of children living with a disability in South Africa. Reasons for questioning the reliability of figures include (DSD et al 2012:30):

- South Africa lacks an official disability measuring instrument in accordance with the ICF, which means that figures were generated from various sources;
- there were challenges in defining disability as well as with the different methods of data gathering;
- measuring child disability is even more complex than measuring disability in adults. The natural developmental processes of children as they grow, such as learning how to talk, walk, read and write result in evolving characteristics (in comparison with the relatively stable characteristics of adults). Therefore, the evaluation of their functioning and identification of impacting limitations from variations in normal developmental processes become complex.

However, since 2009 Statistics South Africa's Annual General Household Survey (GHS) has been using the Washington Group Short Set of Questions (WGSSQ) which inquires as to the difficulties participants experience in seven categories of functioning, namely seeing, hearing, walking, remembering, concentrating, self-care and communicating (DSD 2012:28). According to the WGSSQ a person is classified

as disabled if they have “some difficulty” in two or more of the six categories, or have “much difficulty” or are “unable to” in one or more categories (DSD 2012:28). Following this approach, the GHS 2009 identified nearly 2.1 million children (11.2 percent of the total child population) as children with a disability (GHS 2009:91-95). The prevalence of disability appears exceptionally high in young children: 28 percent of children in the age group 0-4 years and 10 percent in the age group 5-9 years were classified as disabled (DSD et al 2012:28). The findings of the GHS 2009 are the following (DSD et al 2012:31-39):

- that blindness and deafness are the most common;
- that approximately one in 10 children with disabilities was reported to have multiple disabilities;
- that there are significant differences in the levels of child disability based on location, sex, age and other socioeconomic characteristics: more male than female children are affected by disability, disability increases gradually with age and orphans, institutionalised and street children are at a higher risk of disability.

These findings indicate that the disparities in the prevalence of child disability can reflect the general conditions and means of a community, such as access to healthy nutrition, exposure to environmental or infectious influences, or social and other risk factors for disability.

Early detection of disability and early intervention are essential for adequate and effective treatment and rehabilitation. However, findings indicate that disability is often only detected in an advanced stage (DSD et al 2012:40-41). South Africa lacks a standardised developmental screening tool in the primary health care sector, which means that children rarely are thoroughly examined in order to determine developmental progression, such as crawling, walking, speaking, as well as hearing and vision (Baez 2000:19-20). The University of the Western Cape identified some challenges with the implementation of screening processes: 25% of primary health care providers did not have screening services, 11% of primary health care providers performed screenings according to protocol, but no register was kept of children at risk of disability (Children’s Institute of the University of Cape Town 2003:i-ii). Despite

the high prevalence of deafness in children in South Africa, fewer than one in ten public hospitals in South Africa provide hearing screening for infants. Deafness is only diagnosed on average by the age of 2. The critical age for intervention is 6 – 9 months old (Swanepoel et al 2009:784). The Situation Analysis (DSD et al 2012:47) also finds that professionals in the health sector are not adequately informed and trained regarding disabilities, referral and intervention protocols. This contributes to late or wrong diagnoses and interventions.

On the positive side there are increased efforts to improve early detection of disability in children (DSD et al 2012:41). The Department of Health revised the Road to Health Booklet (RtHB) in 2011 to include an instrument for the identification of children who are at risk of disability. All parents are supposed to receive this booklet when their baby is born, whether at a private or state hospital. It is designed to assist parents and health care practitioners to evaluate and monitor the development of the child. School health programmes have been designed to now also screen for disability. The Department of Basic Education is distributing the screening, identification, assessment and support (SIAS) assessment instrument to assist educators in establishing the nature of a child's disability and educational support needs. The school health system requires that the hearing, vision, speech and gross motor functions of all Grade 1's should be evaluated and referred for further assessment, treatment and remediation if difficulties are identified.

3.7 The rights of children and youth with a disability in South Africa

The global quest for basic human rights for all people, including children and youth living with a disability, is ongoing. The United Nations Convention on the Rights of the Child (UNCRC) 2010 specifically addresses the issue of children with a disability in Article 23: "Children who have any kind of disability have the right to special care and support, as well as all the rights in the Convention, so that they can live full and independent lives." The African Charter on the Rights and Welfare of Children 1990 addresses the rights of children with disabilities in Article 13 as follows: "Every child who is mentally or physically disabled has the right to special protection to ensure his or her dignity, promote his self-reliance and active participation in the community." However, it is the United Nations Convention on the Rights of People with Disabilities

(UNCRC) 2008 that describes the state's responsibility to children with a disability most comprehensively in Article 7:

- states parties shall take all necessary measures to ensure the full enjoyment by children with a disability of all human rights and fundamental freedoms on an equal basis with other children;
- in all actions concerning children with a disability, the best interests of the child shall be a primary consideration;
- states parties shall ensure that children with a disability have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age appropriate assistance to realise that right.

South Africa forms part of the United Nations and has adopted national legislation concerning adults and children with a disability based on and in correlation with these international conventions. The South African Bill of Rights clearly stipulates that all citizens are equal before the law and that the state may not discriminate against anyone on any grounds, including disability (The Constitution of the Republic of South Africa 1996:5-6). Children and youth with a disability share the same rights as all other citizens of the country and should not, according to legislation, experience any form of discrimination or exclusion. The following rights of children and youth with a disability are stipulated clearly by various international and national legislative documents:

- the right to adequate housing and standard of living (Article 26 of The Constitution of the Republic of South Africa, Article 27 of the UNCRC, Article 28 of the UNCRPD);
- the right to education (Article 29 of The Constitution of the Republic of South Africa, Article 28 of the UNCRC, Article 11 of the ACRWC, Article 24 of the UNCRPD);
- the right to primary health care services, food, water and social security (Art27 of The Constitution of the Republic of South Africa, Articles 24 and 26 of the UNCRC, Article 14 of the ACRWC, Article 25 of the UNCRPD);

- the right to child protection (Art 28 of the The Constitution of the Republic of South Africa, Article 19 of the UNCRC, Article 11 of the Children’s Act 38 of 2005:22-23).

The practical implementation of these rights of children, however, is lacking countrywide. Children and youth with a disability often live under appalling conditions (DSD et al 2012:43). Children with a disability are less likely to have adequate housing, water and sanitation and more likely to live in informal settlements. Inadequate living conditions cause major problems for children with a disability (Clacherty et al 2004:16).

With regard to education, children with a disability have limited access to early childhood development programs (Saloojee et al 2007:230-235). Furthermore, “...children with disabilities are substantially less likely to attend school than their non-disabled peers” (DSD et al 2012:45). The international school dropout rate of children and youth with a disability is two to three times higher than the school dropout rate of their non-disabled peers (Zablocki 2009:2).

The access of children and youth with a disability to primary health care services cannot be determined due to a lack of data (DSD et al 2012:47). However, parents of children and youth with a disability are more likely to report sicknesses and injuries of their children than their non-disabled counterparts (DSD et al 2012:47–48). Due to their vulnerability and dependency, children and youth with a disability are more at risk of HIV and AIDS, mortality, inadequate immunisation, poor nutrition and malnourishment. They have only limited access to much needed rehabilitation, intervention and assistive devices (Philpott & McLaren 2006:271-282). Protection, which is a basic human right of children, is not a reality for many children and youth living with a disability. They are more likely to be orphaned (due to the poor health and often unhealthy living conditions of the parents), institutionalised and become victims of violence, crime, neglect and abuse than other children (DSD et al 2012:50-53).

Despite progress in international and national legislation in the interest of children and youth with a disability over the past two decades, it is clear that inadequate implementation of these efforts have had a negative impact on the status,

development and societal perception of these children and youth. The aim of this chapter was to facilitate a better understanding of disability in general and of the lives of children with a disability and their families in particular. It highlighted the many challenges and frustrations. Awareness and being better informed about disability and status of South African children and youth living with a disability, is the first step to effective, accessible, inclusive youth ministry to this group of individuals and their families.

3.8 Raising a child with a disability

Though this study focuses on the context of South Africa, the challenges of parents who raise children with a disability are similar everywhere. It can bring them to despondence. Some parents reach a point when they consider suicide or murdering the child. Recently news media reported that a mother, Tania Clarence, killed her three toddlers who were suffering from the muscle-weakening condition multiple system atrophy type 2 (see McKinnell 2015). Authorities agree that the family should have had earlier access to intervention, acknowledging that this tragedy could have been prevented. The extreme action or even consideration to take one's own life or that of one's child is an indication of utter hopelessness, loneliness and desperation. From the perspective of this study, the question would be whether a faith community was involved with the family, and if so, in what way. An article published in the Mail Online in 2009, describes the common experiences and utter desperation of some parents who raise children with a disability (Monckton 2009). Considering to end a life because of the often unbearable frustrations and challenges of raising a child with a disability, is a more common thought among parents than might be expected. It is not only a rare individual consideration. Monckton (2009) describes the hardships of parents as follows:

When love is not enough: The joy and hardship in caring for a disabled child

It's the hardest job in the world, but parents caring for disabled children face a shameful lack of support. And, says ROSA MONCKTON, whose daughter has Down's, it's driving some to breaking point - and even murder.

Throughout his childhood, Don and Mavourneen Moore cared devotedly for their 17-year-old son, Cameron. But one evening at their comfortable suburban home in Essex, they suddenly reached breaking point. Cameron has Asperger's syndrome and in the past few months the gentle eccentricities of his youth have given way to increasingly violent and abusive behaviour. 'He banged this door several times,' his still traumatised mother told me, 'Then he attacked me; he got me round the throat and then he got me round the wrist.' She showed me her still badly swollen arm, as her husband continued the story. 'He started hitting himself, gave himself a bruise on his chin, started a nose bleed as well. And that led me to doing something I've never done, and never believed in, which is to raise my hand to him. And that makes me feel such a failure because I've crossed that line - it's a terrible thing. We've never hit Cameron.'

On a recent visit to London, intended as a family treat but ruined by Cameron's behaviour on the train, Mavourneen admitted to me that as she stood on the platform, she had looked down at the tracks and thought how easy it would be to push Cameron - a young man heartbreakingly aware of his own problems - and jump after him herself. The Moores, however, are certainly not the only parents caring for a disabled child to reach breaking point. As I sat on a Devon beach, with 31-year-old Julie Evett and the youngest of her three children, Rose, lying - apparently contentedly - in her push-chair, it must have seemed an almost idyllic family scene. But it wasn't, as Julie's profound despair made all too clear. Not only is her three-year-old daughter blind, she has severe epilepsy, her brain is not developing properly and she suffers from hypotonia, a floppy muscle condition. Rose will never be able to walk, talk or feed herself. She can also cry and scream not just for hours but days, even weeks at a time. Her condition is, as yet, undiagnosed, but looking after her is a physically and emotionally draining, round-the-clock job that one day drove Julie to consider what, for a mother, is supposed to be the unthinkable. 'I left the two older girls with a neighbour and Rose with her dad. I got in the car and I spent the entire day driving and crying, driving and crying. I wanted to scream out loud: "I want to take my own life." I just wanted to be out of this pain.'

However, in her distress and exhausted confusion, Julie came to the dreadful conclusion that killing herself and Rose was not going to be enough. 'My head

was playing around with me so much that I remember thinking: "I'm going to have to kill all three of my girls because I couldn't bear to leave the older two behind."

Thankfully, Julie didn't even begin to go through with this awful plan; just as the Moores' problems with their son went no further than a single, and instantly regretted, raised hand and a momentary dark thought. That's how strong and enduring the extraordinary love between a parent and even a severely disabled child can be.

And that's why many of these parents often end up looking after these children 24 hours a day, seven days a week. They live in an almost permanent state of exhaustion, despairing of things ever getting better, frustrated by the massive battles they have to fight to get even the most minor help. Not surprisingly, research from the charity Mencap reveals that eight out of ten carers get so worn out that they reach breaking point and are unable to care for their child. A mercifully small number of them even end up killing their own child.

Two years ago, Fiona Pilkington, driven to despair by ten years of bullying and abuse from local youths, bundled her seriously disabled, 18-year-old daughter, Francecca, into her car, drove to a Leicestershire layby and set fire to the vehicle. Both mother and daughter died in the resulting fireball. A month later, Joanne Hill drowned her four-year-old daughter, Naomi, who suffered from cerebral palsy, in the bath. Hill was eventually sentenced to life imprisonment, having been found guilty of murder rather than manslaughter.

An article I wrote for the Daily Mail in September last year in response to that tragic case led to me being asked to make a documentary about parents who have children requiring virtually 24-hour care and the tremendous pressures these families face. I know something of what they go through. Our 14-year-old daughter, Domenica, has Down's syndrome and, although she is adored by our entire family, caring for her, at times, has taken me close to breaking point. That's why I've spent the past ten years campaigning not just for the rights of disabled children but for their families, too. I know that awful feeling of being so tired you lose all reason. I remember one particular night with Domenica when I'd done five nights in a row - this was the sixth - and she

just couldn't sleep. She was just raging and raging and I remember picking her up and saying to myself 'I can't take this anymore' and I shook her ... before something snapped in my head and I put her back in her bed. In that moment, I saw how easy it is to lose control.

But having spent the past ten months visiting families facing far worse problems, families who are barely coping and living right on the edge, I know I'm one of the lucky ones. I have a deeply supportive husband and family, I have money and, for all-too short a time, I had the support of my good friend, Diana, Princess of Wales, who volunteered to be Domenica's Godmother soon after she was born, saying simply: 'You're going to need all the help you can get.' Diana was absolutely right; help is exactly what the parents of disabled children need and I've been appalled to discover in making this documentary how difficult it so often is for them to get it. At times, it was hard to believe I was in Britain in the 21st century.

Our standards of care are dismal, our understanding of what these families need is non-existent and the endless bureaucratic process required to access vital services is mind-boggling. Every family I visited had drawers bulging with files; letters from the director of this or the manager of that - all of them passing the buck; not one of them prepared to take responsibility and actually get something done.

Take Asher Nardone, a Dorset mother of two whose eldest son, 12-year-old Callum, has severe cerebral palsy which has left him unable to walk, dress or feed himself and with a mental age of two. Given his condition, it is perhaps not surprising that he is also doubly incontinent, increasing the already huge strain on his exhausted mother.

So, what do local social services do? They arbitrarily decide that Callum can have no more than three free nappies per 24-hour day. Asher, of course, protested - Callum can get through twice that number a day - but to get any more, social services wanted her to measure both 'inflow and outflow'; in other words, which food and drink went into Callum and which waste products came out of him. What were these people thinking? Given that the same social services department had previously advised Asher to 'hose him down in the garden' when she applied for a much-needed downstairs bathroom, I'm not sure they were thinking at all. What the parents of severely disabled children

need is compassion and care, not bureaucratic intransigence. Time and again, I came across evidence of a system that simply isn't working, that too often fails to get money and help to those who so desperately need it. As one exhausted mother put it: 'They should try walking in our shoes for two weeks. Perhaps then they will begin to understand.'

The Moores, for example, have faced an endless battle to secure some sort of life both for their son, Cameron, and for themselves. When his behaviour became more violent and they were in urgent need of a psychiatrist, they discovered that, because he was 17, he was now too old to have a child psychiatrist, but too young to have an adult one. All the grand talk of 'transitional pathways' between child and adult services turned out to be meaningless nonsense. They ended up spending £2,000 of their savings on securing specialist help, an option that simply won't be open to many parents facing a similar situation. How have we come to this? Why do we so consistently let these families down who need our help the most?

David Cameron, the Conservative leader, understands the problem from a very personal perspective. When I spoke to him, he and his wife, Samantha, were still grieving for their six-year-old son, Ivan, who battled cerebral palsy and other complications throughout his short life. 'To start with, we didn't have much help,' he told me, 'and we were just struggling through and getting close to collapse. Then we got a brilliant social worker and lots of help - and, of course, we were able to get extra help - but if we had none of those things, none of that help . . . it would have been desperate. A child like Ivan is 24-hour care.'

What he would like to see introduced here is a passport scheme, whereby a disabled child is given a single assessment that then opens the door for everything that child needs - respite care, specialist healthcare, benefits, schooling etc - without parents having to answer the same questions over and over again.

It seems a sensible and progressive idea and surely at a time when we have a Prime Minister with a disabled son (Gordon Brown's son, Fraser, has cystic fibrosis) and an Opposition leader who has been through the most terrible experiences, we ought to be able to make real progress in how we care for

the disabled and their families. We have to start looking after these people. What we have to avoid is falling into the old trap of brave words failing to be matched by deeds or frontline funds. We've heard a lot from politicians in recent years about getting more help to carers - and quite rightly so - but of the £50million allocated to carers this year, only £10million has reached the families who need it. The rest seems to have disappeared into the murky finances of our Primary Care Trusts. That's got to stop. There has to be less money spent on administration and more on delivery; there needs to be less assessing and more providing. And yet the gap between the rhetoric that spews from Whitehall in the form of endless initiatives - such as Better Lives, Better Care and Aiming High For Disabled Children - and the reality on the frontline is wider than ever.

Faced with the exhausting round-the-clock care that the parents of disabled children have to provide, I find it all too easy to sympathise with those parents who do reach breaking point, and even with the tiny number who end up taking their child's life. They are not evil; they just didn't get the help they needed. But what both heartens and astonishes me is the ability of the vast majority of parents of disabled children to soldier on, to keep on battling the bureaucracy and fighting for a better future - almost any future - for their disabled child. And they do so because they love them as only a parent can. As David Cameron said to me: 'You learn things about bringing up a disabled child that you never expected. You learn that there are all sorts of ways of loving someone who can't tell you that they love you.'

This article illustrates the severity of the frustrations and hardships experienced by parents raising a child with a disability, irrespective of the type of disability, the age of the child, culture and other factors. This reality should not be underestimated by faith communities and youth ministries if the aim is to provide effective, inclusive ministry this group of individuals.

CHAPTER 4

YOUTH MINISTRY

4.1 Introduction

In order to understand the role of youth ministry in the lives of children and youth with a disability, one first needs to understand who the children and youth are and what youth ministry really is about. It is essential to understand to whom “youth” is referring to in order to effectively address their age-specific needs and challenges within the ministry (Nel 1982:121). Due to the complexity of disabilities and the impacts of the various types of disabilities on the lives of children and youth living with these conditions, Chapter 3 focuses exclusively on disability. The purpose of Chapter 4 though is to describe youth ministry as a practical theology discipline. It seems that children and youth living with a disability are often excluded from youth ministries for various reasons – known and unknown (Barone 2008:10-11). The objective of this chapter is to determine whether youth ministry has a responsibility towards children and youth living with disabilities and to what extent.

4.1.1 An overview of the development of youth ministry

The purpose of this study is not to investigate the establishment and development of youth ministry in itself. However, an introduction is necessary in order to better understand the theological positioning of this study. Limited literature is available regarding the historical development of youth ministry (see Senter III 1973:14-15). The origin of youth ministry is debatable and many opinions exist on this matter (Dean et al 2001:77). According to Nel (1998:51) there are three matters regarding the development of the discipline that are certain. Firstly, most scholars agree that youth ministry was established by the latest during the industrial revolution and urbanisation in the nineteenth century. Secondly, youth ministry was originally referred to as “youth work.” Lastly, it is a fact that Sunday school was already a practice in England in 1780.

Although youth ministry became a focus point of the church since the second half of the twentieth century, a misconception formed that youth ministry was nothing more than a stepping stone in the ministerial profession (Dean & Foster 1998:212). The notion that youth ministers are temporarily invested in youth ministry until they can move on to a more official, “serious” type of ministry in the church, is a social construct in its own and far from the truth. Youth ministry is and ought to be a calling from God and a specialised ministry within the theological field (Martinson 1988:13). Youth ministry has come a far way and despite many challenges and stigmas, it is an established and prioritised ministry in the twenty first century. Youth ministry contributes to the establishment of matured faith spirituality in faith communities and is essential in the life of the church. Six characteristics of youth ministry that can help to strengthen the impact and functionality of an entire congregation include (see Bergler 2016):

- parents who are regular church goers and describe faith as “very” or “extremely” important to them;
- faith being of extreme importance in the lives of these adolescents;
- adolescents having multiple religious experiences, including committing their lives to God, had prayers answered, experienced miracles and had an impressive spiritual experience;
- adolescents praying and reading the Bible by themselves on a regular basis;
- adolescents convinced of their religious beliefs;
- adolescents having access to many adult mentors in their churches.

However, if these six characteristics become the norm to determine the impact on and contribution of youth ministry in congregations, it is clear that children and youth with a disability are already excluded. Most children and youth with a disability are not able to read the Bible by themselves or express internalisation of their faith experiences and beliefs for instance. An effort should be made to adapt these six elements in order to be inclusive of children and youth living with a disability.

4.1.2 A theological point of departure

Ministering to children and youth in faith communities is firstly motivated and substantiated from the primary source this study is based on, namely Scripture. Failing to prioritise a theological point of departure in youth ministry will eliminate

youth ministry as a credible faith based contribution in the global faith community altogether (Dean 2001:17). In fact, the entire meaning of youth ministry is based on a strong theological approach (Rahn 2001:390). Youth ministry is all about God (De Vries 2004:17): "... our youth ministries are, first and foremost, God's business." This is also true for the purpose of this study for which the Bible is used as a primary source. The Bible is a book about God, God's people and actions with these people (see Nel 1998:13), including children and youth (see Point 2.1). Effective youth ministry simply cannot have another starting point than God and the Bible (see Dean, Clark & Rahn 2001). The entire purpose of the Gospel is missional and the passing on of Jesus' narrative and message to all people across the globe, including young people (Martinson 1988:19-27). Within the congregation, youth ministry functions on various levels, including that of praise, worship, witnessing and pastoral care. The aim of passionate missionology is discipleship and converting children and young people into dedicated followers of Jesus Christ (De Vries 2004:165):

Our goal in youth ministry is not simply to get teenagers into a relationship with Jesus Christ. We are called to make disciples – men and women who are moving toward Christian maturity and obedience.

In the same way the purpose of youth ministry is to create a platform for children and youth to establish a serving, lively, long term relationship with God (Dean et al 2001:90). Youth ministry is based on activities and ministries such as missionology, praise and worship and discipleship (Fields 1998:47-50) and is all about equipping children and youth to grow towards mature Christian adulthood (De Vries 2004:116). Simultaneously, youth ministry aims to contribute to the establishment and growth of the faith community, as well as the Kingdom of God (Nel 1998:65). The result is that the development of youth ministry and that of the faith community correlates and is similar to each other. Together they are discovering and finding their communal identity as congregation. The focus of this interactive relationship between the youth and the faith community is related to the development of a personal relation with God, cognitive engagement with the Bible and the implications thereof and openness regarding this faith relationship (Nel 1998:65-67). The existential purpose of the faith community is to expand the Kingdom of God, by means of God given peace ("sjalom") in personal and congregational relationships, the formation of community

orientated believers, and the motivation of a serving attitude towards God and to make a difference in the world by spreading the good news of the Gospel (Nel 1998:67-75).

God is a relational God and all of creation exists in relation to others, whether it is other people, the creation or God self (Nel 1982:11). Theologically, youth ministry is based on this relational characteristic of God and God's works with and through people, including children and young people. The following points are of importance when focusing on the Biblical foundation of youth ministry (Nel 1998:11-13):

- as creator, God is involved in the giving and creation of children
- God remains involved in the lives of people, also young people, and is not distant after they are born;
- God is revealed to young people in the Bible, including David, Daniel and Jeremiah. God's actions with and through young people does not change in the New Testament;
- God's love for Christians is reconfirmed through Jesus who sacrifices his life for them. Jesus gives up his own life so that ALL people who believe in him (including young people) will inherit the eternal life.

The theological value of youth ministry is strengthened through God's ecclesiological approach to people. God works with people in groups throughout the Bible, including that of families, friends and audiences (see Nel 1998:17). It is this ecclesiological nature of God that calls for the togetherness and unity of faith communities and also the children and youth within these entities. Young people tend to prioritise group orientation. They want to be part of an expanded group identity. This explains why peer pressure is one of the most encountered challenges adolescents deal with on a regular basis. The faith community (and especially youth ministry) becomes a space where transformation is motivated and the new norm (Nel 1998:22-25). Transformation in the church entails total conversion to God and a life dedicated to Him. This conversion of a person to God is made possible through the work of the Holy Spirit only and is an act of mercy that no human can mediate (see De Vries 2004:161). The faith community, with specific reference to the children, youth and youth ministry, has no power to enforce conversion, but plays a role in God's

revelation to them. Radical transformations are motivated by passionate ministries that truly make a difference in the lives of people. Adolescents will not settle for a ministry offering anything less than extreme dedication and accordingly expressive lifestyles (Dean 2004:247-257). The credibility of Biblical and traditional narratives is partially dependent on the sincerity observed in the retelling, faith and lifestyle of the narrator(s) children and young people are exposed to. Young people respond better to what they see and experience than to what they hear and are told. For the purpose of this study, the way in which the gospel is shared is of particular importance, seeing that the development of the children and youth with a disability is affected. Their capacity to understand and respond is limited and faith communities need to be sensitive and creative in approaching and ministering to these individuals. Spending time to get to know these children and youth, their abilities and limitations will be essential in order to ensure accessible, inclusive youth ministry.

4.2 Youth ministry and practical theology

Youth ministry cannot be understood or discussed without bringing it into the context of what it is: a practical theology field of specialisation. There are different theories to youth ministry as a sub-discipline of practical theology which makes it difficult to determine when youth ministry was in fact classified as a practical theological discipline. Whereas some theologians are of the opinion that youth ministry was only recently acknowledged as a form of practical theology (see Dean et al 2001:19), others accentuate youth ministry as a congregational responsibility from the establishment of the church structure (Nel 1982:2-3). Originally, the term “youth work” referred to organised, evangelical attempts with the youth outside of church entities (Nel 1998:51), which resulted in acceptable limitations and misinterpretations of youth ministry (Nel 1982:29). To complicate matters even further is the argument that youth ministry theories and practices do not correlate. Hence, it is quite impossible to determine when exactly youth ministry was officially classified as a practical theology discipline.

However, youth ministry from a practical theology approach means that children and youth received a divine calling to participate in all Christian practices and ministries, seeing that all believers in Jesus Christ are automatically included in God’s salvation plan. The result is that these young people become practical theologians in their own

right, based on their calling and not their ages, qualifications or professions (Dean et al 2001:19-20). It is about taking Christian action (the main criteria of practical theology) to spread the gospel to the rest of the world. The purpose of any practical theology ministry is taking action in faith, with the understanding that God's own actions and works are not limited to these ministries or disciples. It is this discipleship and obedience to God that gives meaning to ministry at the end of the day. Practical theology (and youth ministry therefore) accepts that Christians practice their beliefs and are consciously living a life of acts of faith. Christian action requires concrete situations to practice these beliefs (see Dean et al 2001:20-21). In the case of youth ministry these concrete situations are firstly about the understanding of the concrete situation from theological sources including Scripture, traditions and dogma. It calls for a description of the concrete situation in which a person receives the calling to become involved in youth ministry. Secondly, depending on the concrete situation described, reflection on the situation leads to the identification of an applicable, effective youth ministry approach. The approach is then monitored and evaluated closely by means of logical implementation of applied theories. The last step is projection or rather the constant search for better and more effective ways to share the Gospel with children and youth in faith communities. Despite all insights and efforts, it is important to keep in mind that youth ministry, the developments and effects of it on young people's lives, like all other practical theology disciplines, is firstly dependent on the renewing actions of the Holy Spirit (Heitink 1999:192-193). God empowers human action through the intervention and guidance of the Holy Spirit. Conversion is an act of grace and mercy by God only, no person can enforce it onto another. The work of the Holy Spirit cannot be methodised or limited. God does not eliminate human action, but rather enables it as long as a person is receptive for the work of the Holy Spirit. This reciprocal relationship between God and Christians is an elementary requirement for youth ministry (Van Ruler 1969:175).

4.3 The youth sub-culture

Although cultural differences constitute a significant challenge in this investigation (See Point 1.6), the notion of two sub-cultures also plays an integral role. These two sub-cultures are the disability and youth sub-cultures. The disability sub-culture is described under Point 3.4. The youth ministry section focuses on the so called youth sub-culture. Society is differently impacted by these two "categories:" whereas

“culture” refers to typical behaviour for an entire society (including secularism, materialism and postmodern thought), “sub-culture” refers to the typical behaviour within a smaller group within the society (see Ratcliff & Davies 1991:9). For the purpose of this study, “culture” will refer to a contextual adult culture, whereas the “youth sub-culture” indicates the adolescent phase with its particular tendencies and needs. It makes sense that the youth sub-culture is influenced by the contextual, adult culture on various levels, globally and in South Africa. Thorough knowledge of both theology and the youth sub-culture is required for effective youth ministry (Martinson 1988:27). It is important to understand that the youth sub-culture refers to the *current* youth culture (Nel 1998:30). In a fast developing, evolving world where the circumstances, influences and orientations change almost daily, so does humanity and what is regarded as important by them. Just imagine the major trends of the postmodern society, namely technology, social media and fashion. These are major influences on people of all ages today, although they were not even in existence a few centuries ago. These constantly changing orientations and beliefs are also experienced by the young people of the world. The result is that the youth sub-culture transforms as time goes by. Therefore, the youth sub-culture becomes a place of safety for youth who might not find adequate support for their faith anywhere else (Strommen & Hardel 1989:187). The sharing of similar influences and challenges unite this group of individuals in a communal identity where they feel comfortable to be who they are as long as they conform to the standards of the majority of youth. In essence, the youth sub-culture is a phase of compensation where youth experience temporary security and belonging (Ratcliff & Davies 1991:9). Typical factors identified with the youth-subculture include music, media, peer pressure, drugs and sex (see Mueller 1994). These are mere examples of influences young people are challenged with on a daily basis and how they conduct their lives. Faith communities (especially youth ministry) need to be aware and informed of these factors in order to effectively identify with this group of individuals. Internal key terms which are applicable to the youth sub-culture include (Nel 1998:31-36):

- “Adolescence” and its typical physiological, biological and social changes. Understood as the phase between biological puberty and socially accepted adulthood, these individuals are not regarded as children or adults. The

result is that they turn to co-adolescents who enjoy the same passions and endure the same challenges, in order to be understood.

- “Narcissism” and the adolescents’ tendency to be self-involved: caused by their insecurities and anxieties in the light of leaving their parents and becoming independent, adolescents experience a significant need for self-development on all levels. Narcissism accentuates the complexities of this developmental phase, which calls for sensitivity to and with the youth. An imbalanced self-involvement can lead to enforced arrogance, also known as narcissism of which the consequences include self-consciousness, inferiority complex and megalomania.
- “Identity finding” as the primary task during adolescence in order for the young person to discover his or her own personality, boundaries and beliefs. During this time adolescents experiment with everything known to them: their upbringing, faith orientations and norms. It is important for them to test their boundaries before they can establish their personal preferences and beliefs (see De Vries 1994:136).

It is because of the specific needs, orientations and challenges of the youth sub-culture that faith communities, and especially youth ministry, has to be sensitive and inviting to the young people of the day. The only way to address their age-specific needs is to be familiar with what they endure daily, to get to know them in such a way that ministry can be impactful and efficient in their lives. The differentiated-focused characteristic of youth ministry plays an integral part here (Nel 1998:88). The children and youth need ministry in a particular private space in order to serve them on their unique level of development, understanding and interests. Consideration and understanding of the youth sub-culture is the only way youth ministry can effectively reach young people and make Scripture and faith essentially part of their life styles, as explained by Dean & Foster (1998:173): “... the ability to translate the gospel is critically important for the crosscultural communication that is part and parcel of ministry with youth.” Therefore, youth ministry needs to take place on a unique platform, though inclusive to the rest of the congregation, but on a

specialised level where their needs are accommodated, considered and addressed effectively. For the purpose of this study, it is this differentiated-focus of youth ministry that ought to be a key element of effective, inclusive ministry to children and youth who are living with a disability.

4.4 Youth ministry approaches

In the postmodern era and in light of postfoundational practical theology, various approaches to youth ministry are identified (Dean et al 2001:20-21). Considering the concrete context of this study that focuses on the status of children and youth with a disability in South African faith communities, the various approaches to youth ministry are discussed in this section. In the final chapter of this study, the aim is to identify youth ministry approaches that are inclusive of children and youth with a disability. An informed decision can only be made once the various approaches are described and familiar. The following four approaches to youth ministry are distinguished:

- **The preparatory approach**

The preparatory approach is defined as follows (Senter III 2001:40):

“...a specialised ministry to adolescents that prepares them to participate in the life of existing churches as leaders, disciples, or evangelists.” The understanding is that young people receive in service training as disciples in their congregations, both for the sake of the present and future. The result is that young people are lead and guided by the leaders of their faith communities towards faith development. Evaluation of the preparatory approach results in the following:

Positive attributes of the preparatory approach (Senter III 2001:40-45)	Criticism on the preparatory approach:
The entire congregation is involved in the spiritual guidance of young people.	There is a risk of adults being regarded as integral to ministries, whereas young people first need to be trained for service within the congregation (Senter III 2001:66).
Youth ministry is not a separate program	Implementation of the preparatory

in the congregation.	approach can be challenging, due to the unwilling attitude of some adults that do not want the youth to form an integral part of the congregation (Senter III 2001:70).
Missionology and discipleship occur simultaneously in youth ministry.	
The preparatory approach allows for an inclusive ministry, as well as for differentiated specialisation.	
The role of parents in their children's faith development is accentuated	

- **The missionary approach**

In the missionary approach the youth is regarded as a mission field (Senter 2001:80). The differences between the youth and adults are accentuated, which results in a sensitivity to sub-cultures and more effective ministering to this group of individuals. Another benefit of this approach is that it is especially receptive to "broken" people. Young people with many problems and sadness will benefit from such an approach. With a specific focus on the youth sub-culture, youth ministry tends to become an increasingly caring environment, rather than a congregational activity (Senter III 2001:92). The first criticism on the missionary approach is that the general understanding of missionary work in the church is often misunderstood, whereas relationships established through this approach tend to be more friendship based than spiritually inspired (Senter III 2001:97-99). Secondly, the accentuation of outreach devalues the elementary element of mentoring and education in youth ministry (Senter III 2001:102). The missionary focus can also cause shortfalls to children and adolescents who have already been converted to the Christian faith (Senter III 2001:106).

- **The strategic approach**

The strategic approach entails that the youth is lead and formed to such an extent that they establish an entire new congregation based on the principles of the mother church (Senter III 2001:136-148). The goal of this approach is to ensure that the church always remains relevant to times and society it is functioning in, hence accommodating the complexities of the current youth sub-culture optimally. A second benefit of the strategic approach is that it allows for a community orientated ministry and is less dependent on the efforts of the youth worker as individual. Long term impact is ensured seeing that a new congregation is established, with extended contingency in relationships, memberships and involvement. However, this controversial approach results in extensive criticism (Senter III 2001:139-147): church members are not expected to make adaptations in the interest of others, church unity no longer exists when the youth functions separately, the credibility of youth ministry is threatened because the focus is to establish a new church, rather than facilitation of a faith enriching ministry, intergenerational and family relationships are threatened because of the illusion that the youth is allowed to function exclusively within their comfort zone, age and interest groups and lastly, this approach is regarded as a superficial solution that is quantity driven and encourages conflict between generations.

- **The inclusive congregational approach**

The inclusive congregational approach to youth ministry regards the youth as an integral part of the congregation in its entirety. The essence of this approach is that the youth is unconditionally part of the congregation and not just a separate congregational project. The inclusive congregational approach to youth ministry is defined as follows (Nel 1998:96):

- it is a comprehensive congregational ministry;
- through all types of ministry;
- that specifically takes into account the role of the parents (or caregivers);
- on a differentiated-focused manner;
- under the leadership of and through the officials;
- to, with and through the youth as an integral part of the congregation;

- and with and through the youth to the world.

In this approach it is clear that the spiritual lives of the youth are never viewed separately from that of the adults in the congregation. They never function separate from the congregation and are not allowed to be ignored or neglected. Youth ministry is the responsibility of the entire faith community and not just that of the youth worker(s). Benefits of the inclusive congregational approach to youth ministry include that it has a strong theological point of departure and focuses on God, not on the members of the church or the people in charge. It also focuses on the unity of the congregation according to Scripture (Senter III:13-14). Because the youth has such an acknowledged place in the congregation, they tend to remain part of the faith community and do not often leave the congregation following their confirmation (Senter III 2001:4).

Criticism regarding the inclusive congregational approach to youth ministry include that adults are not always willing to grant the children and youth their rightful place in the holistic functioning of the faith community (Senter III 2001:27). There is a fine line between differentiation and inclusivity, which is not always easy to distinguish and can make the implementation of this approach difficult. To have an extensive knowledge of the youth sub-culture within every ministry of the congregation is somewhat impossible in practice (Senter III 2001:25), whereas the effectiveness of this approach in larger faith communities is questioned (Senter III 2001:33-34).

In Chapter 7 of this study the inclusive congregational approach to youth ministry is investigated further in order to determine whether the inclusive focus of this approach can be effectively extended to ensure the integration and inclusivity of children and youth with disabilities in faith communities.

4.5 Challenges in youth ministry

Social constructionism is relevant and causes challenges in all postfoundational investigations, including the field of youth ministry. There are various falsifications of youth ministry one needs to be aware of in order to ensure proper understanding of this discipline and its rightful place as ministry in faith communities. These social constructs include:

- That youth ministry is a temporary extracurricular activity for reverends to be (Martinson 1988:13). This simply is not true, since youth ministry is a Godly calling and academic field of specialisation that needs to be regarded as such.
- That the purpose of youth ministry is to ensure faith communities or churches for the future. The first and foremost objective of youth ministry is to lead children and youth into a long term, personal relationship with God (Dean 2004:13-14).
- That youth ministry is focused on a particular group of youth for whom certain programs are presented or who hosts particular programs. In fact, youth ministry is a congregation and community matter involving *all* people, not just a selective few (Martinson 1988:13).
- That youth ministry is first and foremost about the children and youth. Youth ministry is primarily about God (Dean 2004:14).
- That youth ministry is the responsibility of the youth worker. Youth ministry is the responsibility of the entire congregation, parents and family (Martinson 1998:11).
- That youth ministry takes place in separation from the rest of the congregation. It is true that youth ministry is uniquely focused and differentiated. However, the youth is not superior to any other congregational ministry and participates in the faith community as all other ministries (Nel 1998:78).
- That youth ministries are always highly prioritised by all faith communities. Although this is true for many congregations, the experience is that in practice youth ministry does not receive the same attention and prioritisation and can easily become a neglected part of the faith community (Martinson 1988:15).
- That the successes of youth workers are determined by their physical appearance, age and popularity. Although this often seems to be the case, the

effectiveness of youth ministry does not depend on the influences of any individual, but on the calling of God and God equipping people to perform the task at hand through faith and dedication (see Stone 1979:55-57).

It is clear that these social constructs will influence opinions of youth ministry and of its impact. The field should be understood as a practical theology discipline in order to eliminate such misconceptions and constructs.

On a secondary level youth ministry faces challenges in the congregations. Firstly, faith communities tend to isolate the youth to operate separate from the rest of the congregation (Nel 1998:78). Isolation or separation are not ideal and should not be confused with differentiation. Although a specialised setting or environment is justified to accommodate and develop Christianity within the parameters of the youth sub-culture, the children's and youth ministry is not an independent organisation from the church and should not be treated as such. Secondly, adults and parents often find it difficult to understand the children and youth, which impacts actions to, with and through the youth negatively (Dean & Foster 1998:77). Although adults and youth differ, such differences should be embraced by Christian adults, who should appreciate these young people for who they are and what they contribute to the faith community. Lastly, it seems to be a challenge to faith communities to retain children and youth in the faith community, whether as youth (Dean 2004:7-9) or as young adults (De Vries 1994:24-26). Internationally, the church is losing young people at a rapid rate, and also in South Africa. The implication is that approaches to and the implementation of youth ministry are often ineffective and call for serious reconsideration. The purpose of this study is to determine whether children and youth with a disability are sufficiently reached through youth ministry in their faith communities, and how disability inclusive youth ministry can be accomplished. Once the status of children and youth with a disability is established in South African faith communities, the impact of youth ministry on their faith development will be indicated more clearly.

External challenges from a postmodern society are also experienced in youth ministry. Every era comes with unique societal orientation, beliefs and social constructs. These factors influence all people and institutions, including faith

communities and youth ministry. In this 21st century, a mixture of modern and postmodern orientations with tendencies such as materialism, secularism, capitalism, a focus on science and technology, pose problems to youth ministry that have to be addressed in creative ways in order for the ministry to remain relevant and effective (Nel 1982:169-176). Children and youth grow up absorbing the values and ideas of culture which become part of their frame of reference and their identity. These matters should be addressed from a theological, youth ministry point of view in order to counteract negative effects that contemporary patterns of thinking can have on these individuals. The influences of the media, globalisation and especially also social media on the lives of children and youth are profound (Dean & Foster 1998.995:155-156). What they perceive as acceptable, does not necessarily correlate with a Christian lifestyle according to the gospel. Youth ministry should provide a platform for young people to understand the differences between various worldviews and that of the Christian faith.

The impact of busy, rushed lifestyles has consequences for children and the youth (see De Vries 1994:74-78). Where in the past young believers often invested their free time in their faith communities, they barely have time available to spend with their families and loved ones these days. They do not have the time to spend hours at the church or church activities, such as outreaches and camps. School, examinations, sports and other extracurricular programmes cause severe time limitations. All of this should be taken into consideration when faith communities and youth ministries plan for a feasible, practical ministry with this group of believers. The impact of limited time is also a problem for children and youth with disabilities and especially for their parents. Fatigue is one of the major reasons parents give for not attending church (see Ault 2010).

The complex structures and circumstances in postmodern families present challenges to youth ministry on various levels, including on social, psychological and religious levels. Parents of caregivers' general attitude toward religion and to what extent they prioritise of faith in their lives, has an impact on the faith development of children and youth. It also has an effect on youth ministry in general and particularly on ministry with children and youth with a disability.

Youth workers' attitude towards the faith community and vice versa can be beneficial or detrimental to ministry with young people. Youth workers tend to be exhausted much quicker than other people in other ministries (Dean 2004:91). Reasons for this fatigue experienced by youth workers have been identified as, firstly, an erroneous approach to youth ministry by the youth workers. This especially is the case where God is not the central objective of the ministry activities. Other caveats are the desire to be liked by all, having others become dependent on them, or trying to keep everybody happy at all times (Dean & Foster 1998:59-66). These notions form an incorrect and damaging point of departure for youth ministry and youth workers and can have a devastating impact on the children and youth, youth worker and the congregation. Tendencies such as these lead to opportunities and people being abused. It can also lead to arrogance and a false attitude of being independent of God.

On the other hand faith communities can abuse youth workers by expecting too much of them or by frustrating their work by restricting funding and resources for youth ministry (Strommen et al 2001:41). Particular frustrations caused by faith communities as identified by youth workers include extensive, time consuming administrative responsibilities, feeling disrespected in their profession, a struggle to find balance between their professional and personal lives, as well as inadequate counselling training (Strommen et al 2001:36). Attempting to reach children and youth effectively through youth ministry in this day and age is already a challenge. If external factors make it even more difficult, this can lead to youth workers feeling incompetent or unsuccessful. It is important to invest in the vision and work of youth workers and empower them as much as possible. The ultimate goal is to facilitate long term relationships with God.

The life stage in which children and youth find themselves also contribute to making youth ministry a challenging enterprise. Youth ministers and workers have to cope with the unique demands and phenomena of the life stages of childhood and adolescence. Issues such as narcissism, hormonal changes and low self-esteem have to be dealt with. Many of these challenges are exacerbated by the prevalent youth sub-culture. These should receive extensive attention in order for youth ministry to be effective, sufficiently differentiated, but also sufficiently inclusive.

4.6 Children and youth in South Africa

In South African, a “child” is legally regarded as “a person under the age of 18 years” and has the right to state protection (The Constitution of the Republic of South Africa Act 108 of 1996 28(3) & The Children’s Act 38 of 2005 (1)). In this study “a child” will refer to a person under the age of eighteen. The focus group of this study is not limited to “children”, but also includes “youth” in order to gain a broader insight into the situation of young people with disabilities. The reason for this choice is that disability is often not sufficiently diagnosed during the early life stages, which causes problems and unique challenges for the families who care for such children.

Unlike with the term “child” about which there is general agreement, the term “youth” is interpreted differently by various disciplines. Whereas the term “youth” is defined as: “being young; early part of life, esp. adolescence” (Coulson et al 1980:983), official South African legislation defines youth as young people between the ages of fourteen and thirty five years (National Youth Policy 2015-2020:11). Theologically speaking, “youth” is understood to be persons in their early life stages, with emphasis on the adolescent phase (Dean, Clark & Rahn 2001:21-22):

As you explore this text, you will notice a number of terms for young people: youth, adolescents, teenagers, students ... you may consider these terms synonymous ... Today a youth may be any young person between the onset of puberty and fully individuated adulthood ... Adolescents in the United States today often begin during late childhood (ages of 9 or 10) and extends through the mid-20s or sometimes later (when the young person makes enduring commitments relative to vocation and intimacy).

Depending on the severity of the disability, developmental progress (physical or cognitive) occurs slowly and in some cases not at all. The challenges and hardships that the affected children or youth and their family endure during these early life stages are unique, especially since the diagnosis of disability more often than not takes place during this time of a person’s life. Considering all the various perspectives, for the purposes of this study children and youth will be regarded as persons below the age of 35 years. Therefore the focus group consists of the Christian parents of children and youth with disabilities below the age of 35 years.

4.7 Youth ministry with children and youth with a disability

Limited data is available regarding youth ministry with children with a disability on international front, but even more so in South Africa. Because of the lack of data regarding youth ministry with children and youth with a disability, this topic was identified as the research gap of this study (see Point 1.3). Children and youth with a disability experience exclusion from all spheres of life (Philpott & McLaren 2011:3-4). Despite a political will to better the circumstances for this group of individuals globally, knowledge about disability is fragmented, resulting in many gaps in service delivery. The objective of this study is to determine whether children and youth with a disability are also experiencing such exclusion from faith communities and its activities in South Africa. In the South African context the only studies with regard to theology and children or youth with a disability is limited to the contributions from Mercy Shumbamhini (2008) who focused on narrative therapy to children with a disability in the Mary Ward Children's Home, and Patrick Mdluli (2012) who investigated disability from a theological and socio-economic perspective. Neither of these studies investigated youth ministry specifically, indicating a research gap in South Africa. Various studies were done regarding youth ministry and disability on international front, even though more investigation is necessary. A recent study in the US found that more than half of parents with children with a disability reported that their child was excluded from church activities (see Dingle 2016). Melinda Ault (2010) studied 400 parents of children with a disability and their experiences with their child in faith communities.

The situation with regard to churches and children with a disability in South Africa is still relatively unknown and has prompted this investigation. The majority of parents in this study report that their child experiences exclusion from churches, religious activities, and that they encounter a lack of awareness and knowledge about disability among members of the congregation. Churches make provision for participation by children with a disability, require parents to be present. The objective of the study is to investigate the church attendance of children and youth with a disability and to establish the reasons for their attendance or non-attendance, to ascertain whether they are ministered to effectively. The study also aims to investigate the factors that contribute to the non-participation of children and youth with a disability in faith communities and to establish whether an "inclusive

congregational youth ministry” model could effectively facilitate increased inclusion of this group of individuals.

Increased inclusion of persons with a disability can be facilitated by means of congregational efforts such as designing activities for participation by all members, cooperation with external facilities that support people with disabilities, the orientation and empowerment of church leadership with regard to people with disabilities and their needs, and arranging practical interventions to enable the full participation of individuals with a disability (Carter et al 2017:582-583). From an understanding youth ministry as integral to congregational ministry, these principles should be adopted not only by the congregation at large, but also specifically by the enterprise of youth ministry. To accommodate young people effectively in congregational ministry requires a diversified focus. Including children with a disability requires even more specialised knowledge and efforts.

The basic principles of youth ministry remain applicable with regard to children and youth with a disability. However, the personal needs of the child or youth should be understood and accommodated within the ministry. Getting to know children and youth on a personal level, is a requirement for effective ministry. Osmer (2008:34) describes it as follows:

It is a matter of what is going on in the lives of individuals, families and communities... It is a matter of opening ourselves to the forming and transforming Spirit of God who remakes us in the image of Christ within his body. Unless we first learn to attend to, we cannot really lead.

It is the sincere presence and interest in the lives of these children and youth with a disability that will grow into transformed, inclusive youth ministries.

Because of its focus on inclusivity, Malan Nel’s (1998) model of “inclusive congregational youth ministry” is explored as a viable option for facilitating inclusive ministry to the disability community. This model emphasises the importance of creating accessible, inclusive ministry structures to all, including children and youth. In Chapter 7 of the study this model is evaluated as a possible youth ministry approach to facilitate the effective inclusion of children and youth with a disability

(See Point 7.3 and 7.4). In this chapter guidelines will be given for youth ministry with children and youth with a disability in South Africa.

CHAPTER 5

EMPIRICAL INVESTIGATION

5.1 Introduction

The purpose of the empirical investigation of this study is to listen to the narratives of the parents of children or youth living with a disability in order to gain insight into the complex challenges of their lives and to identify ways in which faith communities and youth ministry specifically, can contribute to improving their lives and experience of faith and spirituality. If these families could be more effectively included in the activities of their faith communities a feeling of belonging and the experience of practical support, an effective care system and a safe space for sharing and debriefing can strengthen their Christian faith. The purpose is to inform and guide ministerial and youth ministry practices to evolve into becoming inclusive spaces for children and youth with a disability and their families.

The theoretical framework of the empirical section of the study is Julian Müller's (2004:301-304) 7 Movements of Practical Theology. This chapter deals with Movements 1 and 2:

- Movement 1: conducting investigations within a specific context by means of interviews with the individual participants.
- Movement 2: listening to and describing the narratives of participants takes place in the form of structured interviews with the parents of five children or youth with disabilities. The purpose is to investigate to what extent whether children and youth with disabilities are included in the services of their faith communities and in the youth ministry activities of their congregations.

5.2 Qualitative investigation

The aim of this qualitative investigation is to explore the status and situation of children and youth with a disability in various South African faith communities. Data will be collected by using qualitative investigation methods, both a perusal of literature and by means of structured interviews (see Annexure A) with the parents of

five children or youth with a disability. Their narratives will provide insight into the challenges and realities they face in society and in churches. These insights can contribute to a better understanding of what can be done by churches to provide a more effective and inclusive ministry. The qualitative investigation aims to achieve what McLeod (2001:3) explains as follows:

Qualitative investigation is a process of careful, rigorous enquiry into aspects of the social world. It produces formal statements or conceptual frameworks that provide new ways of understanding the world, and therefore comprises knowledge that is practically useful for those who work with issues around learning and adjustment to the pressures and demands of the social world.

The purpose of the qualitative investigation of this study is to listen to and describe the narratives of each of the participants, considering the impact of their different experiences and interpretation in each of their unique social setting. From a postfoundational perspective the own unique values, perspectives and wisdoms will be respected and no attempt at generalisation will be made (see Gergen 1994:24). The aim is to understand “the issues being investigated from the perspective of the investigation participants” (Struwig and Stead 2007:12). The influence of my personal experiences, culture and background in the interpretation of these narratives can also not be denied. The role of social constructionism in the narratives of people (and also in this study), distinguishes the qualitative method of investigation from that of quantitative investigation. Van der Stoep and Johnston (2009:166) describe the difference as follows:

A qualitative perspective assumes that knowledge is constructed through communication and interaction; as such, knowledge is not “out there” but within the perceptions and interpretations of the individual. In short, knowledge is constructed or created by people. A qualitative perspective assumes that you cannot analyze and understand an entity by analysis of its parts; rather, you must examine the larger context in which people and knowledge function. This concept is called the social construction of reality.

This study also implemented the four characteristics identified with the qualitative investigation model in general (Struwig and Stead 2007:12-13):

- Perspectives of the participants and the investigator: qualitative investigation prioritises the perspectives of participants, their experiences and understanding of these experiences.
- Contextuality: investigation takes place in a specific context that should be understood by the investigator. Physical and historical contexts should be taken into account. People's interpretations of experiences are also formed within specific personal and social contexts. Contexts consists of "actions" and "agents." Continuous interaction takes place among the different contexts This provides a complex dynamic.
- Process: qualitative investigation demands investigations to be procedural. The development and continuum of events are considered, more than the event itself. Consequently, investigation becomes a circular process guided by paradigms and models.
- Flexibility and the use of theories: although qualitative investigators are reliant on and make use of literature and theories, the inputs and contributions from participants are prioritised in order to ensure an openness to the data received from the people who experience the situation. Behaviour and expectations should therefore not be prescribed or dictated by theory.

This study opts for a combination of the qualitative and quantitative investigation methods as is required by the nature of the investigation. With regard to the sample selection of this study, a non-random, convenience sampling selection method was chosen (see Van der Stoep & Johnston 2009:27). Participants were identified based on their availability and willingness to participate in a structured interview about the status and situation of their child with a disability in their faith community. An invitation to participate in the study was distributed electronically to different organisations and institutions in the disability sector. Parents of children and youth with a disability indicated their willingness to participate in the study and made contact with me by means of the contact details provided on the invitation. Consequently, parents who do not have access to any of these institutions did not get the opportunity to participate. Two participating parents were known to me. I

personally invited them to participate in the study. A survey investigation strategy in the form of a face-to-face, structured interview took place with the parents (see Van der Stoep & Johnston 2009:37-38). Interviews were conducted only once with each participant, classifying the design of the investigation as a one-shot design (see Van der Stoep & Johnston 2009:38-39). The interviews took place in settings convenient to the participants and varied between visiting them at home or at the particular disability organisation, while others preferred to have the interview at my office in Rietondale. All interviews took place in a secure, private and safe context. Upon completion of the transcription of each interview, the written version was supplied to each participant for their agreement and approval. The design and outline of the interviews were guided and directed by the following guidelines of Rubin and Rubin (1995:4):

... conversations in which a researcher gently guides a conversational partner in an extended discussion. The researcher elicits depth and detail about the research topic by following up on answers given by the interviewee during the discussion.

Though the interviews were structured, with set questions, they often spontaneously digressed into a more informal conversation between myself and the participants. Many of them were eager to talk about their circumstances and experiences raising a child with a disability. Even though not all of the information shared was specific or relevant to the primary purpose and questions of the structured interview, these conversations and information added to the insight and knowledge of the experiences and interpretations of participants. Additional, informative data collected this way was noted in the transcription of the individual interviews. This style of interviewing is also known as “responsive interviewing”. In this way more could be learned about what was important to participants, rather than interviews remaining a static tool to collect data (Rubin & Rubin 1995:15).

5.3 Structured interviews with the parents of children with a disability

The structured interviews with parents took place in different settings. Once parents indicated their interest to participate in the study, a meeting was scheduled with them at a time and venue convenient to them. Interestingly enough, with the exception of Zodwa, not one other parent opted for the interview to take place at their homes. All interviews took place in an office setting (whether it was theirs or mine) or a public meeting area, such as a coffee shop.

5.3.1 Hope in Hammanskraal: Sophie and Maria

1. Background:

In the heart of Hammanskraal resides a single mother, Sophie Kgobe, with her 25-year old daughter, Maria Kgobe. Maria was diagnosed with Cerebral Palsy as a toddler. They are Tswana speaking, black women living with their family in this previously disadvantaged community. Despite experiencing many hardships in life, their story is one of hope for faith communities and people with disabilities across South Africa.

2. Describe the composition of your family?

It is just me and Maria and her sister. Her father left us when Maria was five years old.

3. Describe your living environment?

My parents and niece stay with Maria and myself in a small house in Hammanskraal. We have little space and only two rooms. I sleep with Maria and my niece in one bed due to her disability. It is very difficult. We also use an outside toilet.

4. When and how was your child diagnosed with his/her disability?

Maria developed normally as a baby, and was already walking by the age of 9 months. However, the illness and treatment was severe, leaving her unable to sit or walk upon discharge from hospital. Doctors did not know what caused

her illness and she was admitted to hospital for a long period of time. Eventually, she was diagnosed with Cerebral Palsy.

5. Did you feel that someone was responsible for the disability? Explain.

Yes. Even until today. During Maria's treatment in hospital, a drip was inserted in her skull, causing her head to swell for two days. The drip was inserted despite the brain scan not indicating any brain damage at that time. After this swelling of her head, her condition worsened and her behaviour regressed to the point where she was not able to do any of the things she was able to do before. In my opinion, her condition was caused by this drip.

6. Explain the limitations caused by the disability(-ies)?

Up until the age of four years old, Maria wasn't able to do anything by herself – she did not sit, walk, speak or use the toilet by herself. With treatment and a lot of hard work she eventually mastered most of these daily living activities, but is still not able to speak. Her brain function is underdeveloped and she functions at the age of a young teenager, but she is 25 years old.

7. Does your child receive any treatment?

She is only getting medication to calm her down and help her sleep, nothing else.

8. Does your child attend a care facility or special school?

Yes, she is attending a care facility in Hammanskraal.

9. Where does your child reside? Provide reason(s).

She stays at the care facility and comes to visit when I am home. I work on a fortnightly rotation basis and cannot leave her home by herself when I am at work.

10. Does your child make use of special devices?

Maria developed well and is capable of walking by herself and getting around with assistance. She does not need a wheelchair or crutches. I raised her to be as independent as possible.

11. How would you describe the mobility of your child?

She is mobile and moves around independently. She can walk without any assistance, although not fast.

12. What does caring for your child entail on a typical day?

Although Maria is fairly independent physically, she cannot function on her own mentally. She has to be assisted and supervised all the time. She likes to sneak out when everybody else is sleeping, which puts her in grave danger of criminals and bad people. One day she snuck out and was raped by a neighbour – being mute makes her vulnerable and an easy victim. Consequently, three of us sleep in one bed: me, Maria and my cousin. Now that she sleeps in the middle of us, she cannot even go to the toilet without us knowing. She also will take any money lying around at home and run off to the shops. Fortunately, the shop owners know her by now. Every time she sneaks off, I have to look for her, sometimes it takes hours and I get worried. Most of the time I find her at church, she loves going to church. She will also try dangerous things when she is alone, like cooking. Even though she cannot operate the stove, she tries. It is easy for her to get injured. She also gets aggressive and destructive. She hits my father and breaks our stuff at home. She does not have friends of her own age and literally still “plays” with the younger children. She likes standing with them and listening to their conversations. We don’t know what she understands from it, but she laughs a lot when she is with them.

13. How does raising a child with a disability affect you on the following levels (in the past & currently)?

- *Emotionally*

Emotionally it is very hard you know. At the beginning I just cried and cried, until I accepted her condition just recently. I was angry and I was especially angry with God. Looking around and seeing young people her age in the streets and shops... I cannot explain the feeling; it is just very bad for me.

- *Socially*

We had to deal with a lot socially. Maria's father left us when she was only five years old. He could not cope with raising a child with a disability. I had to raise her and her sister alone with my parents. When we go to the shops, people who don't know us or are not familiar with disability just stare at us. Just recently I confronted a taxi driver who shamelessly stared at her for a long time. I wanted to know if he has never seen somebody like her before. He said that there was no problem, but it was clear as daylight. And of course, one is always concerned about her safety in a poverty-stricken high-crime community.

- *Physically*

Physically I am fine now. There was a time when I had to do everything for her that I was extremely tired and did not know how I was going to get through this ever. She did not sleep at all and I was very tired. Luckily, the medication helps her to sleep and we are better now.

- *Financially*

Oh, financially it was and is extremely hard for us. Life is expensive and she will never be able to work or stay independently, I will have to provide for her for the rest of her life. Luckily, the community and church helps us a lot with food and clothes.

14. Explain the general attitude towards disability in your community and/or culture?

We are very fortunate that the headquarters of the House of Prayer Churches is located in Hammanskraal, doing a lot for awareness and support of people with disabilities in the community. The fact that most people are aware of and care about people with disabilities, helps a lot. Mostly, people are friendly and supportive of us. However, there still are individuals who judge us and think that we are witches, especially my mother. They believe that she is a wizard, because how can we have a child like this? Or others do not want their

children to play with Maria, because they think her condition is contagious and their children will also become like her. How can that be?

15. Do you participate in church services and other events in your faith community?

Yes, on a weekly basis. Like I said, our church cares a lot about people with disabilities and the old people, mostly thanks to our pastor. He is passionate about these people and motivates the community to help them and care about them. People at church are very welcoming to Maria and this includes various Christian churches in the community. Maria chooses which church she wants to attend and goes there- of everything, she likes going to the church most. She enjoys dancing and clapping hands thoroughly. Even though she cannot read, she steals my Bible to go to church regularly.

16. Does your child benefit in any way from services, activities and interventions of the church? Explain.

Yes, for sure. Except for attending church regularly, the church does a lot for us, including counselling. They also help us with food and clothing. The church has different groups that reach out to different groups of people, such as people in hospitals, prisons, old people and people with disabilities. They enquire about our needs and will do what they can to help us. They reach out to us always.

17. Does your child participate in the youth ministry services or activities at your church? Motivate.

Yes. The young people also visit us and care for Maria. She goes to church with them sometimes. Even though she does not talk, they can see that she enjoys being with them and they allow her to be with them. They are her friends. However, these are teenagers and not people of the same age as her. But they all come and visit us at home, age does not matter.

18. What efforts have been made by your congregation to reach out to you and your family since your child's diagnosis?

They helped us a lot with the situation through counselling and support from the time Maria was diagnosed. They always ask what they can do for us and act on it. The church has been our strength through all these years.

19. What are your biggest concern(s) regarding your child?

I fear for her safety every day. But my biggest fear is that I don't know what will happen to her if I pass away. Who will take care of her? I lie awake at night wondering about this.

20. Do you have any suggestions as to how the inclusion of your child and family in the faith community can be facilitated or improved?

I just think awareness is of the utmost importance. As long as people know what disability is and that they have to care about these people, everything will be ok. There even are some parents who hide their children at home because they are ashamed or are scared of what people will say about their child and themselves. But with time, as they see people are more familiar and comfortable with disabilities in general, they relax and start to take their child with them. I worked as a community care worker for a long time, and from there I know how tough it is to do basic things with people with physical disabilities in the community. Simple things like mobilising them or organising transport to hospital becomes very difficult and we had to make plans, such as taking the medication for the patient from the clinic, rather than taking the person to the clinic themselves. The church needs to do the same: understand their needs and abilities and if they cannot come to church, take the church to them!

Additional observations

During this interview with Sophie, she spoke about her experiences as a professional caregiver in the community of Hammanskraal. As a caregiver, she is expected to provide care and support to the sick, aged and people with disabilities. Through her personal observations she is especially concerned about people with physical disabilities, since the infrastructure of the area is not accessibility friendly to those in

wheelchairs or people walking difficultly. They also have limited transport options available since most public transport providers drive pass them. Drivers do not want to spend “unnecessary” time on loading and unloading people in wheelchairs or with crutches, and also are of the opinion that these people take up extra space. Their income is dependent on the number of people they transport daily, and therefore space and time are not to be compromised. Being frustrated by these systems as a caregiver, she and her colleagues have decided to rather take essential services to the people they care for, than to let them endure strenuous challenges when they need to go somewhere. Typically, they would rather let a doctor or nurse do a home visit or fetch medication for the person from the clinic and bring it to him or her. It is this experience that leads her to believe that when people cannot get to the church, the church should get to them.

5.3.2 My child with Autism and the ZCC in GaRankuwa: Rose and Phume

1. Background

Mrs. Rose Naane is a 47 year old Tswana-speaking female resident of GaRankuwa, an informal settlement situated in the province of Gauteng. Rose raised three daughters, of whom her middle child, Phumelele (Phume), has Autism. Phume is currently 24 years old.

2. Describe the composition of your family

I have three daughters, of which the eldest is a medical doctor in Johannesburg, Phume is my middle daughter with Autism, whilst my youngest daughter is 11 years old. She helps to take care of Phume. My mom also stays with us.

3. Describe your living environment?

We stay in a RDP house and I have extended it. It has 2 bedrooms, a lounge, kitchen and a bathroom.

4. When and how was your child diagnosed with his/her disability?

Phume was diagnosed with Autism at the age of 5 years.

5. Did you feel that someone was responsible for the disability? Explain.

Yes, partially I do. Phume was fine until she fell ill with Pneumonia and asthma. She was in hospital receiving intensive treatment and injections to help her get better. However, soon after this treatment her behaviour changed – she started rocking backwards and forwards, stopped speaking and even walked funny- she walked on her toes. When she recovered from the Pneumonia, she was sent to TMI in Johannesburg where she was diagnosed with Autism.

6. Explain the limitations caused by the disability(-ies)?

Phume experience various limitations – she cannot talk, her movements are strange and she rocks rhythmically. At times she did not sleep at all, she would sing right through the night. She is a very alone child, she does not trust anybody and will only stay with me or my mother. She does not like big groups of people and we cannot take her out of the house for long periods of time. Mentally she is underdeveloped and functions at the level of a young teenage child.

7. Does your child receive any treatment?

Yes, she is on Risperdal to calm her down & help her sleep.

8. Does your child attend a care facility or special school?

No.

9. Where does your child reside? Provide reason(s).

She stays at home with me. When I am at work, my mother takes care of her. She does not like to be with people she does not know, or strange places. She only wants to stay with me or her grandmother.

10. Does your child make use of special devices?

No.

11. Explain the mobility of the child.

She walks by herself and does not need assistance.

12. What does caring for your child entail on a typical day?

Phume is a very quiet child. She will just stay in one place and watch you what you're doing and try to do the same. If I wake up, she wakes up, if I go to the kitchen, she goes to the kitchen. She listens nicely – even if I leave her and tell her to stay at a specific spot, she will stay there until I come back. She doesn't bother us, she's very sweet. At times it was difficult when she did not sleep or would cry for no reason, but now she is fine and we are not frustrated with her.

13. How does raising a child with a disability affect you on the following levels (in the past and currently):

- *Emotionally*

It is difficult. When she was diagnosed I could not understand why this had to happen with me. However, when they made her diagnoses they said that her speech could come back at the age of 6 years. I waited and waited, until today. She is 24 and she does not talk. I look at my sister's child who is almost the same age as Phume and I cannot help to think that my child should have been like her at this age. It breaks my heart.

- *Socially*

Socially I really struggle – you know, I literally cannot go anywhere. Phume does not want to stay with anybody else than me or her grandmother. When I am at work, my mother takes care of her, but when I go home, she is with me all the time. Not all people accept her, you know. They just look at us and will sometimes ask what is wrong with her. Her dad left us soon after she was diagnosed with Autism, because he said it was my fault that she was like this. When I stopped breastfeeding by the age of two years, I had to take her to my mother so that she could sleep with her. You know children when they are weaning. She fell ill with Pneumonia and asthma at my mother's place and the father said if I did not stop breastfeeding her, she would be ok. And now, when a man shows interest in me, it is very my difficult – I cannot go out on dates,

they have to come to my house. They have to accept and love Phume, otherwise they cannot be part of my life. Most men cannot cope with this. It is a very lonely life, but I am strong.

- *Physically*

No, I am ok. I only have to supervise Phume a little – she does most things by herself. It is just when she doesn't sleep that we get tired, you know?

- *Financially*

It is very difficult. Phume only eats certain foods and I cannot just buy anything for her. Medically, we had to see so many doctors, go for treatment and even scans, EEG's – everything. Her father used to help, but he passed on a few years ago and we have to cope on our own.

14. Explain the general attitude towards disability in your community and/or culture?

The people of GaRankuwa are not bothered with disability much. They don't bother us, but they also don't know much about disability. They will just look at us and leave us alone. Sometimes when Phume's making rocking movements they will ask what's wrong with her.

15. Do you participate in church services and other events in your faith community?

I go to church regularly and sometimes take Phume with me. Church gives me strength to go on.

16. Does your child benefit in any way from services, activities and interventions of the church? Explain.

Yes, I sometimes take Phume to church with me. She will go to church, but not for long, not longer than an hour. So I cannot take her to the services, which are three to four hours long. She will also tolerate the obligatory head gear we wear in the ZCC for a short period, but then she takes it off of her head. Because she doesn't want to be without me or her grandmother, I

cannot let her attend any church events by herself. Except for letting us attend church and praying for Phume, they don't do anything else with her.

17. Does your child participate in any youth ministry services or activities at your church? Explain.

No. She does not have friends at church. She only goes with me and her grandmother. She does not like to go out of the house. She did not go to Sunday School or anything like that, she will not go without us.

18. What efforts have been made by your congregation to reach out to you and your family since his/her diagnosis?

The church let Phume attend and will not bother us when I take her there.

19. What are your biggest concern(s) regarding your child?

My biggest concern is when I pass away. Who is going to look after her when something happens to me? My mother is already sick and old, she is still taking care of Phume, but she won't be able to for much longer. Even Phume's sisters, she knows them and they know her well, but you know, she cannot talk. They don't know her like I do. They also have to work and live their own lives. Even if she has pain, she doesn't show it often and she cannot tell you she is not feeling well. It is very difficult. I don't know who will be able to care for her like me or her granny. I am very worried.

20. Do you have any suggestions as to how the inclusion of your child and family in the faith community can be facilitated or improved?

I never actually thought about this, you know? I am so used to cope by myself that I don't really expect anything much from others, including the church. We are a private family that likes to stay home, so we don't feel that we miss out on too much other than what we choose to. However, if I think a little about it, awareness will make a difference. You know, people in GaRankuwa do not know disability. Some are judgemental or don't understand. I don't see other people with children with disabilities at the church, and I know they are there. Where are they? They hide their children at home. Maybe they are shy? Even recently, I had to change Phume's details on the funeral cover we have at

church. Because she is older than 21 years she has to get the plan in her own name, but they want her to sign for it! She cannot write, how is she going to sign? In the history of the ZCC church, we surely cannot be the first people with a child with a mental disability. If the church cannot help people with disabilities with these issues, it just means they don't know or understand. Even our pastors – I have never heard them talk about disability, ever. So if they do not talk about it, people will not know what to do or treat them. We never had a home visit or counselling in all these years. So yes, I like church because it gives me strength. But they haven't been supportive in our journey with Phume much. I am not angry with them, but maybe in future they can help people with disabilities a bit more.

5.3.3 Helpless in Holfontein: Zodwa and Thandeka

1. Background:

Zodwa Mnguni is a 36-year old Zulu mother of a daughter with severe Cerebral Palsy. Her 12-year old daughter's name is Thandeka and they reside in the rural area of Holfontein, North West.

2. Describe the composition of your family?

It is only me and Thandeka. We stay with my mother in Holfontein.

3. Describe your living environment?

We live in a small sink house in the area. The house is only one room, we sleep on mattresses on the floor. We do not have electricity and have to fetch water from the dam. We have a toilet outside.

4. When and how was your child diagnosed with his/her disability?

Thandeka was born like this. I struggled to give birth to her and she did not get enough oxygen. This injured her brain badly and the doctor said she has Cerebral Palsy. She is retarded.

5. Did you feel that someone was responsible for the disability? Explain.

Yes. I had to flee from my husband in Kwazulu Natal when I came home with Thandeka. He did not want the child. He said the ancestors cursed me because I lied with another man. But I did not. The ancestors made her like this and it was not me!

6. Explain the limitations caused by the disability(-ies)?

Thandeka cannot do anything – she cannot sit, stand or walk. She cannot eat properly and struggles to swallow. She can only eat soft food. She cannot go to the toilet. She cannot speak and she is sick all the time.

7. Does your child receive any treatment?

We give her the medication from the hospital to help her with pain and relax her muscles a bit. She gets cramps and contractions all the time.

8. Does your child attend a care facility or special school?

No. There is no place where she can go where we stay.

9. Where does your child reside? Provide reason(s).

She stays at the house with me and my mother.

10. Does your child make use of special devices?

We borrow the wheelchair if we go to the hospital. But now, the wheelchair is broken by the bad road. The hospital says we have to wait three years for the wheelchair that is the size for Thandeka.

11. Explain the mobility of the child.

No, she cannot move. Even when she lies on the mattress, we have to turn her. She cannot do anything by herself.

12. What does caring for your child entail on a typical day?

It is so difficult. Thandeka just lie on the bed. We switch on the radio that she can hear the music. If it is warm, we'll put her mattress outside. But I have to feed her with pap. She cannot chew, so she can only eat the soft food. She

likes pap only. It takes me an hour to give her a little pap as I have to hold her head when I feed her. I wash her on the bed and we put clean clothes when my mother is at home to help me. Thandeka is heavy to move now, my back is so sore. If I gave her food I leave her to sleep or lie on the bed. She wears the nappy and I have to clean her. Her body gets pain because she can just lie down, so I rub her with cream.

13. How does raising a child with a disability affect you on the following levels (in the past and currently):

- *Emotionally*

I cannot speak about that child and not cry. I don't know why she has to suffer like this. Why was she born to live like this? It would be better for her to be dead.

- *Socially*

I leave Thandeka at home when I go somewhere. My mother takes care of her then. Many people don't like us, so I don't go out of the house often. I just go to the shop and to the hospital. We are very alone.

- *Physically*

Jo-jo, I am struggling so much. That child is heavy now and I am not a big woman. I am so tired when I wash her or have to take her to the hospital. I cannot do it alone, my mother must help me. My back is sore all the time.

- *Financially*

No, we don't have any money. My mother she cleans the house at the farm and she buys us food, but I have no job. We get the grant for Thandeka that helps with her nappies. That is all we have.

14. Explain the general attitude towards disability in your community and/or culture?

You know, people do not understand. I fled from my husband with Thandeka – he wanted to kill us when he saw her. The Zulu people believe we are cursed for doing the wrong thing, so every time they see Thandeka they get angry. They don't want her there. So I came to stay with my mother. Her father never saw us again. The people are better here, but they still are scared of Thandeka. They don't want us. The sangoma came to help us, but that medication is not good. Thandeka cannot swallow it. They say the sangoma must fix her, but nothing is helping. She is already 11 years old. So I hide Thandeka here at home, because people get too upset when they see her.

15. Do you participate in church services and other events in your faith community?

No. Just my mother goes to church sometimes.

16. Does your child benefit in any way from services, activities and interventions of the church? Explain.

No. The church is too far. We cannot take Thandeka there, it is too difficult for us.

17. Does your child participate in any youth ministry services or activities at your church? Explain.

No. We do not go to church because of the distance. It is difficult to travel anywhere with Thandeka. And the people they do not like us.

18. What efforts have been made by your congregation to reach out to you and your family since his/her diagnosis?

Nothing. We do not go to the church, except my mother.

19. What are your biggest concern(s) regarding your child?

That she will suffer like this for a long time.

20. Do you have any suggestions as to how the inclusion of your child and family in the faith community can be facilitated or improved?

We cannot go to the church. I asked the pastor must come to our place, but he did not come. I wish he can pray for my child.

5.3.4 Deaf and sceptical about the church: Daleen en Herman

1. Background

The Smit family is a Afrikaans speaking, white family. They reside in Tuine, Pretoria. Their last born, Herman, is a 16 year old deaf boy.

2. Describe the composition of your family?

My husband and I have been married for 22 years now and we have three children, two girls and a boy. Herman is the youngest and still staying with us. The girls are grown up and moved out of the house to live on their own. My husband is a policeman, I do not work. I stayed with the children when they grew up and struggle to find employment now.

3. Describe your living environment?

We stay in a three bedroom brick house in Tuine. We are not rich and it is not a big house, but at least it is ours. We have a small garden and at least have privacy here.

4. When and how was your child diagnosed with his/her disability?

Herman was only diagnosed when he was 5 years old. We did not know that something was wrong with him and only took him the doctor when we became concerned about his speech. He made strange sounds and did not listen to us, we always thought he just took long to speak. But when he turned five, we took him to the doctor.

5. Did you feel that someone was responsible for the disability? Explain.

No. Not necessarily. For a long time I thought maybe I did something wrong when I was pregnant with him, but the doctors said it had nothing to do with that and I am not feeling guilty anymore.

6. Explain the limitations caused by the disability(-ies)?

Well, mainly Herman cannot hear – he is completely deaf in both ears. Consequently he never learned to speak or communicate properly. He is a healthy boy and is interested in all things teenage boys are interested in, but he is lonely and only has a few friends from school. Because he struggles to communicate he is very shy and does not like to be between people who do not understand him, he gets frustrated. Being deaf is also dangerous in our country – we cannot rely on Herman for any security matters. He does not hear the dogs barking or the alarm when it goes off, he relies on his sight only when he needs to cross a street by himself. I am always worried when he is alone somewhere.

7. Does your child receive any treatment?

No, he is not receiving any treatment. Only the stimulation and therapies he is exposed to at school.

8. Does your child attend a care facility or special school?

Yes. He attends a school for deaf children in Pretoria.

9. Where does your child reside? Provide reason(s).

Herman lives with me and his dad. We wanted to put him in a hostel for children with special needs a while ago, so that he can learn to be more independent and socialize with friends. But the hostel is full and we are close enough to school to provide transport for him. So he will stay here with us.

10. Does your child make use of special devices?

No.

11. Explain the mobility of the child.

His mobility is not affected, only his hearing and speech.

12. What does caring for your child entail on a typical day?

Because we only found out so late that Herman was deaf, we “babied” him for a long time and even after his diagnosis also – in fact, especially then. You know, we waited a long time to have a boy and when he finally came, he was also our youngest. When we found out he was deaf, our hearts were broken, we felt so sorry for him. We still do. He will never have a normal life like you and me. So even though he is possibly capable of doing much more for himself, we spoil him a lot. I do everything I can with him and for him: put out his clothes, pack his lunch box, tidy his room and assist with homework... Luckily he is not a difficult child, so he does what I tell him to do. However, he is a teenager now and you know, the hormones and everything affect him as well. During the week I take him to school, after which he participates in his extracurricular activities. I fetch him when his done. Then we come home and do homework and prepare for the next day. Weekends we like to stay home and have a barbeque, watch TV – just relax. Herman likes swimming, so in summer we will be at the pool whenever we can.

13. How does raising a child with a disability affect you on the following levels (in the past and currently):

- *Emotionally*

It was very difficult at the beginning. Just imagine not understanding your own child or him understanding us. We did not know what to do with this child and we wanted a boy for so long. Now we have to make peace with the fact that he probably never will be able to stay all by himself, travel, get married – things like that, you know. He will stay my baby forever. But even though he is deaf, we love him so much. He is a sweet kid. I just wish we could help him more, if he was able to hear he would be a remarkable young man. But now he struggles at school with the academics and he struggles to make friends. His self-esteem is affected a lot, because he was so behind with his

development. In general we are used to him, but there are days that we get sad for him, any parent would.

- *Socially*

Like I say, Herman does not like being between people who do not understand him. So we socialise only with friends we've had for years and some family who do not reject us. Because many people cannot communicate with Herman, they feel awkward coming to our house or inviting us to theirs. Luckily, we made good friends with some of the parents at Herman's school. We are totally estranged from some family members, due to Herman's condition: they don't want people to know we are their family, they say it is too strange for them and they simply are not interested in our life.

- *Physically*

Luckily, we are not affected physically anymore. At the beginning Herman got very aggressive because we did not understand him. Whenever he got frustrated, he would get very aggressive and would physically hurt us: kicking, hitting and biting. But as the communication improved and we understood each other better, that behaviour stopped totally.

- *Financially*

We are not a rich family. My husband often works overtime to just get us through the month. I cannot find a job. Luckily, the girls are grown up and working. It is the school fees and all these extracurricular activities that cost money, but you know – we cannot keep Herman away from things that he actually wants to participate in. Live is expensive, but that is so for all of us, hey?

14. Explain the general attitude towards disability in your community and/or culture?

This is a difficult question to answer, since where we stay we have so many different people and cultures. In our own culture, I think it is an individual thing – some people are ok with it, others are not. We do not have specific believes

regarding disability. However, one would think that people who believe in God would be less judgemental. We do experience a lot of judgement from people, especially family. We are not good enough for them. They are self-conscious about being seen with Herman. I guess it is the volume and big hand movements that make them shy. But we decided a long time ago that other people will not affect us – if they are too good for Herman, it's the end of the road. God gave us this child and we love him just like he is.

15. Do you participate in church services and other events in your faith community?

No. Not really. There is no time for that. Most of the time my husband works on a Sunday, he takes the car and it is too far to walk to church. If he does not work, we really just want this one day to relax at home by ourselves.

16. Does your child benefit in any way from services, activities and interventions of the church? Explain.

No. (Daleen laughs). We haven't been to church in many, many years. I think since Herman was about two or three years old, we never went to church.

17. Does your child participate in any youth ministry services or activities at your church? Explain.

No. Herman likes to attend the service they have at school, he loves reading Bible and is a firm Christian believer. However, it is because he can understand the service at school with sign language and the way in which the service is adapted especially for the deaf kids. We never took him to church, because how will he understand and how will they understand him? Young people often make fun of Herman when we are in the shops or somewhere public. It hurts his feelings. He does not have one friend who is not deaf. The young people at church won't understand him, it will be no different.

18. What efforts have been made by your congregation to reach out to you and your family since his/her diagnosis?

No, we never informed the church of our situation. They don't know about Herman, so they never helped us.

19. What are your biggest concern(s) regarding your child?

My worry is that something will happen to me. What will become of him? I have a very special bond with that child, you know? As much as they love him, I don't think his dad or sisters can take care of him full time, they also need to work. They also don't always understand what he's trying to say to them. Oh no, my biggest fear is for sure that I cannot care for him forever.

20. Do you have any suggestions as to how the inclusion of your child and family in the faith community can be facilitated or improved?

At this late stage, this would be very difficult. We know that there is a church in Pretoria for deaf people only, I am thinking of taking Herman there. If only we had transport. Just to try, maybe he will like it. I want to protect my child from being hurt at regular church; they will make fun of him, especially the children of his age. They are teenagers now, you know? If I KNEW that he'd be accepted there, I would have to go with him to interpret conversations and sermons, except maybe if there is an interpreter available – and I can promise you, there is not. No, at this stage of the race I, and many other parents, are sceptical about inclusion efforts of any sort – it's much more complex than people think. Even if you overcame all logistical issues, I would not expose my child to a place where he can end up experiencing more rejection and judgment.

5.3.5 “It must start with you ...”: Sylvia and Oratile

1. Background

Sylvia Chilwane (47) and her 8 year old son, Oratile, resides in Mamelodi East in the Tshwane district. Oratile has Down Syndrome. Sylvia is a qualified health professional and working as a nurse.

2. Describe the composition of your family?

Oratile's biological father passed away when Oratile was 7 months old. We had two boys, of whom the eldest is now 23 years old and then Oratile years later. The past four years I have been staying with my friend, the two boys and our nanny at our house.

3. Describe your living environment?

We stay in a 4-bedroom house in Mamelodi East. The main bedroom has an en suite bathroom. The other three bedrooms share a second bathroom. The lounge and kitchen is an open plan area.

4. When and how was your child diagnosed with his/her disability?

I had a normal pregnancy, during which there was no diagnosis of Down Syndrome. Oratile was born by means of a caesarean section and we were discharged after a few days, there were no complications or suspicions of Down Syndrome. It was only with his 6-weeks check up at the paediatrician that she started to suspect something was not right, due to floppy neck muscles. Oratile's neck was not as stiff as it should have been at that stage of development. She consulted with her colleague, they did blood tests and Oratile was diagnosed. It came as a major shock to all of us.

5. Did you feel that someone was responsible for the disability? Explain.

No, not at all. I just felt that it would have been better for me if they had made the diagnosis during my pregnancy. At least I would have been able to prepare myself better for Oratile's condition.

6. Explain the limitations caused by the disability(-ies)?

The main limitations are with his speech and of course the typical developmental delays associated with Down Syndrome. Oratile is not able to speak properly and express himself verbally. He uses single words and does not form sentences. His mental and academic development is of course also affected and he is not able to attend school like his 8-year old peers.

7. Does your child receive any treatment?

Yes. He receives grow hormone therapy to compensate for his hypo-active thyroid. The Eltroxin helps that his length is not affected and that he is the height he ought to be at this stage of his life.

8. Does your child attend a care facility or special school?

Yes. He attends a day care facility for children with special needs in Prinshof, Pretoria.

9. Where does your child reside? Provide reason(s).

Oratile stays with us at home. We have a nanny to help care for him. There is no need for him to stay anywhere else.

10. Does your child make use of special devices?

No.

11. Explain the mobility of the child.

His mobility is not severely affected. It is just that when he runs he does not bend his knees, he runs with stiff legs – a typical feature of children with Down Syndrome.

12. What does caring for your child entail on a typical day?

Well, in general Oratile is fairly independent. He can bath and dress himself, he runs his own bath. He does not sleep during the day at all, causing him to sometimes get over tired. He then does not wake up during the night to go to the bathroom and wets his bed from time to time. One of our biggest accomplishments was to have him potty trained. He was potty trained by the age of 7 years. Before this, he wore nappies which was not only very expensive, but an effort to change at the best of times. So yes, due to his independent functioning, caring for him is not as intensive as it was previously. It also helps to have a nanny that assists him whenever he is at home.

13. How does raising a child with a disability affect you on the following levels (in the past and currently):

- *Emotionally*

In the past, especially following his diagnosis, it was very difficult for me emotionally. As a health care professional I was very aware of the limitations caused by Down Syndrome and it broke my heart for my child. But then somewhere along the path I realised that this child was my gift from God and that God Himself would equip me and give me the strength to raise this boy for Him. Since then, I have accepted and loved this child unconditionally and never became emotional again. I realised that these are beautiful children given to us by God and that is also my message to the parents of other children with disabilities.

- *Socially*

No, we are not affected on a social level. You know, how people treat your child depend on how you treat your child. If you show him unconditional love and care and let other experience that, they will do the same. It all starts with you.

- *Physically*

No, we're fortunately not affected physically, due to Oratile's fairly independent functioning.

- *Financially*

On a financial level caring for a child with a disability is just so much more expensive. You know, every service is just specialised and charges a lot – the school, the transport, the speech therapy, the nappies – it is a long, long list. That is why I quit my job recently: to have my pension monies paid out in order to care for him next year when the school fees and expenses are much more. I did not quit my job for any other reason. In fact, I already applied for other posts and have an interview scheduled in next week.

14. Explain the general attitude towards disability in your community and/or culture?

No, if there are issues regarding disability in my community or culture I am not aware of them. I realised a long time ago that people's reactions to my child and his condition depends on how I treat him. I take him with me anywhere I go and treat him like a normal child. This has a direct impact on how he perceives people – he is a friendly, adorable boy and people love him for his affection and charming personality. I would never hide my child from society and have no doubt whatsoever that it all starts with you as the parent. You cannot care about what the other people say or think, you have to care for your child only.

15. Do you participate in church services and other events in your faith community?

Yes. We attend church on a regular basis and I participate in the Human Organisation at church.

16. Does your child benefit in any way from services, activities and interventions of the church? Explain.

Yes. Because I take Oratile with me wherever I go, he also goes to church with me.

17. Does your child participate in any youth ministry services or activities at your church? Explain.

No. Church with us is a family matter. We do not have activities such as youth groups and Sunday School. You go to church with your child and that is it, he stays with me throughout the service and is very quite in church. He is a well disciplined, sweet boy and does not bother anyone during services. I do not want him to be treated differently than other children because of his condition, also not at church.

18. What efforts have been made by your congregation to reach out to you and your family since his/her diagnosis?

No, nothing. But I also don't expect anything else from church, other than receiving the Word of God and worshipping Him. If I had any needs or concerns, I would ask to meet with the pastor.

19. What are your biggest concern(s) regarding your child?

I am so worried about what will happen to him when I am no longer around. With him I need to plan more for his future – more intensive education, a healthy financial position. It is stressful. How will I ever know that people will not take advantage of him when I am not there anymore? Will the family really care for him like I do, understand him like I do? For me it is important that he bonds with the people I trust to care for him when I am not around anymore. He needs to bond with them now, not later. He cannot only get to trust them in a moment of losing his mother, he needs to know and trust them now already. You know, a normal child is like a little bird: you care for it, groom it and teach it to fly and then you expect the child to fly when the time comes. But with Oratile, I still have questions. And it is questions that I won't have the answers to as the future is unknown to us. We cannot see the future.

20. Do you have any suggestions as to how the inclusion of your child and family in the faith community can be facilitated or improved?

No, I do not think that this has ever bothered me much, since I specifically do not want my child to be treated differently or exclusively at church. If he was missing out on activities that would have been of concern, but he is not. He's just like all the other children and I know I can speak to the pastor when I feel that I cannot cope anymore. That's all we need. In some way I do think it is about spiritual growth. I have grown a lot spiritually over the years. I feel content with my child; we are in a good place everywhere in our lives. And yes, possibly because we chose this perspective on our journey. The way in which we perceive Oratile's condition makes our lives with him so much easier and enjoyable. I wish that for all other parents.

5.4 Quantitative investigation

The empirical investigation of this study required statistical data, which necessitated a quantitative component (Van der Stoep & Johnston 2009:7). Firstly, the statistics with regard to the prevalence of disability, specifically in children and youth with disabilities on local and international front are relevant. These statistics provide an understanding of the reality of disability in general and to what extent South Africa is affected by it. Secondly, statistics of children and youth with disabilities in faith communities is required in order to ascertain whether this group of individuals is sufficiently included in faith practices of churches, especially from a youth ministry perspective. The relation between national and church statistics is an indicator of whether the children and youth with disabilities are reached by their congregations. The quantitative component consisting of numerical and statistical data derived from various organisations and institutes, internationally and in South Africa are presented and discussed in Chapters 1 – 3. Secondly, a questionnaire or survey regarding the status of children and youth with disabilities in five (5) faith communities (different Christian denominations) was completed by the pastors of these churches.

Most of the statistical data was collected by means of literature and from a the health sector. However, the questionnaire or survey completed by the five pastors of various denominations regarding the status of children and youth with disabilities in their churches was based on the self-reporting data collection technique (see Van der Stoep & Johnston 2009:66-67). An invitation to participate in the study and complete the questionnaire, was sent to a variety of faith communities across various Christian denominations. Pastors who indicated a willingness to participate, were sent a questionnaire to complete electronically or manually, depending on the most convenient option available to them. As was the case with the collection of the qualitative data, a non-random, convenience sampling selection method was used (see Van der Stoep & Johnston 2009:27).

The survey was sent out to faith communities and theologians. Leaders who indicated their willingness to participate, were contacted. They completed a consent form. Most participants submitted their completed surveys electronically, with the exception of Pastor Ndhlandhla who submitted his in written form and in person.

5.4.1 Rev. Pieter Visser

1. Introduction

Reverend Pieter Visser is a 34 year old, Afrikaans speaking Caucasian reverend in the Dutch Reformed Church Wierdapark, Centurion. He has ten years experience of working as a reverend in this congregation with its 2069 members, of whom 416 are children and youth

2. What is your personal approach to disability?

People with disabilities are marginalised by society, therefore the needs of these people are important. Especially in a church setting people should feel welcome and their needs should be addressed. Jesus always stood up for the marginalised, likewise the church should follow in His footsteps and include all.

3. Are there any cultural and social beliefs or predispositions regarding disability that you regard as relevant to how people with disabilities are treated in the church?

I think that somehow people with disabilities' intelligence are questioned. In a culture that is very knowledgeable driven people may talk down to people with disabilities.

4. What is your congregation's policy on disability?

We do not have a specific policy. The building is checked for safety and accessibility, with parking spaces close to the entrance for people with a disability. The toilet facilities, however, are not.

5. Describe your experience of working with children or youth with disabilities in your congregation?

We currently do not have disabled young congregants, and have not had since I worked here. My colleague told me that they were included in the normal activities, like the confirmation class and those that needed extra explanation because of mental disability were given extra time. In the past and at another church a young lady with down syndrome formed part of our beach

outreach team, and she actually was a great help in getting all the children together for the activities.

6. What do you regard as obstacles in working with children or youth with disabilities within the faith community?

A lack of knowledge about the needs of disabled children and young people.

7. How do families with disabilities integrate or not in your congregation?

Motivate.

The “children” that have disabilities are older now, they went through their faith confirmation and are integrated with the “main stream church.” I do, however, not think that our Sunday school classes and the congregants presenting are fully equipped to fully cater to the needs of disabled children.

8. Do you have any suggestions on how youth ministry can become more accessible to children and youth living with disabilities?

I think informative workshops that help congregations, youth personnel and clergy understand the needs of congregants, especially children and youths with disabilities should be presented.

5.4.2 Pastor Carina Fischer

1. Introduction

Pastor Carina Fischer is a 38 year old, Afrikaans speaking pastor of the Hatfield Christian Church, located in Pretoria. She describes her background as multi-cultural and has been working with the young people in this congregation as volunteer and employee for the past 17 years. Hatfield Christian Church has a total number of more than 6000 congregants, but Pastor Fischer is responsible for 380 of these members. She is uncertain of the number of children and youth in this group.

2. What is your personal approach to disability?

God created everyone. God is sovereign. Things on this earth is not all as heaven will be. God loves and cherishes everyone and so should we. Every

life is a gift and those with disabilities is among God's special gifts to the world.

- 3. Are there any cultural and social beliefs or predispositions regarding disability that you regard as relevant to how people with disabilities are treated in the church?**

People in general are afraid of those who are different.

- 4. What is your congregation's policy on disability?**

We embrace people with disability. I think we can grow more in this. We started a special needs class in children's church named C4E.

- 5. Describe your experience of working with children or youth with disabilities in your congregation?**

I don't have such direct experience with it. In my own experience it can be difficult to cope with ADD / ADHD children. We have mothers' rooms. I think more can be done, especially in Life Group Ministry.

- 6. What do you regard as obstacles in working with children or youth with disabilities within the faith community?**

Unfamiliarity and a lack of awareness, training and information. Too many people to care for (high volumes in the church).

- 7. How do families with children with disabilities integrate or not in your congregation? Motivate?**

I can only speak personally. It was more difficult during the toddler years with ADD / ADHD and speech apraxia. But now that they are older they can integrate more. Large crowds is still not the best environment for them. It's important for parents of children to also get undistracted input.

- 8. Do you have any suggestions on how youth ministry can become more accessible to children or youth living with disabilities?**

Our venue for youth is not very accessible to those with disabilities. I would suggest smaller group ministry, with trained, compassionate staff. The best would be to have embracing arms for creative ways to integrate. If all has a

value for treating those with a disability with love, respect and care, we can come far. Secondly, more interaction with special schools like New Hope and Unica, so that skills can be transferred and there can be a mutual beneficial relationship.

5.4.3 Pastor Veli Ndhlandhla

1. Introduction

Pastor Ndhlandhla is 62 year old Swazi pastor who has 20 years of ministry experience in the Swedish Free Church. The branch of the church he is serving is located in Leandra, Mpumalanga and consists of 300 members, of who approximately 120 are between 5 to 15 years of age.

2. What is your personal approach to disability?

Disabled people are just the same as others. They are of blood and flesh, just like you and me. In fact, they are me. They deserve dignity and they know when you are not treating them accordingly.

3. Are there any cultural and social beliefs or predispositions regarding disability that you regard as relevant to how people with disabilities are treated in the church?

Not particularly that I know of. But people do not think as one, you know. People differ and so do their opinions and interests.

4. What is your congregation's policy on disability?

We do not have a policy specifically related to disability. However, our entire constitution is based on the fact that we must treat people the same, NO classifications for better treatments. In fact, if someone complains about this, it is regarded as an offense. No one is to act individually.

5. Describe your experience of working with children or youth with disabilities in your congregation?

I worked with four of these young ones before, of whom two unfortunately have passed on. It included muteness and Autism. Despite their disability, they could

understand. Today, I am not ashamed to have this young man going with me where I go. I am not ashamed to go around with him, I understand him.

6. What do you regard as obstacles in working with children or youth with disabilities within the faith community?

The image of pastors. You know, I have experience of working in the police and also served on the school governance body. These platforms gave me the understanding of what is going on in the community. As a policeman, I had to deal with crimes against people with disabilities often. As pastors, we have to be trusted by the community and advocate for important matters such as disability. If we don't, we don't only fail the people, but God. The image of the pastor is very important and trusting them even more so.

7. How do families with children with disabilities integrate or not in your congregation? Motivate?

Firstly, we need to treat these people like anybody else. Don't judge. Don't discriminate. Don't classify. As an example, I have this one member in church who is blind. It is my responsibility as pastor to go and collect him from his house and bring him to church. It is me who take him to the toilet and take him back home. It starts with you, the pastor. Secondly, we cannot expect a person who is dependent on a grant to donate to the church. We cannot sideline him because he cannot contribute.

8. Do you have any suggestions on how youth ministry can become more accessible to children or youth living with disabilities?

Yes. Charity begins at home. Firstly, if you do not respect your own, how then are others going to do it? I am saying that families with children with disabilities cannot hide them and then expect the community to care about them. If they are ashamed of their God given children, people will not be aware and reach out. In any case, when they die, who is going to bury them? The church, of course! Secondly, pastors play an integral role. When the pastor understands the situation and train the congregants, they will understand.

5.4.4 Dr. Riaan Stander

1. Introduction

Dr. Stander is a 61 year old, Aftikaans pastor at DRC Langenhovenpark in Bloemfontein. Dr. Stander has been in the ministry for 32 years. This congregation has 1300 members of whom 450 are children and youth. He is aware of three young people with a disability in this congregation.

2. What is your personal approach to disability?

It is a huge responsibility and challenge for the church. I believe we can do more and should be more.

3. Are there any cultural and social beliefs or predispositions regarding disability that you regard as relevant to how people with disabilities are treated in the church?

No, not that I am aware of.

4. What is your congregation's policy on disability?

No formal policy. In general we reach out to anyone in need of help or assistance.

5. Describe your experience of working with children or youth with disabilities in your congregation?

I did not have the opportunity so far.

6. What do you regard as obstacles in working with children or youth with disabilities within the faith community?

To be honest, I haven't experienced it firsthand. My wife is an occupational therapist at a school for children with disabilities, so we are very focused on the needs of such kids. I think the biggest threat is when such children are stigmatised.

7. How do families with children with disabilities integrate or not in your congregation? Motivate?

It is such a normal situation that all people are accepted and inaugurated into all the aspects of the congregation that I don't regard the children as people that should be treated different from others.

8. Do you have any suggestions on how youth ministry can become more accessible to children or youth living with disabilities?

I think a good training document for the youth leaders of churches could help a lot.

5.4.5 Mr. Nardus Dodds

1. Introduction

Mr. Nardus Dodds is the 35 year old youth worker and care elder at the Dutch Reformed Church Silvertonkruin. He has been active in this position for six years. The congregation is based in Silverton, Pretoria and has a total membership of 451, of whom 82 are children and youth.

2. What is your personal approach to disability?

I believe that all people are created by God and that no one is better than another. With or without a disability, we are all just the same in God's eyes.

3. Are there any cultural and social beliefs or predispositions regarding disability that you regard as relevant to how people with disabilities are treated in the church?

No, there are no official beliefs that I am aware of. However, people with disabilities are discriminated against and not valued enough by society in general.

4. What is your congregation's policy on disability?

Silvertonkruin does not have an official policy on disability. We are governed by the Synod of the Dutch Reformed Church, which advocates for the care and inclusion of all people.

5. Describe your experience of working with children or youth with disabilities in your congregation?

I had one boy who is mute and mentally challenged in my confirmation group a few years ago. I know his family well and at church he preferred to attend services and activities with his family, who understand him. He attended catechism with his cousin and brother. Even though he did not understand everything, he liked to participate and be part of whatever was taking place. Fortunately they were all more or less the same age, so Donovan fit in perfectly well with the others. The daughter of our administrator also has a mental disability. She is older and I never worked with her in our youth group, but she loves attending church with her mother and is well known and loved with all members.

6. What do you regard as obstacles in working with children or youth with disabilities within the faith community?

I think the bigger the congregation the more difficult it gets. We are a fairly small church and know each other. We still do home visits and are in close contact with our youth and their families. This helps a lot in understanding their needs.

7. How do families with children with disabilities integrate or not in your congregation? Motivate?

As I said, because we know our people on a personal level, it is easier to meet their needs. All congregants are invited to participate in the various ministries at church and it is no different for disabled people. We will rather investigate to see how we can effectively realize opportunities for them in practice than have them excluded from everything.

8. Do you have any suggestions on how youth ministry can become more accessible to children or youth living with disabilities?

Yes. There needs to be a personal relationship with the child or youth and their family. How can we serve people if we do not know what their needs are? The situation is different for each individual and we need to meet them on their terrain. There will always be options to care and support someone if we are familiar with their circumstances. The congregation also gets involved when the leadership of the church leads by example. Our church premises and building is also not structurally as accessible it should be. A lot still needs to be done in order to accommodate people with physical impairments and assistive devices better.

CHAPTER 6

PROCESSING AND INTERPRETATION OF DATA

6.1 Introduction

This chapter focuses on the processing and interpretation of the data gathered in the study. The theoretical and empirical data gathered in the study are brought into dialogue with each other. The purpose is to process and interpret the empirical data in the light of the theoretical data gathered in the previous chapters. Interpretation of the empirical data can only take place once commonalities and differences in the empirical and theoretical data have been identified. Without this dialogue between the theoretical and empirical data, the investigations serve no purpose. It is this dialogue between the theoretical and empirical investigations that gives meaning to the data.

Movement 3 of Julian Müller's (2005:82) is applied in this chapter. This movement addresses interpretation traditions in the field of investigation. The interpretation traditions followed in this study result from the theoretical data gathered with regard to practical theology, specifically youth ministry and disability. The experiences of the parents who were interviewed and the clergy who completed the questionnaires are analysed and interpreted at the hand of the multi-professional contributions in Chapters 1 to 4. The multi-professional inputs represented include contributions from the fields of psychology, social work and the health sector. Interpretation of the experiences of the parents and clergy at the hand of the multi-professional inputs is the implementation of Müller's (2005:82) sixth movement in this study. Observations from the empirical investigations either confirms or objects the theoretical data gathered with regard to disability and youth ministry, which will result in the findings made in Chapter 7.

6.2 The exclusion of children and youth with a disability

6.2.1 Exclusion in South African faith communities

According to Philpott and McLaren (2011:3) children and youth with a disability are among the most excluded in the world. Various international studies indicated that these children and youth also experience exclusion in the structures of faith communities (see Jones Ault 2010; Dingle 2016). However, in the South African context investigations on the inclusion and integration of children and youth with a disability in faith communities are lacking to a large extent. The aim of the study was to contribute toward filling this gap especially by providing some empirical data and to give a voice to the narratives of a previously largely unheard section of the population. The empirical data shows that three out of the five children or youth with a disability represented in this study do attend church, but their participation is limited and sometimes also conditional. Though the majority of the children and youth represented in this study are members of a faith community, faith communities tend to “allow” their attendance *on condition* that the parent, family or caregiver is present and accompanies the individual to services or activities. Also, only one congregation offers youth ministry as a specialised ministry. Two of these faith communities do not offer youth ministry services or activities and regard the general church ministry as adequate to the children or youth of their community. There is no possibility for children and youth in these congregations to attend catechism. Of the five faith communities represented during the interviews with parents, The House of Prayer Church that Maria attends seems to be the most welcoming to children and youth with a disability. The reason for the inclusive attitude of this congregation is the positive attitude of the pastor. Though The House of Prayer Church offers youth ministry as a differentiated ministry and Maria participates in their services and activities, her mother points out that she does not participate with her peer group, but with children much younger than herself. This means that Maria always stands out in these groups since she is much older and physically bigger than the children and youth in the group.

From the international studies it can be seen that parents refrain from attending services and activities at their faith communities for the following reasons (see Jones Ault 2010):

- exclusion from services and activities;
- lack of spiritual, emotional and pastoral support from the congregation;
- the expectation that parents have to support their child with a disability themselves and be with them all the time;
- lack of awareness and education about disability;
- challenges with the mobilisation of especially older, heavier children;
- fatigue;
- embarrassing behaviour of their children such as making noises, unpredictable outbursts of aggression and touching people.

The empirical data gathered in this study indicates that parents who raise a child with a disability do experience a measure of exclusion from their faith communities. They refrain from attending church services for similar reasons to those reflected in the results of the international studies.

A second indicator of the exclusion of children and youth with a disability in South African faith communities is the statistical imbalances. The prevalence of children living with a disability is high. International figures indicate that 10% of the global child population between 0 – 19 years are born with or have obtained a disability (United Nations Convention on the Rights of the Child 2006:16). Locally, the South African Census of 2011 recorded that 28% of children between 0 – 4 years and 10.8% of children between 5 – 9 years as living with a disability (DSD, DWCPD & UNICEF 2012:11). Despite it being difficult to measure childhood disability for various reasons (Mont 2007:1), statistics indicate a high prevalence. In order for youth ministry to be considered accessible and inclusive to children and youth with a disability, similar disability prevalence figures should be found in the youth membership statistics of South African faith communities. This would mean that some 10% of children and youth who are involved in faith communities should be expected to have a disability of some kind. However, considering the empirical data gathered from the questionnaires completed by the five representatives of faith communities in this study, this is not the case. In fact, two of the church officials had no experience whatsoever of working with children or youth with a disability. Others reported only minimal contact with such children and youth throughout their career. Having worked with four individuals with a disability throughout his twenty years in

ministry, Pastor Veli is the most experienced. Furthermore, the disabilities these church employees have encountered throughout their careers exclude children and youth living with a severe physical disability. The statistics with regard to the prevalence of children and youth with a disability represented in the theoretical investigation of this study differ from the data gathered in the empirical investigation. A statistical imbalance is indicated in the theoretical and empirical investigations. The prevalence of children and youth with a disability is much less than 10% in South African faith communities and youth ministries. The processed data therefore indicate that many children and youth with a disability are not members of faith communities or attend church.

6.2.2 Barriers

Raising a child with a disability is challenging (Grose 2011:1). Families experience various challenges on a regular basis. These challenges are referred to in this study as “barriers.” The “barriers” are frequently not caused so much by the disability itself, as rather by a combination of social, cultural, attitudinal and physical factors (World Health Organisation 2001:214). Barriers experienced and reported by the parents of children with a disability include exclusion, reduced basic human rights and access to educational and health services, vulnerability with regard to violence, abuse and exploitation and “broken” family structures (Philpott & McLaren 2011:3). This study was inspired by a statement by a father of a girl with Cerebral Palsy who referred to these barriers by saying that the increased inclusion of children and youth in faith communities was “not about putting up ramps, but about breaking down walls.” The “walls” that Mr. H. referred to as “barriers” are experienced by both children and youth with a disability and their families. The interviews in this study particularly address the barriers experienced by the parents. This was done on four levels, namely emotional, social, physical and financial. Parents also reported experiencing other barriers. The following barriers were identified from the interview with Sophie, the mother of Maria who has Cerebral Palsy:

- a “broken” family structure, since the father left when Maria was five;
- structural difficulties at home with limited space and only an outside toilet;
- the struggle of a working mother who cannot care for Maria full-time;
- emotions such as anger and sadness because of the disability;

- experiencing judgement and misunderstanding from individuals in their community;
- concern about Maria's safety since she does not know how to act in a responsible manner;
- Maria was a victim of rape due to her vulnerability;
- the mother is physically and mentally exhausted;
- they struggle with financial difficulties;
- they are stigmatised as witches in their culture;
- they are excluded because of the belief that Maria's disability is contagious;
- concerns about Maria's future and care when Sophie passes on.

Rose reported experiencing the following barriers with regard to raising Phume, who has Autism:

- being a working mother;
- Phume only allows Rose and her grandmother to take care of her;
- emotional struggles to accept Phume's disability;
- a "broken" family structure due to Phume's father leaving them;
- judgement from individuals who think there is something "wrong" with Phume;
- being blamed for Phume's disability;
- tiredness;
- social limitations due to Phume not allowing others to take care of her;
- financial challenges;
- unfair expectations from Phume by the faith community, such as expecting her to attend long services, wearing of obligatory headwear and signing of documentation;
- concerns about who will take care of her when Roses passes on.

Zodwa reported experiencing the following barriers with regard to Thandeka's disability:

- structural difficulties at home, such as limited space and an outside toilet only;
- no water or electricity at home;
- a "broken" family structure, due to Thandeka's father leaving them;

- being stigmatised as “cursed” by the ancestors;
- Thandeka has poor health and is sick regularly;
- poor infrastructure, such as rough terrain that is not wheelchair friendly;
- long waiting periods for assistive devices from the hospital;
- feeling very emotional about Thandeka’s disability;
- being judged, rejected and alone;
- body pain due to taking physical care of Thandeka;
- financial challenges;
- non-practical traditional medication;
- not being supported by the community or faith community.

Daleen reported experiencing the following barriers with regard to Herman’s deafness:

- financial challenges;
- self-blame;
- feeling frustrated and saddened by Herman’s disability;
- judgement by family members and other individuals;
- lack of transport;
- a lack of sign language and other services to make church services accessible and understandable to Herman;
- exclusion and rejection;
- Herman is made fun of by his peers;
- Concern about Herman when Daleen passes on.

Sylvia reported experiencing the following barriers with regard to Oratile’s Down’s Syndrome:

- developmental and educational impediments because of Oratile not being able to attend school;
- emotional distress after diagnosis;
- financial challenges;
- concerns about Oratile’s future care when Sylvia passes on.

The empirical investigation has shown that the barriers experienced by the parents of children or youth with a disability can be categorised according to six themes:

Barrier theme	Category
<i>Emotional:</i> parents have to deal with various emotions with regard to their child's disability	<ul style="list-style-type: none"> • sadness; • anger; • self blame; • blame of others; • disappointment; • anxiousness about the future.
<i>Social:</i> the social interaction of families with a child with a disability is affected on various levels	<ul style="list-style-type: none"> • exclusion from interaction, friendships and socialisation; • loneliness; • disintegration of family structures; • unfair or uninformed expectations; • non-intentional exclusion from faith communities.
<i>Attitudinal:</i> people's attitude towards disability and people with a disability impact directly on the individuals and their families	<ul style="list-style-type: none"> • social constructionism; • individual judgements; • mockery; • stigmatisation; • rejection; • ignorance; • lack of disability awareness.
<i>Cultural:</i> convictions and interventions regarding disability that are particular to specific	<ul style="list-style-type: none"> • stigmatisation; • believes; • traditions;

cultures	<ul style="list-style-type: none"> • spirituality; • healing orientations.
Physical: physical challenges caused by the disability	<ul style="list-style-type: none"> • discomfort due to demanding care tasks; • fatigue.
Resources: challenges with regard to resources needed to care for a person with a disability	<ul style="list-style-type: none"> • finances; • medical care; • transport; • assistive devices; • infrastructure.
Human rights issues: limited access to basic human rights impacts both the individuals and their families	<ul style="list-style-type: none"> • house structures; • health services; • education; • water; • sanitation; • safety.

Barriers identified in the theoretical and empirical investigations of this study correlate. Parents of children and youth with a disability share similar challenges or barriers globally. However, in the South African context the influence of cultural barriers with regard to disability affects many people and has to be considered in the implementation of increased inclusive youth ministries in faith communities. Although stigmatisation of disability is a global phenomenon (see Martz 2004:139), some South African cultures have strongly negative preconceptions with regard to people with a disability. They are often seen as “cursed” (see Eskay et al 2012:478 and Franzen 1990:21-26). The interviews with Zodwa and Thandeka have shown this to be true for Zulu culture. The community they once were part of interpreted Thandeka’s disability as a curse, caused by the alleged infidelity of Zodwa. They believe that their ancestors cursed Zodwa because she had an affair. The effects of such a perception of disability as a curse are devastating. Thandeka’s father was so angry that “... he wanted to kill us when he saw her.” Zodwa fled with Thandeka in an

attempt to save their lives, but also to escape the harsh judgements from the community where they were no longer welcome.

Besides disability being perceived as a curse in some cultures, traditional beliefs and orientations also play a role in the general attitude and “treatment” of disabilities. In Sophie and Maria’s narrative, some people believe that her disability is an indication that they have been bewitched. Sophie’s mother is especially affected by the rejection of some people. Rose was blamed by her husband for Phume’s Autism. According to cultural belief, a baby’s health is directly influenced by breastfeeding. According to Rose’s husband Phume became Autistic because Rose had ceased to breastfeed her when she was two years of age. In all three these narratives the cultural interpretations of disability led to the fathers leaving the family. The mothers are now single parents who have to raise their children with a disability and provide for them by themselves.

From a postmodern, postfoundational perspective the following can be identified in the narratives (see Freedman and Combs 1996:22): how knowledge (truth) is socially constructed; the effect of language, for example labelling and stigmatisation; how realities are sustained by the sharing of narratives. Social constructions (see Point 2.2) are the result of continuous social interaction with others. They form people’s beliefs, norms, and interpretations of reality that remain largely unquestioned. (Freedman & Combs 1996:1). In Chapter 3 social constructs identified with particular types of disabilities were discussed. The narratives of the participants have shown that individuals with a disability and their families do experience the consequences of such social constructions on a regular basis and that societal stigmatisation of disability is a reality even in these postmodern times. Sophie and Rose reported being stared at because their appearance and behaviour differ from societal norms and is therefore misunderstood. Some children are prohibited from interacting with Maria, because their parents believe disability to be contagious. The children are kept away from Maria for fear of their becoming like her. Sophie, Rose and Sylvia found that children with a disability were kept hidden in their home because the parents were afraid of what the others would say about them. Pastor Ndhladhla interpreted the concealment of these children as an act of shame and spoke out against it. Rose is worried that some people would ask her what is “wrong” with Phume. This social construct is an indication that people with a disability are

perceived as different from the norm and that this “difference” is misunderstood. Rose explains how this misunderstanding manifests in GaRankuwa:

You know, people in GaRankuwa do not know disability. Some are judgemental or don't understand. I don't see other people with children with disabilities at the church, and I know they are there. Where are they? They hide their children at home. Maybe they are shy?

Zodwa stated that they do not leave the house often because people “do not like them”. The people in their community are afraid of Thandeka because of her disability. They demand that Thandeka must be “fixed” or cured by the sangoma. She is perceived as a broken object that poses a threat to the community, rather than as a human being. The lack of understanding goes even further: Thandeka is not even able to swallow the sangoma's medicine.

The social construct of blame and an interpretation of a cause and effect relationship becomes clear in the narratives of Daleen and Rose. According to Daleen, Herman's deafness is construed by the community as a consequence of her having done something “wrong” while she was pregnant. Rose was also blamed for Phume's disability because she stopped breastfeeding her. In both these narratives the social construction identified was that mistakes made by the parents resulted in the disability of the child. Daleen shared that they have experienced judgement and rejection by various friends and family members because of Herman's disability. People do not know how to deal with the situation and are embarrassed by the sounds and signs Herman makes. He is made fun of by his peers when they go out to public places. This behaviour indicates that some in society disability is perceived by some as a matter of mockery.

Rev. Visser pointed to the social construct that people with a disability also lack intelligence. Pastor Fischer identified the underlying fear many people have of coming into contact with disability. According to Pastor Ndhladhla their faith community subscribes to the idea of unconditional integration of all people. However, some individuals are judgemental and discriminate against people with a disability. Some families are ashamed, do not trust the faith community to be welcoming to all and therefore hide their child with a disability from the community. This indicates that stigmatisation remains a common social response to disability. Mr. Dodds expressed

emphatically that people with a disability are discriminated against and undervalued by society.

Youth ministry with the objective of being welcoming to and inclusive of children and youth with a disability will have the task of deconstructing the prevalent harmful social discourses with regard to disability that are still rife in most societies and especially so in some culture. Youth workers and congregants should be aware of these discourses and their effect on people with disabilities and their families. They themselves should approach all young people with the utmost respect. They should be self-critical as to the extent to which these social discourses have formed their own constructs and interpretations of disability, lest they do more harm to the people in their charge.

Language plays a major role in the constitution, reflection and interpretation of people's narratives (Freedman & Combs 1996:27) as was seen in the narratives of the participants. South Africa has eleven official languages (Statistics South Africa 2011:21-24). This could possibly have presented a serious challenge to the execution of this study. Five different languages were represented among the participants. These were Afrikaans, Zulu, Sepedi, Tswana and Xhosa. Although no interpreters were needed and all interviews and questionnaires were conducted and done in English, English is not the first language of any of the parents, the clergy or myself. The lack of language proficiency could be an obstacle to the adequate expression and interpretation of the narratives and questionnaires. The extent of the impact of this cannot be ascertained with any measure of accuracy, but the issue should be kept in mind when reflecting on the meaning of the communication that has taken place. In the light of this, Lindbeck's cultural-linguistic model was useful to facilitate a better understanding and interpretation of the responses from interviewees and clergy. The impact of society, their traditions and the way in which language was used in their cultures was mirrored in participants personal views of their religion and faith communities.

To complicate matters further, two sub-cultures were identified in this study. A sub-culture refers to typical behaviour within a smaller society (Ratcliff & Davies 1991:9). The two sub-cultures that were identified as integral fields of understanding in this

study are the youth sub-culture (see Point 4.3) and the disability sub-culture (see Point 3.3).

In order for youth ministry to be effective, a thorough knowledge of youth sub-culture and the developmental phase of adolescence is necessary (Martinson 1988:27). Key terms with regard to the youth sub-culture include adolescence, narcissism and identity formation (Nel 1998:31-36). Due to these specific needs, challenges and interests a differentiated platform for youth ministry is justified and necessary in faith communities (Nel 1998:88). It is important for the youth to have a dedicated space in which they feel comfortable and understood. However, the results of the empirical investigation of this study show that only one of the faith communities has such a differentiated youth ministry. The other two faith communities do not have specialised ministries. They indicate that all their services and activities at church are accessible to the entire family. In practice, however, children and youth, especially those with a disability, do not feel included. There is no specialised platform where their needs and challenges are understood and accommodated. In this study people's idea of what "youth ministry" entails, varied. Christian faith communities, as impacted by their own histories, culture and social environments have different interpretations and expectations of their faith communities, youth ministries and pastors with regard to the inclusion and support of their child with a disability and their family. According to two out of the three parents who do attend church with their child with a disability, their congregations do not offer a differentiated youth ministry. They regard "church" as a family matter. Parents and children attend services and activities together. This should then also be the case for families who are raising a child with a disability. Sylvia also made the following statement regarding her expectations from her faith community: "But I also don't expect anything else from church, other than receiving the Word of God and worshipping Him. If I had any needs or concerns, I would ask to meet with the pastor." Zodwa expressed her needs from the faith community with regard to her child as that she would like a visit and prayer from the pastor. These are all limited expectations that they have of the faith communities. Sophie receives a much more comprehensive spiritual and pastoral support from her faith community. She is also supported by the congregation with goods such as clothing and food. It is clear that the understandings and expectations of these parents regarding their faith communities and the role of faith communities in their lives vary. It seems that the

differences in the understandings and expectations of faith communities and youth ministries are not only related to denominational differences, but have a societal and cultural basis. Their perspectives are also influenced by their individual, personal preferences and interpretations.

Various basic principles apply with regard to the use of appropriate language and etiquette in the disability community. Correct terminology and rules for interaction with people with a disability are important in order to convey respectfulness to this group of individuals. International guides are available with regard to the appropriate terminology and use of language (see Barking & Dargenham Centre for Independent, Integrated, Inclusive Living Consortium 2001), and etiquette (see Cohen 2015:1-52). Awareness of the disability culture and the appropriate use of language and correct etiquette are essential to ensure a welcoming and inclusive ministry to children and youth living with a disability. However, the lack of awareness of the disability culture and appropriate language and etiquette was clear in the majority of interviews with parents and the questionnaires completed by the representatives of the faith communities in this study. Inappropriate references or etiquette identified in the empirical investigation include:

Source	Inappropriate reference or etiquette
Rose (Phume’s mom referring to her diagnosis of Autism).	“...we surely cannot be the first people with a child with a <i>mental disability</i> .”
Zodwa referring to Thandeka’s Cerebral Palsy as if she is “broken” and should be “fixed.”	“They say the sangoma must <i>fix</i> her, ...”
Zodwa describing Thandeka’s disability.	“She is <i>retarded</i> .”
Rev. Pieter Visser	<ul style="list-style-type: none"> • “We currently do not have <i>disabled</i> young congregants, ...” • “... those that need extra explanation because of <i>mental disability</i>...” • “A lack of knowledge about the needs

	of <i>disabled</i> children and young people.”
Pastor V. Ndhlandhla	<ul style="list-style-type: none"> • “<i>Disabled people...</i>”
Mr. Nardus Dodds	<ul style="list-style-type: none"> • “I had one boy who is mute and <i>mentally challenged...</i>” • “... also has a <i>mental disability...</i>” • “... it is no different for <i>disabled people.</i>”

A youth ministry model that is inclusive of children and youth with a disability requires being respectful of the youth and disability sub-culture, language and etiquette. The empirical investigation confirms that people in general lack awareness of the correct use of language and rules of interaction with people with a disability. Most of the representatives of faith communities and parents who took part in the empirical investigation made use of inappropriate references and language. Familiarisation of the terminology and etiquette is a basic requirement of any institution with regard to disability and the inclusion of this community. A general lack of understanding and the inability to accommodate the youth and disability sub-cultures can lead to the exclusion of children and youth with a disability from South African faith communities.

Language remains the dominant medium of communication. The communicative abilities of all five children and youth with a disability represented in this study are affected. Maria, Phume and Thandeka are non-verbal individuals, whereas Herman is deaf and makes use of sign language and lip reading. Oratile is not able to express himself in structured, full sentences. This presents a major challenge to the families. Daleen names it as one of Herman’s main frustrations that he struggles to communicate. It was also most difficult for the family when they were unable to understand Herman when he was a small child. He would be so frustrated at not being able to hear and being constantly misunderstood, that he would become aggressive towards his family members. Sophie stated that Maria is vulnerable because of her inability to speak or communicate. She was a victim of rape, most probably because the rapist knew she was not capable of verbalising what had happened to her and identify the rapist. This case was also dismissed from court because of Maria’s inability to testify. The empirical investigation presented some challenges with regard to language. One such challenge is the multi-language

character of South Africa. Another challenge is the cultural-linguistic influences related to disability. However inadequate language communication is in this context, it remains the only communication tool available.

The results of the empirical investigation provided insight into the lives of the families who live with a child or young person with a disability. The interviews created a platform for the people to share their stories of what it entails to raise a child with a disability. They could also relate their experiences of inclusion and exclusion in faith communities. These narratives contributed to a better understanding of the social identities and narratives of the communities in which the families reside. These include Hammanskraal, GaRankuwa, Holfontein, Pretoria, Mamelodi as well as a Zulu community in Kwazulu Natal where Zodwa and Thandeka lived previously. Their narratives revealed their personal experiences and thoughts, and provided insight into societal and cultural orientations, attitudes and the functioning of the faith communities of which they are members. The purpose of sharing these narratives was to come to a better understanding of the lives and challenges of these individuals (see Müller 2000:9-10), especially with regard to the effects of living with disability. Cultural and societal perspectives with regard to disability, social constructs, discourses and orientations were identified. Through communicating their experiences in this manner, the realities of these families could be described and expressed.

The narratives of the parents and the representatives of the faith communities attested to a great variety, due to factors such as personality, culture, tradition and religious interpretation. What is perceived as true, real and necessary for one person, was not necessarily true, real and necessary for another. There are “no essential truths” (see Freedman & Combs 1996:33), also not with regard to living with a child or young person with a disability in the context of South Africa. As their experiences and cultural contexts differ, so did their realities and their perspectives on disability. Even the reality of a single narrator can be interpreted differently by different readers. The result is that the same narrative can reflect different meanings to different people. Despite these various interpretations and meanings, the narratives of Sophie, Rose, Zodwa, Daleen and Sylvia contribute to the development of an inclusive youth ministry to children and youth with a disability.

6.3 Perspectives on youth ministry

In Chapter 4 where youth ministry and its development was traced, different models of were explored and the inclusive congregational approach was identified as particularly relevant to the aim of this study. From my own denominational background I had assumed that churches in South Africa have a differentiated platform for the children and youth, in other words some form of youth ministry to accommodate youth-specific needs (see Nel 1982:121). Youth ministry as a practical theology ministry should, first and foremost, be about God (De Vries 2004:17). Effective Christian youth ministry prioritises knowledge and interaction with the individual children and youth of the faith community (Osmer 2008:34) and requires insight into the youth sub-culture (see Point 4.3). In order to ensure that youth ministries are inclusive of children and youth with a disability, further insight into the disability sub-culture is also required (see Point 4.7). The understanding of youth ministry by the clergy who completed the questionnaires, was more or less in line with these theories. Though they were not asked to comment directly on what youth ministry entails, their perspectives on the inclusion of children or youth with a disability showed that they perceive youth ministry as a theological field of specialisation that accommodates the differentiated ministry to the children and youth in their congregations.

However, the study showed that not all Christian faith communities do have a differentiated, functional youth ministry in place as I had assumed would be the case. Two of the three parents indicated that their churches do not have a structured youth ministry. Sophie referred to the youth at her church, but that seems to be informal rather than a structured congregational programme. Maria attends services with the youth at her faith community and they visit her at home. She does not refer to youth ministry as a specialised ministry. One of the objectives of this study is to determine whether the implementation of an inclusive congregational youth ministry model could contribute to greater inclusion of children and youth with a disability in faith communities. However, a specific youth ministry model cannot be implemented where the idea of youth ministry as a differentiated ministry has not yet been adopted. These faith communities regard church as a “family matter”. The entire family is welcome to attend all services and activities together. There are no differentiated ministries. Sylvia explains it as follows:

Church with us is a family matter. We do not have activities such as youth groups and Sunday Schools. You go to church with your child and that is it, he stays with me throughout the service.

Both the congregations that do not have differentiated youth ministry models are conditionally inclusive of children and youth with a disability. As long as the children and youth with a disability are accompanied by a family member, their attendance and participation are welcomed. The point of departure of these denominations is that all people should be treated equally and that judging, discriminating against or excluding any person, including persons with a disability, are to be regarded as sin. The inclusive orientation of these faith communities is a general congregational attitude towards disability. Despite these churches not having a differentiated youth ministry model, children and youth with a disability are treated the same as all others and are not excluded based on their disability.

However, in spite of the sound underlying theological approach, in practice Rose did find that, although Phume is welcomed by their faith community, the people in the congregation generally lack awareness of what disability entails and how to deal with people and families who live with disability. They often have unrealistic expectations of her, such as that she should be able to attend lengthy services of three to four hours or that she should be able to sign documentation. This is not possible for her.

The assumption that all Christian faith communities in South Africa have a youth ministry model of some sort, was not accurate. The inclusion of children and youth with a disability in faith communities cannot be dependent on the implementation of a specific youth ministry model if the culture of that congregation is not differentiation orientated. The inclusion of children and youth with a disability should be prioritised nonetheless. Increased awareness will result in the increased inclusion and effective care of children and youth with a disability.

6.4 The impact of the severity of a disability

One of the findings of this study done in the context of South Africa is that there is a lack of available data on children and youth with a severe disability. The narrative of Thandeka provides some insight into the challenges of having to raise a child who is affected severely by disability. The four other children or youth represented in this study are fairly mobile and to some extent even independent. Thandeka, however, cannot do anything by herself. She is bedridden. Many factors contribute to the difficult living circumstances of this family, but considering all options, it is physically impossible for Thandeka to attend any faith community service or activity. The slightest movement is an effort or painful to her. A child in her condition cannot attend events outside of her care environment. Whereas in all other cases attendance of youth ministry services or activities is hindered by various barriers, no initiative taken by the church would enable Thandeka to be able to participate in church activities and events.

However, this does not mean that nothing is to be done. Thandeka and her family do require the support and care of the faith community. In fact, Zodwa longs for their pastor to come and pray for Thandeka. This has not yet happened. The study therefore emphasises that there is a direct correlation between the severity of a disability and the possibilities for the child or youth to participate in events that form part of the church's youth ministry. In order to ensure that children or youth who are severely affected by their disability are not excluded from youth ministry based on their inability to attend or participate in the initiatives of faith communities, youth leaders should be familiar with and know the limitations of these individuals. It is in situations such as Thandeka's where Sophie's idea "to take the church to the people" would be the solution, rather than to focus on access and attendance. Since religion is an important aspect of the lives of many people with a disability and their families (see National Organisation on Disability 2004), it can be a source of support, comfort and motivation to them (Boehm et al 2015). Zodwa's plea for support by her pastor should be heard. In this case the church should come to the family.

The literature on children with severe disabilities and their parents has shown that the incredible hardships and unbearable frustrations sometimes bring them to a point where they consider to end the life of the affected child (see Monckton 2009). In this

investigation Zodwa said of Thandeka: “I cannot speak about that child and not cry. I don’t know why she has to suffer like this. Why was she born to live like this? It would be better for her to be dead.” Parents often feel devastated and defeated by the suffering their child with a severe disability. Witnessing their pain and suffering on a daily basis and not being able to help their children can end tragically, such as in the case of Tania Clarence who killed her three children who all were diagnosed with atrophy (see McKinnell 2015). This reality attests to the urgent need for meaningful support from faith communities for children and youth with a severe disability and their families. Practical theological services such as pastoral care, home visits and prayer are indicated as part and parcel of an inclusive youth ministry model. In order to “break down the walls” insight into the challenges experienced by the child or youth living with a disability and their families is required. Although children and youth with a severe disability can most probably not attend services and activities at their faith communities, other initiatives can be suggested in order for them to experience the practical care and outreach of the youth ministries at their congregations.

6.5 Disability specialising faith communities

People with a disability tend to form a sub-culture (Brown 2002:34). Of the parents who participated in this study, only Herman’s mother, Daleen, indicated that they would consider joining a specialised faith community. The Pretoria Church for the Deaf is a faith community specifically for people with a hearing disability. Daleen states that they also have the option to attend religious services and activities at Herman’s school, where specialised ministry to the deaf community is offered. Although separation and specialisation of services to people with a disability is not the ultimate objective of the disability sub-culture, people with a particular disability can prefer to join such groups where they are better understood and accommodated. The people there share the same interests and encounter similar obstacles and frustrations in the broader society. If this kind of separation is not regarded as ideal, then faith communities should provide a truly inclusive youth ministry for children and youth with a disability. For this an in-depth understanding of the disability sub-culture would be required. Daleen was the only South African participant who referred to the disability sub-culture, and that only in an indirect way. None of the other parents or representatives from the faith communities gave an indication that they had much of

an awareness of the disability sub-culture. In South Africa an awareness of the disability sub-culture could contribute to more effective advocacy on behalf of people with disabilities than is currently the case in this country.

In an informal conversation with Rev. Anel Pienaar of the Pretoria Church for the Deaf she pointed out that deaf people are often on the receiving end of unintentional exclusion in faith communities. Despite the efforts of particular congregations to provide sign language or interpretive services, a deaf person is necessarily excluded from the informal conversations and socialisation at church. People are not sufficiently aware and tend not to look directly at them when they speak since they are not used to the presence of a deaf person in conversations. They are unaware or tend to forget to be considerate of the deaf individual's needs with regard to communication. The Pretoria Church for the Deaf was not established because the deaf community did not want to be included in other Christian congregations, but because they feel more comfortable among those who understand and respond to their needs spontaneously. Based on their common disability and the impact of the deafness on their lives and communication, they people prefer a differentiated, specialised space where they can worship God in a way that they all understand, enjoy and are included unconditionally.

The need expressed by Daleen and The Pretoria Church for the Deaf with regard to differentiated, specialised youth ministry is indicative of a lack in awareness and understanding of people with a disability in South African faith communities. Failure to understand and accommodate people with a disability and the disability sub-culture in Christian faith communities resulted in the establishment of worship environments exclusive to deaf people. Parents of children or youth with a disability regard such specialised spaces as a solution to fill their religious needs in a welcoming, understanding setting. Even with the best intentions and sound theological attitudes on the part of faith communities in South African, though people with a disability are not excluded deliberately, they nevertheless do experience exclusion.

6.6 The inclusion of children and youth with a disability

A thousand suggestions to improve the inclusion of people with a disability in faith communities were identified by Erik Carter (2017:575-594) and his team. These suggestions were categorised as: disability specific-efforts, internal activities, external activities, influencers and resources.

Of the congregations investigated in this study only one made a disability-specific effort. The congregation of Pastor Carina Fischer recently established a ministry for children with a disability. This is a recent development in that faith community and a new ministry speciality of which the congregation as yet has no experience. None of the other faith communities of the participating clergy or parents, has initiatives that focus on the support or training of people with a disability or any deliberate efforts to foster awareness of disability. Furthermore, not one of the faith communities represented in the questionnaires has a disability policy in place. In theory, all five faith communities indicate that they believe in the unconditional inclusion of all people, including individuals with a disability. However, they all lack an official policy of plan of action with regard to disability. Three of the five participating parents thought that increased awareness would lead to a better understanding and inclusion of their child in society and faith communities. The majority of the parents expressed their need for disability-specific efforts in their faith communities. Only one out of the ten represented congregations makes such an effort and this is only a recent development. The study has shown a need for disability-specific efforts to increase the inclusion of individuals with a disability. However this need is not met by the South African faith communities investigated in this study.

The inclusivity of internal congregational activities such as worship, religious education and discipleship groups differs from one faith community to another. According to the three parents who indicated that their children with a disability do attend church services and activities with them, their faith communities have a positive attitude towards people with a disability. For these faith communities their internal activities constitute a family matter and people with a disability are welcome as long as they are accompanied by a family member. All five of the personnel of the faith communities who completed the questionnaires implicated that their congregations welcome the membership and participation of all people, including

people with a disability. From the empirical investigation it seems that society and faith communities in general are positive about the inclusion of people with a disability in all spheres of life and that judgement or antagonistic attitudes are individual perspectives, mostly based on a lack of awareness and knowledge of disability.

In theory, people with a disability are welcome to participate in the internal activities of their faith communities. Their youth ministries should also then be inclusive of children and youth with a disability. However, all five church officials who completed the questionnaire indicated that they have limited to no experience in working with children or youth with a disability with regard to internal congregational activities. Furthermore, the two parents who are not members of any faith community indicated that their non-attendance of church is specifically due to the judgemental attitudes of Christian people and institutions towards disability. Daleen feels that she should prevent her son from experiencing more hurt and exclusion rather than expose him to an environment that is supposedly welcoming and understanding of disability, but is in fact not. Zodwa states that they do not attend church for various reasons, including travelling distance, challenges with Thandeka's mobilisation and the experience of being disliked by the people. People are not tolerant of Thandeka's disability and demand that she should be "fixed" by the local traditional healer. Despite expressing their desire for a visit and prayer from their pastor, this has not taken place once during Thandeka's life.

The finding of this study is that the faith communities across various Christian denominations welcome people with a disability in theory, but not necessarily in practice. Internal activities such as youth ministry ought to be inclusive of children and youth with a disability, but are not. The following matters are indicative of a lack of disability inclusive internal congregational activities:

- non-attendance of services and activities of faith communities because of previous experiences of exclusion and judgement at church;
- no efforts from congregations to reach out to and involve families who are affected by disability in any internal congregational activities;
- a lack of awareness, understanding and accommodation of disability and the needs of persons living with a disability in internal congregational activities;

- conditional inclusion of children and youth with a disability in internal congregational activities;
- youth workers or clergy reporting to have limited to no experience of working with individuals with a disability on the front of internal congregational activities.

The study has shown that the exclusion of children or youth with a disability from internal congregational activities is not intentional. The three parents who do attend services and activities at their faith communities seem to be fairly satisfied with the inclusion of their child at the congregation. Sophie and Maria experience unconditional acceptance and inclusion in their faith community. Rose and Sylvia are of the opinion that the conditional inclusion of their children at their faith communities is the same for all members and that church is a family matter. The condition that their children can attend internal congregational activities only as long as they accompany them is the same for all parents and they do not feel not discriminated against because of their children's disability. Although all five officials of the faith communities indicated that they have limited to no experience of working with children and youth with a disability on the level of internal congregational activities, individuals with a disability are welcomed liked all other people. The Christian perspective is that no person should be excluded from a faith community or discriminated against as this would be in direct contrast with Jesus' teachings and expectations. The majority of incidents of discrimination and judgement experienced in the faith communities as reported by the parents seem to be identified with individual perspectives of disability and not that of the society or faith community in general. Though the exclusion of children or youth with a disability from internal congregational activities does not seem to be intentional, a general lack of awareness and understanding of disability in faith communities does exist and can influence the attendance of internal congregational activities by the families with a child or young person with a disability.

External congregational activities focused on people with a disability are also rather minimal in South African faith communities. Not one of the participating parents or clergy reported any cooperation with other organisations or individuals outside of the faith community with regard to disability. Pastor Carina Fischer did suggest working with institutions that specialise in services to the disability community, such as the

local schools for learners with special educational needs. She finds that an exchange of knowledge and skills between these specialising services and faith communities will improve the inclusion of children and youth with a disability in youth ministries. Dr. Stander is convinced that cooperation with disability specialising facilities will assist faith communities in becoming more inclusive of people with disabilities. Dr. Stander is married to an occupational therapist at the local school for children with a disability and states that this exposure has made him aware of the needs and challenges of this group of individuals. There is a gap with regard to external congregational activities aimed at people with a disability. Youth ministry activities should include cooperation with other disability orientated congregations, social services and community organisations.

The theme identified as “influencers” by Carter (2017:582-583) is of great importance to the issue of the inclusion of children and youth with a disability in South African faith communities. Youth ministry is undoubtedly influenced by the attitudes and approach of youth workers (Dean & Foster 1998:59-66 and Dean 2004:91). Therefore the orientations, approaches and actions of youth workers should be appropriate to facilitate inclusive congregation youth ministry. The study has shown that leaders of faith communities also have a considerable influence on the general attitude towards disability, not only in the congregation, but also in the extended community. Sophie emphasised that her faith community, as well as the community of Hammanskraal in general, are aware of disability and the needs of people with a disability due to the influence of their pastor at the House of Prayer Church. The pastor’s dedication to the cause of disability has led to a general awareness, support and care of the disability community. Rose, on the other hand, reported that the ZCC congregation she attends makes no effort with disability. She is upset that the church expects Phume to do things that she is simply not capable of, such as signing documents. Phume is welcome at church on condition that Rose attend services and activities with her. According to Rose they experience judgemental attitudes of individual people on a regular basis. Despite Phume’s inclusion in internal congregational activities, there is but a limited understanding of her disability and capabilities. The expectations that she should be able to do what she is not capable of doing attests to a lack of understanding of disability and the special needs of individuals with a disability. Rose regards consciousness raising with regard to

disability as a necessity in the church. From the point of view of the clergy, Pastor Ndhlandhla emphasises the importance of the attitude of the pastor towards people with a disability. He has no doubt that the welcoming attitude towards people with a disability in his congregation and community is the result of his personal commitment and prioritisation of this issue:

As pastors, we have to be trusted by the community and advocate for important matters such as disability. If we don't, we don't only fail the people, but God. The image of the pastor is very important and trusting them even more so.

Oratile's mother, Sylvia, is of the opinion that society's attitude towards people with a disability starts with the attitudes of parents and families and the way in which they treat the individual with the disability. She regards herself as an advocate for disability matters and believes that people's responses to Oratile are primarily influenced by how she as a parent treats her son in the first place. Pastor Ndhlandhla shares this opinion:

Charity begins at home. Firstly, if you do not respect your own, how then are others going to do it? I am saying that families with children with disabilities cannot hide them and then expect the community to care about them. If they are ashamed of the God given children, people will not be aware and reach out... Secondly, pastors play an integral role. When the pastor understands the situation and train the congregants, they will understand.

The study has shown that "influencers" or leaders in the field have a major role to play with regard to the awareness, understanding and inclusion of children and youth with a disability in faith communities. It must be stressed that this leadership should not be limited to that of the personnel of faith communities, but also refers to the leadership and advocacy by the families of the child or youth with a disability and other interested members of the congregation.

According to Carter's (2017:582-583) study, doctrine and theology also have a role to play towards the inclusion of individuals with a disability in faith communities. However, all five faith communities in this study as represented by the youth workers

indicated that they have no official disability policies in place. Investigating the governing structures of the faith communities represented by the parents and the clergy in this study, there also are no official disability policies or documents available on a national or provincial level. A general Christian orientation or beliefs with regard to people with a disability and their inclusion in faith communities is not sufficient to ensure the effective inclusion of this group of individuals. Where a lack of administration and documents in congregations should not stand in the way of the implementation of effective practical theology, these do have a role to play in the guidance and organisation of the structures and functions of faith communities. A disability policy on congregational level will not only raise awareness of disability in the faith community, but will ensure the increased inclusion of individuals with a disability. On a national and provincial level such measures will contribute to ensuring a positive orientation and the implementation of the necessary measures with regard to disability in faith communities of that denomination. Since all these Christian denominations share the same theological perspective with regard to the inclusion of people with a disability, such policies and documentation can contribute to putting this very sound theory into actual practice.

The last theme regarding the increase of the inclusion of persons with a disability in faith communities, is resources. Resources include accessible transport, structures and financial support (Carter et al 2017:582-583). All five parents indicated that raising a child with a disability is extremely expensive and that they are struggling to afford the specialised goods and services that their children require. Sophie specifically referred to the challenges they experience in Hammanskraal with regard to transport, especially for people with a physical disability who make use of wheelchairs. People in Hammanskraal (and most South Africans) primarily make use of public transport, namely taxi's, buses and trains. According to Sophie the infrastructure in Hammanskraal is not good and consequently not accessible to people who make use of wheelchairs. Secondly, where there is transport available it is often not accessible to people with wheelchairs. These assistive devices take up space and taxi drivers do not prioritise transporting people with a physical disability. If they are willing to transport a person who makes use of a wheelchair or crutches, it has cost implications and additional fees are charged. In Daleen's case they have only one vehicle and cannot go to church when Herman's father is working.

Thandeka's wheelchair broke because of rough terrain. This and the distance makes it difficult for them to attend worship services. They have such limited access to resources that it is even difficult to take Thandeka to hospital.

Two of the participating representatives of the faith communities stated that the structural accessibility of their congregations was inadequate or impractical to persons with a disability. On the other hand Pastor Ndhlandhla fetches a blind person himself in order to ensure that the man can attend the services and activities. The provision of adequate resources and the support of people in the congregation can contribute to improved inclusion of people with a disability in the activities of faith communities in South Africa. The study has shown that Carter's (2017:575 – 594) ideas for the increased inclusion of persons with a disability in faith communities can be fruitfully applied to the South African context.

CHAPTER 7

NO MORE WALLS

7.1 Existing walls

This chapter presents the findings of this study on youth ministry and disability. Movements 4, 5 and 7 of Müller's (2004:301-304) method for a postfoundational practical theological investigation are played out in this chapter. These movements focus on: the interpretation of participants' experiences and the ways in which these have been influenced cultural traditions and societal discourse; reflection on participants' views of the presence and involvement of God in their situation of having to raise a child with a disability; developing alternative interpretations of their situation, that go beyond the limitations of society. The aim of the study was to provide insight into present practices, evaluate those practices and point the way to improved practices toward the greater inclusion of children and youth with a disability in faith communities.

This study was inspired by Mr. H's metaphor that the inclusion of children with a disability rather is about breaking down walls than putting up ramps. Structural accessibility seems to be less of a challenge to individuals with a disability than the more "invisible barriers" often caused by a combination of social, cultural and attitudinal factors. As persons who are among the most excluded globally, children and youth with a disability face various challenges on a daily basis, including basic human rights and access to services. They face judgemental attitudes, rejection, exclusion, isolation and stigmatisation. In African contexts people with a disability can even be perceived as "cursed."

Despite the fact that religious faith often plays a prominent role in the lives of individuals with a disability and their families or caregivers, they often have but limited access to church services and congregational participation. This is the case not only in Africa, but is also internationally as especially some studies in the US have shown.

An objective of this study was to determine whether children and youth with a disability share a similar experience of exclusion in South African faith communities. National and international statistics indicate a fairly high prevalence of children and youth affected by disability. In 2013 UNICEF reported some 93 million children under the age of fourteen years diagnosed with a moderate to severe disability and the South African Census of 2011 found that at least of 10% of young children were affected by disability. Had these individuals been successfully integrated and included in faith communities, these relatively high numbers would have been reflected in the statistics of churches. However, it is not the case. The membership and attendance statistics of faith communities globally do not reflect a high prevalence of children and youth with a disability. The inclusion of children and youth with a disability is furthermore a theological responsibility, the foundations of which can be found in the inclusive spirit of the gospel message. Three out of the five parents who participated in the study reported that their child does attend church with them. Though the situation seems more positive in South Africa than in many other international contexts, the South African parents did not feel that their child was really actively involved in the youth ministry of their faith community. The tendency is to only allow children and youth with a disability to participate in the activities and ministries of their churches if the parents are also present. Parents are expected to be there with them and provide the support their child requires. This is not indicative of a disability inclusive ministry model in general and also not of a disability inclusive youth ministry model.

The five congregational leaders who took part in the study and were representative of four different church denominations, were of the opinion that Christian faith communities and youth ministries *ought to* be inclusive with regard to individuals living with a disability. However, in practice they did not have much experience of working with children or youth with a disability in their faith communities. The findings with regard to the experiences of children and youth with disabilities in South African faith communities can be summarised as follows:

- The prevalence of children and youth with a disability in faith communities is low in comparison to national statistics. This means that the majority of children and youth with a disability in South Africa do not attend church for some reason or another.

- Reasons for families with a child with a disability not attending church services and participating in church activities include logistical challenges such as inaccessible infrastructure, an insurmountable travel distance to local congregations, stigmatisation and judgement by other congregants, spontaneous exclusion from activities and conversations and the children being made fun of by peers without a disability. Other factors include time management, fatigue and a general lack of understanding of disability encountered by them in society and the church.
- All the people representing Christian denominations in this study agreed that individuals living with a disability should be included in faith communities and activities, also the church's youth ministry. In theory, individuals with a disability are welcome in all these faith communities. However, the inclusion of children and youth with a disability in faith communities and youth ministry is not reflected in practice.
- The attendance of church services and participation of children and youth with a disability in congregational activities is dependent largely on the presence of the parents. The fact that children and youth mainly do not attend the activities of faith communities or activities without their parents is in itself indicative of a form of exclusion.

Church attendance figures and a lack of ministerial experience with children or youth with a disability clearly indicate that the majority of children or youth with a disability in the South African context do not attend church at all. The majority of parents whose child with a disability does attend church, indicated some form of congregational exclusion, especially with regard to youth ministry. These parents generally did not find structural inaccessibility to be the main challenge.

Findings with regard to the exclusion of children and youth with a disability in South African faith communities do not differ much from those of international studies. Therefore, Mr. H's reference to "breaking down the walls" is applicable to both international and local contexts. The existence of these "walls" cannot be denied. A

question explored by this study was whether these “walls” are a typical, general phenomenon encountered in a similar way by the parents of children and youth living with a disability, or whether there are elements of the exclusion that are context specific. The study has established that barriers do exist for children and youth with a disability and their parents internationally, as reflected in the literature, and locally as reflected in the empirical part of this study. The following focuses on what the barriers experienced by participants entail, and provides some guidelines to facilitate the removal of those barriers in order for faith communities to be truly inclusive, also of children and young people who live with a disability. Despite South Africa being a leader in the field of legislation and policies regarding people with a disability, from the perspective of theology and the church not much progress has been made as yet. South African theological studies on this topic are minimal. This study aims to contribute insights in this regard specifically from a youth ministry perspective.

With regard to faith communities and the participation of children and youth with a disability and their families, findings of international studies were similar to the findings of this study. In the US, more than 55% of the parents kept their child with a disability from participation in religious activities due to a lack of support from the church or the expectation of the church that they should stay with their child at all times in order to provide the support themselves. In this study, all three parents who do attend church indicated that their child only attends services and activities with them being present. The percentages of parents who were of the opinion the their congregation needed more education on disability and increase their awareness of the issues surrounding disability, are also similar. Across the board parents named fatigue as one of the main reasons for not attending church. Whereas US parents reported that their children with disabilities often make it difficult to attend church because of being noisy, having complex needs, not being able to sit still, touching others, being overwhelmed by the noise and chaos, being loud, unpredictable and aggressive towards other people, not being able to understand religious education lessons, becoming over stimulated, which causes embarrassment, South African parents report a feeling of embarrassment in this study. According to them, their children are welcomed despite their behavior. However, the church does expect of the parents to be with the children at all times. The study finds that, though there were some differences, generally the experiences of parents raising children with a

disability are not context specific. The experiences of US parents are much similar to those of South African parents.

Similarities were also identified with regard to what factors could lead to an improvement the inclusion of individuals with a disability in faith communities in the US and South Africa. Three themes featured in this regard. The first is disability-specific efforts: congregational initiatives specifically designed for people with disabilities and their families. In the US studies this included family support, individual support, consciousness raising and training. In this study South African parents reported the following:

- church attendance and pastoral care is a family affair;
- the lack of inclusive youth ministry means a child or youth with a disability receives no support ;
- an increased awareness of disability and what it entails in the congregation and community makes a great difference and consciousness raising should be a priority;
- training with regard to what disability entails and how to best engage with young people with a disability, will make a significant difference to people's understanding of disability.

A second theme is the role of influencers: those in leadership and their orientation have a direct effect on the attitudes and actions of the faith community. In the US studies congregational culture and climate, leadership, staffing and governance, as well as doctrine and theology were highlighted. The findings of this study confirm the general trend that the congregational attitude towards disability is largely determined by influential individuals. This means that the role of the pastor is prominent in the care and inclusion of individuals with a disability. In theory all faith communities agree that persons with disabilities should experience uncompromised inclusion in the Christian church. The more traditional denominations in South Africa specifically regard the role of the pastor or clergy as most influential in the general attitude of the congregation towards people with a disability. Another theme where noticeable similarities were found is resources. The resources mentioned in the US study included the availability of transport, structural accessibility and financial assistance.

In South Africa, logistics and practicalities were the focus. This includes available, accessible transport, structural accessibility and support with finances, food and clothing.

These comparisons indicate that the experiences of parents with children and youth with a disability are similar in local and international contexts. Although individual contexts differ, parents of children and youth with a disability generally share similar experiences regarding the inclusion or exclusion of their children in faith communities globally. The exclusion of children and youth with a disability in general has been found not be context-specific with regard to the main challenges and services.

7.2 Engaging with the South African context: A reflection

Though the main challenges and services for people who live with disability are similar in different contexts, the South African context does present some unique challenges. In this sense some aspects of the lives of children and youth living with a disability and their families and faith communities are certainly context specific.

Despite having worked in the disability sector for almost a decade, I did not anticipate the empirical results the study yielded. I was convinced that parents would agree that their children with a disability (and consequently themselves as a family) were subject to severe exclusion from their faith communities. This was not the case. While the majority of parents experienced some form of exclusion in their faith communities, there were also positive narratives of fairly successful inclusive practices. Secondly, it was not my expectation that all participants from the various faith communities would advocate so uncompromisingly for the inclusion of individuals with a disability in their congregations. Their theological view was that all people are included in the kingdom of God and should be treated by Jesus followers as Jesus himself would have treated them. Especially in the African context where the stigmatisation of disability is harsh, I did not expect to find such an inclusive orientation among the faith communities. Extreme prejudice and overt exclusion of people with a disability were only found in two cases. In one case the disability was seen as a curse that resulted from the mother's supposed sins. The child with the disability was rejected by the father and he even threatened to kill her and her

mother should they approach his community again. However, this father's rejection of his daughter and her condition was primarily influenced by his traditional Zulu beliefs rather than religion.

As a South African I have seen people's struggles with disability and poverty from close by having grown up in a farming community with its simple rural life style. This provided me with some preparation for the living conditions I encountered in this study. Most of the clients with a disability with whom I have engaged in a professional capacity over the past decade, come from a disadvantaged background. The frustrations of poor infrastructure, inadequate state health services and poor living conditions were a familiar reality. However, when it came to the participants in this study I found it rather difficult to refrain from getting personally and emotionally involved. Knowing of and experiencing people's circumstances first-hand is very different. Having to focus the sharing of their narratives on the purpose of collecting data was an almost impossible task. I hope now, more than ever, that the study will on some level, make a meaningful contribution to their lives.

Despite the fact that most participants were welcome in their congregations, the results of the study did show that youth ministry in general is not accessible to or inclusive of people with a disability and their families. At most only partial participation, and that in the presence of the parents, is possible for children and youth with a disability. This warrants a closer look at the inclusive quality of youth ministry. Although the incorporation of a child or youth with a severe disability into the life and activities of the faith community can be rather complex, there are ways to ensure that this group of individuals is not excluded from participation on account of their condition. However, the effort made by faith communities in this regard, proved to be rather limited. The contribution of this study is therefore to provide insights for the empowerment and guidance of such ministries in order to facilitate an increased inclusion of children and youth living with a disability.

The influence of the social-economic status of the participants was less of a challenge than anticipated. Although economic inequality is a reality in South Africa and had to be taken into consideration, the economic circumstances of the

participants did not keep them from participating in the study. Parents generally preferred interviews to be conducted in a space other than their homes. Only one respondent, who lives in a rural area far from town and has severe financial restrictions, had to be visited at home. For all the participants regarded it as a priority to participate in the study and share their narrative of living a child with a disability, in order to contribute to making a difference in the lives of their and other children or youth with a disability. The least privileged members of society, however, were not reached through this study, since they had no means to access the invitation for participation. People from extreme poverty stricken areas mostly do not have access to technology (i.e. computers or the internet and phones), or service providers in the disability sector such as nonprofit organisations or stimulation centers. The socio-economic status of participants also presented some challenges. My personal socio-economic position differing greatly from that of most of the participants, it was difficult at times to form an understanding of the urgent needs of people who are dependent solely on government grants. Most of the parents who participated in this study rely on a disability grant for their child. The maximum amount for disability grants in South Africa is R1600. This small amount barely covers basic living costs such as food and clothing. All participating parents reported financial challenges, not only due to the current economic situation in the country, but also because of the additional costs of having to care for an individual with a disability. This includes necessities such as medication, nappies, assistive devices, and a range of therapies or rehabilitation treatments. In some cases the parents can barely survive on what little they have.

The living conditions of participants varied immensely, which made it challenging to me to observe and interpret the narratives. Also, the differences between an urban and a rural lifestyle made interpretation difficult. For instance, what is taken for granted in the city is considered a luxury in a rural area. Travelling distances has an effect on how accessible basic services, such as health care, would be. Other challenges to the accessibility to services include poor infrastructure and a lack of municipal services, such as water, sanitation and electricity. The size and space of residences are another factor that can make it difficult for families living with a person with a disability. Of the participants, 60% live in simple, small housing structures consisting of one or two rooms in total. It is common for multiple members of one family to share one bed, because of the limited space. Toilets are mostly outside,

which makes it difficult and dangerous for a person with a disability to access, especially at night. The socio-economic position of participants impact on their health and functioning. Most of the participating parents do not have the means to provide for the needs of their child with a disability. A nutritious diet, for instance, is not always affordable. Though parents do the best they can for their child, their socio-economic circumstances have a direct negative impact on the health, development and functioning of their children.

Cultural and ethnic diversity also presented a challenge for the investigation. All interviews were conducted in English and no interpretation service was required, since all participants understand and speak English. Since English is not the first language of the participants, their responses were not always grammatically correct English. I elected to leave the language as it was, since language editing could, even unintentionally, change the meaning of the communication. Despite language difficulties, the intention of what was communicated came across sufficiently clearly for the purposes of the study.

The challenges of language were relatively small in comparison to those of culture and the different cultural perspectives and understandings of disability. Specific reference to cultural and traditional beliefs with regard to disability was made especially in three interviews. What made this matter more complex than anticipated was the extent to which Western influences were adopted by some more than others in the same culture. People in the same culture therefore do not necessarily share the same opinions on a matter such as disability. The tendency of the participants in this study was to have a broad and inclusive perspective on disability in general. However, even people with such an attitude and approach to disability can be affected emotionally and socially by members of their family or their community who are often still rooted firmly in cultural and traditional orientations, where ideas about traditional healing, and spiritual and ancestral influences regarding the “manifestation” and “curing” of disability, are prevalent. All participants in this study opted for westernised medical care, treatment and stimulation of their child with a disability, though these views were not shared by all others in their culture. This made it difficult for me to assess the impact of cultural views on disability on the person with a disability and their family.

It also was challenging to understand and interpret disability culture in South Africa. The guidelines from various sources regarding disability language and etiquette differ as preferences and contexts differ. In their response to the invitation to participate in this study, organisations and professionals in the disability sector used different terminology. Parents and the representatives of the faith communities were often not aware of disability etiquette and language preferences. This became clear in the language used by participants in the interviews and with the surveys. The disability sub-culture remains a unique and challenging field. There is much more to it than just “the spontaneous formation of an exclusive group of individuals with disabilities based on their commonalities and interests”. It is an ever evolving field and keeping up with the latest preferences remains a challenge. Besides different preferences across the globe, individual perspectives also differ. Advocacy plays a central role in terms of the need to raise awareness.

Not all who are part of the disability culture share similar ideas on the preferred terminology. Because of the great diversity, attempts to formulate policies have often failed because people with different disabilities have different emphases and interests. For example, people with a mental disability often feel excluded from the disability policies that tend to prioritise the wellbeing of people with physical disabilities. To complicate matters even further, groups representing a specific disability such as blindness tend to prioritise their specific disability rather than disability in general. In South Africa policy workshops have not yielded results, which leave the country without an official disability act. The White Paper on the Rights of People with Disabilities (2015) was approved by the cabinet, but has not yet been adopted as a legal act as yet.

A further challenge in the South African context is the great cultural and language diversity. Change is the only consistent. As developments take place in the disability sector, so terminology changes. This contributes to the complexity of understanding and interpreting disability culture. An example is the use of sign language by deaf people. Firstly, there is no international sign language. Sign language is particular to the country in which it is used. South African sign language is a “local dialect”. Even this dialect is not used in the same way by the whole South African deaf community.

The reason is that, prior to 2014, sign language was not taught in schools. This meant that deaf learners picked up the language from their peers. The result was great semantic differences, so much so that schools for deaf children can often be identified by the type of sign language they use. If disability culture is complex for people with a disability themselves, then it is even more so for outsiders. People who have no or only a limited awareness of and insight into the world of people living with a disability, can find this world puzzling and the structures daunting.

The study has shown that Christian believers generally agree that people with a disability are to be treated with the same human dignity as all other people. This is based on the gospel message. Parents who raise a child or youth with a disability and who participated in this study, present various perspectives. Church attending parents experience a welcoming, non-judgemental congregational attitude towards their children and themselves. However, the presence of the parent or family is a requirement in order for the child or youth to attend or participate in services or ministries. Leaders of the participating Christian faith communities generally agree that people with a disability should be unconditionally integrated and included in church life and activities. However, none of the faith communities have an official policy or plan regarding the inclusion of people with a disability. The idea that people with a disability should be treated the same as all other people and should not be excluded in any way, is similar in South African faith communities to what international studies have shown. The Bible as source document of the Christian faith sheds light on the responsibility of Christians and how they structure their faith practices. This can be applied also to youth ministry and the inclusion of children and youth living with a disability. Jesus set the example and his followers are called to do the same. As a discipline, practical theology, a theology of action, aims to transform theological theories into practices that are in accordance with the gospel. Therefore this study aimed to facilitate change in the lives of children and youth with a disability and their families by means of a theoretical and theological, as well as an empirical investigation into their inclusion in South African faith communities.

7.3 Breaking down the walls

The discussion of the contexts of children and youth with a disability in South African faith communities constitute the first movement of Müller's model for practical theological investigation. The focus was specifically on the prevalence of children and youth with a disability globally and in South Africa, the various disabilities and the effects thereof on the persons themselves and their family as well as the practical theological interpretations and responsibilities regarding this group of individuals.

The second movement was applied by means of the empirical investigation with regard to children and youth with a disability in South African faith communities. This investigation was conducted by means of five structured interviews parents who are raising a child or youth with a disability, and a survey regarding the inclusion of these children and youth that was completed by various professionals of Christian faith communities. Müller's third movement was not applied in this study. The narratives of participants were not developed with their input or cooperation, since the aim was only to collect data. The description and interpretation of the data with regard to the experiences of participants against the background of cultural traditions and social discourses represent the fourth movement. Their experience of God and faith community's involvement in their lives and situation were articulated and they also voiced their opinion on what they expect from faith communities with regard to people with a disability. The spiritual and religious aspects of participants' experience constitute the fifth movement. The sixth movement focuses on interdisciplinary consultation, in this case focusing on disability and people living with a disability. Insights into disability, the disability sector, types of disability and the disability culture from the perspectives of the fields of social development, psychology, education and health care were appropriated. Given the limited data available on children and youth with a disability in South African faith communities, the contributions from these disciplines were vital to the study. Limitations in society with regard to disability were identified and alternative interpretations and practices proposed. The aim of the study is to provide some momentum for change which could improve the lives of children and youth living with a disability and the specific role that youth ministry in local churches can play in this. This constitutes the seventh movement of Müller's model of practical theological investigation.

From the perspective of the postmodern paradigm of this study, results are to be interpreted as specific to persons and contexts and are not to be generalised as “absolute truths” applicable to all people and contexts. The people who participated in this study and their experiences were respected as uniquely individual. The contribution of each individual has added to the value to the body of knowledge with regard to children and youth living with a disability in South African faith communities. In the search for meaning and the inclusion of these individuals, the aim was not to gain “objective knowledge”. My personal background and expectations played a significant role in the execution of the study. Despite my serious effort to not allow my own presuppositions and assumptions to determine the direction of the investigation, this possibility could not be completely eradicated. Subjectivity and engagement on a personal level with the people and the material undoubtedly played a role in this study.

Youth ministry is first and foremost about the relationship God and young people. The objective of youth ministry is to spread the good news of the gospel and to foster discipleship among young people. Youth ministry is about the faith community guiding young people in their midst to become dedicated followers of Jesus Christ. Therefore the development of a youth ministry and the development of the faith community go hand in hand. The relational character of God is emphasised in youth ministry. God created human beings to live in relation to God and one another. This characteristic is to be nurtured by the faith community and its youth ministry. Youth ministry and the faith community should be such that children and youth can experience these relationships. This can strengthen their sense of belonging and give a deeper meaning to their lives.

Youth ministry does not function separately from other ministries. A holistic approach is preferred in most of the current youth ministry literature. All Christian believers belong to the household of God irrespective of factors such as age or disability. Effective youth ministry also requires a thorough knowledge of the youth sub-culture. Although youth ministry does not function separately from the broader faith community, childhood and adolescence are unique phases of life that justify a unique platform, though this ministry remains an integral part of congregational ministry. Specialised needs should, however, be accommodated, considered and addressed

effectively. The role of the family in the faith development of the children and youth is essential. The study has shown that family is of even greater importance in the lives of children and youth living with a disability, since they remain dependent on their parents and families throughout their lives. The result is that parents and family of children and youth with a disability have an integral role to play in youth ministry.

The inclusive congregational approach to youth ministry is found by this study to be eminently suited to facilitate the integration and inclusion of children and youth with a disability. The element of “inclusion” is central to this approach and is also of the greatest importance in the disability sector. People with a disability are particularly focused on inclusion in all spheres of life. According to the inclusive congregational approach to youth ministry, youth are seen as an integral part of the congregation itself and not just a separate congregational project. A comprehensive congregational ministry emphasises inclusivity. With regard to youth ministry three focal points are of consequence. The first is the characteristic of *interdependence*. Youth ministry stands in an interdependent relationship with the other ministries of the faith community. The second characteristic of youth ministry is that, though it is a unique ministry in the faith community, the same principles that apply to other ministries also apply to youth ministry. It is therefore not so much about “youth ministry” as it is about *ministry*. A third characteristic is that youth ministry does not function separately from the rest of the congregation, but as part of the whole. It is the *inclusive* focus of this approach that is relevant to this study, since a central concern in the disability sector is inclusion.

Paul’s metaphor of the congregation functioning as a whole body in 1 Corinthians 12 provides a theological motivation for the inclusion of children and youth, as well as individuals with a disability in the activities and ministries of faith communities (see Nel 1998). In an inclusive congregational approach, all the various ministries are part of youth ministry and vice versa. Such ministries include *kerugma*, *leitourgia*, *paraclesis*, *didache*, *cubernetics*, *koinonia*, *diakonia* and *marturia*. An interdependent relationship between these faith practices would mean that youth ministry cannot function without the support of these ministries and that all of these ministries should be incorporated in youth ministry.

The effectivity of youth ministry depends to a large extent on the successful cooperation between adults and the youth of the congregation. Parents have been shown to be one of the greatest influences on the lives of children in many aspects and also in the children's faith development. It is for this reason that an inclusive congregational approach to youth ministry focuses specifically on parents and families. Families should be empowered to be a trustworthy environment where it can make sense for young people to learn about God and the gospel. Families are primarily responsible for the formation of discipleship in their children. Families should be established, reliable structures where a (Christian) lifestyle is passed along through experience and observation. If families (and specifically parents) do not succeed, the influence is similarly strong to the negative side: there is clear connection between problems youth experience at home and a sense of alienation from the church. Family problems and structures are becoming increasingly complex. Such problems can include complex non-traditional family structures, minimal, quality family time due to busy lifestyles and immature faith development of the parents themselves. The faith community then becomes only secondary to the child or youth. The key to developing a strong and committed faith is a close relationship between the two formative families, namely the biological family and the faith community. Parents and families of children with a disability often have to act as "spokespersons" for them, since those who live with a disability are often not understood by others. The study aims to contribute to meaningful relationships between the families and the faith communities of children and youth living with a disability.

The inclusive congregational approach to youth ministry is about being aware of and sensitive to the youth sub-culture. Although the youth is entirely included in the function of the whole congregation, youth do have specific needs, find themselves in a specific developmental phase and are faced with unique problems and changes as they negotiate the transition from childhood to adulthood. People tend to be more receptive when they operate in familiar systems where others understand them and their situation, and share their views and challenges. Faith communities, especially youth workers, should have an understanding of the youth sub-culture in order to share the gospel with them more effectively.

A definitive element of the inclusive congregational approach to youth ministry is leadership. The right leadership and leaders do not replace the authority of God, but serve according to God's calling and the guidance of God's Spirit. Among youth leaders there are those with a formal education in youth ministry and those who become involved in voluntarily. Both groups are of significance and they operate in conjunction with each other, not separately or in opposition to one another. Irrespective of their background in formal education, the training and continued education of all members of the faith community involved with youth ministry is of great importance. Characteristics of youth workers should include: their reliance on God alone; their willingness to be of service; their sincere interest in and care for the lives of the children and youth; their calling; a teachable spirit.

An inclusive congregational approach to youth ministry will entail a ministry on three levels simultaneously: *to*, *with* and *through* the youth. *To* the youth implies that they are on the receiving end of the ministry. This facet focuses on the provision of a special space in which the youth is served. Opportunities for praise and worship, engaging with Scripture, youth activities, socialisation and camps are provided. Before they can become progressively involved in the ministry and congregation, children and youth first need to experience being part of a faith community. Youth ministry entails reaching young people effectively for the kingdom of God. This is the main criterion for any church to grow and transmit the gospel to others. Ministry *with* the youth refers to participation of the youth in various church ministries. They become more than "objects" of ministry. They themselves become agents of ministry in their own right. Their spiritual gifts, reliability in and familiarity with the faith community empower them to take responsibility and leadership on various levels. Youth ministry *through* the youth refers to ministry "owned" by the youth. Youth ministry is no longer lead by adults. The youth themselves take ownership of and responsibility for the future and development of the youth ministry in which they are involved.

A decisive element of the inclusive congregational approach is ministry with and through the youth *to the world*. Bringing the good news of the gospel message is not limited to particular persons, but is the calling of all the followers of Jesus Christ. A missional orientation is a basic requirement of being church. This missional

characteristic of the faith community is also applicable to the youth and youth ministry. God equips believers for the task at hand and empowers them through God's Spirit to communicate effectively with other children and youth with whom they have much in common. To function independently in this way, provides the youth with a sense of meaning and being of value in their faith community.

The study has shown that an inclusive congregational approach to youth ministry is a useful way of working toward ensuring the optimal inclusion of children and youth with disabilities in faith communities. The various elements of this approach to youth ministry can be further adapted and refined to also be suitable for youth with a disability. From the point of view of a comprehensive congregational ministry, the entire faith community is involved in youth ministry. The result is that the entire congregation should accept responsibility for caring for and welcoming children and youth with disabilities in their midst. As this approach allows for the incorporation of a great variety of types of ministry in the faith community, it has the potential to provide sufficient opportunity for children and youth to participate in the activities of the church. The more the opportunities available to the youth to participate and serve, the better the chance that also youth with a disability will be able to engage in activities for which they have the gifts and the ability.

The central role of the parents in this approach to youth ministry is especially appropriate for children and youth with a disability, since their dependence on parents is greater than in the case of their peers. Parents of children and youth with a disability will, of necessity, be more involved in the youth ministry for the sake of their child. The study has shown that access is of primary importance for children and youth with a disability. If access to the church building and the venue where youth activities take place, is difficult or impossible, they cannot participate. It is also a problem for parents if the church expects of them to remain with their child at all times, since they alone should provide all the support required by their child themselves. The study has shown that such a "hands-on" involvement of the parents of children and youth with a disability is a common expectation from faith communities both in South Africa and internationally. Some parents find this difficult, whereas other parents welcome the involvement in church activities as a family.

They would have chosen such a level of involvement regardless of whether their child had a disability or not. The emphasis of the role of the parents in the inclusive congregational approach to youth ministry is therefore suitable also for youth ministry with children with a disability.

The focus on inclusion and differentiation in the inclusive congregational ministry approach is also particularly appropriate to youth ministry with children with a disability. This element of differentiation emphasises the importance of the uniqueness of the children and young people in faith communities. Differentiation can be expanded from acknowledging the difference of the youth sub-culture and each young individual to acknowledging also the difference of disability culture and unique circumstances of each child or youth with a disability. This will result in a better understanding of the person, the family and their life with a disability. Being present with and showing an authentic interest in the lives of children and youth with a disability will afford faith communities the opportunity of coming to a better understanding and an improved practice. Both their “presence” and their “understanding” are vital to children and youth with a disability, since their needs and abilities are so extraordinary and unique. Initiatives to facilitate the inclusion of and ministry to one child or youth with a disability may not be effective for another. The individual needs of children or youth with a disability are to be prioritised by faith communities.

The study has shown that leadership is crucial to effective ministry to persons with a disability. Spiritual leaders’ awareness and care of people with a disability in the congregation and community are central. They are the ones with the authority and the platform for advocacy on behalf of people with a disability and their families. If they are passionate about care, support and ministry to individuals with a disability, they can positively influence members of the faith community and set an example. The results of the study have shown that where the pastor was caring and supportive to the family of the child with a disability, the congregation and community were more welcoming and reached out to them. Pastor Ndhladhla was adamant that, if pastors do not advocate for important matters such as disability, “we do not only fail the people, but God.” The study has shown that people in a leadership role, especially

pastors, have a significant impact on the inclusion of individuals with a disability. They can set an example of awareness, caring and advocacy.

In order for a youth ministry *to, with* and *through* the youth as integral part of the faith community from the perspective of an inclusive congregational approach to come to fruition, some possibilities are briefly discussed. In order to expand their knowledge of and passion for the kingdom of God, children and youth with a disability should be included. For this to be effective, their individual needs and abilities should be taken into account. The gospel message should be brought to them in creative ways that are suitable to their level of development (cognitive and physical). The type of disability plays a role, as well as the individual's preferences and dislikes. Once the congregation is familiar with the child's likes and dislikes, ways in which the gospel message can be shared with them in an appropriate way, can be identified.

In order to do youth ministry *with* the youth, children and youth should participate in various ministries at church. This could present some challenges and the study has shown that not all adult congregants are receptive to such an approach. Although it can be more of a challenge to include children and youth with a disability in the various ministries of faith communities, it is necessary for them to be afforded the opportunity to become involved. Depending on their abilities, they can greatly benefit from participation in other ministries. They should be presented with options that are appropriate to their skills set and preferences. Expanding these options can undoubtedly lead to increased inclusion of children and youth with a disability.

In order to minister *through* the youth, they should be given the opportunity to take responsibility for and ownership of particular ministries in the faith community. When they are no longer dependent on the leadership and actions of adults, they can organise these ministries themselves. There is no reason why a child or youth with a disability cannot take ownership of a ministry that is within the range of their specific abilities. The characteristic of the inclusive congregational approach to youth ministry namely that ministry should take place with and through the youth *to the world* focuses on the missional element which is the purpose of any ministry. Just like adult believers, children and youth should also develop their spiritually to the extent that they too bring the good news of the gospel message to others. Children and youth

living with a disability should not be excluded if they have the ability to participate. God equips people for the task they are given. Children and youth with a disability are not exempt from a divine calling.

The inclusive congregational approach to youth ministry can therefore be appropriated effectively for the inclusion of children and youth with a disability in South African faith communities. Although this approach was not designed for this group of individuals specifically, the six requirements of the approach can be adapted to facilitate the optimal inclusion of children and youth living with a disability. Social constructs are an inevitable challenge faced by children and youth with a disability and their families. Societal norms and perspectives on disability have a direct impact on the integration of children and youth with a disability in various sectors of life. The results of this study have confirmed that social constructs are also experienced by children and youth with a disability in the context of South African faith communities. Various social constructs were identified during the interviews with parents, as well as the surveys completed by the church leaders. Comments such as that they are often stared at because of the child's condition, that the mother of a child with a disability is regarded as a witch by some, that children believe the child with the disability to be contagious illustrate this point. Such social beliefs are hurtful and experienced by the family as judgemental. Some people still tend to see disability as a defect and assume that there is something "wrong" with a person with a disability. Some families with a child with a disability hide the child from social scrutiny, because they are ashamed and in other cultures disability are seen as punishment for past sins, whereas others see it as a curse. Families with a child with a disability often experience rejection and judgement not only by society but also by their own family. This illustrates that individuals and families living with a disability are often "victims" of social constructs.

Insights from church leaders confirm that social constructs with regard to disability are harmful to people who live with disability. The leaders highlighted issues such as: that people often underestimate the intellect of people with a disability and this affects the way in which they interact with them; that people are often afraid of those who are different; that children and youth with a disability are often stigmatised; that people often discriminate against people with a disability. The church leaders

attribute such attitudes to inadequate knowledge and awareness of disability, also in South African faith communities. They acknowledged that disability is generally misunderstood and does not receive the attention it should in faith communities. This means that socially constructed attitudes and prejudice with regard to disability affect the lives of children and youth living with a disability, also in faith communities. This then becomes an issue of youth ministry. Misconceptions, a lack of awareness of and insight into the lives and world of people living with a disability are harmful and prevent them from being included in the life and activities of faith communities also youth ministry and activities. The study has shown that the exclusion is often not intentional. Social awareness and understanding of disability is generally still inadequate in the South African context. This highlights the need for consciousness raising, information and training. Faith communities are ideally suited for this.

From a postmodern and postfoundational perspective, the focus of the study was on *inclusion*, specifically of young people with disabilities and their families. The approach was interdisciplinary. Insights from social development, psychology, education and the health sciences were brought into dialogue with theological insights. The context played a significant role since the point of departure of this study was that knowledge is embedded in local discourses of tradition which contribute to the formation of epistemologies which, in turn, have a direct impact on people's narratives and realities. In the empirical part of the study the voices of those affected by disability themselves were heard. Their narratives provided valuable insights from their own experience and context.

The objective of this investigation was to firstly determine whether children and youth with a disability do experience exclusion from South African faith communities, especially from a youth ministry point of view. The study has shown that this group of individuals do experience exclusion. Reasons for this were explored and social discourses were identified and interpreted in order to come to a deeper understanding of the particular experiences of some young Christian believers and their families who live with disability. The study makes some suggestions in support of faith communities who aim to work toward greater inclusion of both children and youth with a disability and their families. These suggestions focus on the following

five categories, namely disability-specific efforts; internal activities; external activities; influencers; resources.

- **Disability specific efforts**

The congregations that took part in the study do not have a specific vision and policy with regard to the inclusion of children and youth with a disability and their families. Disability-specific efforts are therefore needed. The four categories of services that can be rendered include: 1) individual support to the affected persons; 2) support to their families; 3) efforts to increase awareness in congregation, and 4) training focused on disability in order to facilitate a better knowledge and understanding of the people and their needs. Participants either appreciated the existing pastoral care or were in need of pastoral care and home visits by the pastor and congregants. In the case of severe disability, the only access to the faith community would be visits at home or in hospital, since going to church is not possible. The church should be brought to them. It is only through getting to know these children and their families on a personal basis that pastors and congregants can come to a deeper understanding of the challenges and needs of these families. Even though there are commonalities among people who live with disability, each set of circumstances remains unique and therefore differentiation should be the point of departure. Faith communities can contribute by means of support or help if they are familiar with what is needed. Programmes for and with people with a disability and their families in faith communities can facilitate greater involvement, since opportunities for participation are mostly limited. A programme of skills development at the church can, for instance, enable persons with a disability to interact with others and empower them to develop to their full potential.

- **Internal activities**

Events and activities for congregants that focus on *koinonia* in the faith community, can be expanded to also include opportunities for fellowship, worship, religious education and small group discipleship for individuals with a disability. Internal activities are those activities in which persons with a disability can participate together with other members of the faith community. It is here where children and youth with a disability would often experience exclusion or be on the receiving end of judgemental attitudes. If the attitude of the faith community towards people with a

disability is warm and welcoming, that could also spill over to their youth ministry. If the faith community is well informed and aware of what living with a disability entails, they will be more accepting and supportive of the people who live with disability and will be less likely to be agitated by them or judgemental about them.

- **External activities**

If the faith community cooperates with other stakeholders, the outcome for people with a disability, including children and youth, will be much improved. A team effort with others and a larger variety of participants than only the own congregation, can benefit children and youth with a disability and their families. A multi-disciplinary approach to the efforts made on their behalf would mean that the contribution is not restricted to the knowledge and actions of the faith community only, but includes the expertise of others, such as for instance non-profit organisations in the disability sector, state departments and schools. Faith communities and youth ministry can learn much about living with a disability from such external specialists.

- **Influencers**

Leadership in the faith community has a direct influence on what the faith community does and what it contributes with regard to people and families who live with disability. The leadership or pastor has an effect on the attitude of the faith community towards individuals with a disability. If the leadership and pastor are passionate about the issue, are advocates on behalf of people with a disability, and regularly addressed the matter publicly, the congregation and community become aware of and sensitive to the needs of people with a disability. People with a disability experience such congregations as welcoming and caring and feel that they are truly part of the congregation, just as all other members are. However, if the pastor and the faith community are not noticeably involved with or supportive of people and families who live with disability, the responsibility of the faith community towards these people is largely neglected. Where the pastor leads by example and is hands-on in her or his involvement with people with a disability, the members of the faith community are encouraged to act accordingly. Though the leadership of a faith community should not have such a determinative influence on the life and direction of the congregation, they do have an effect on the people through their example or lack thereof. If pastors increase their level of awareness, knowledge and insight into what it means to live with a disability, they can educate and influence the faith community

to become involved in an intentional effort to include people with a disability and their families in the community.

- **Resources**

Often logistical and structural issues keep people with a disability from attending the services and activities of their faith community. Access and transport can be practical impediments to the inclusion of people who live with disability. People are often reluctant to provide a service to a person using a wheelchair, because of the additional time spent on getting the person in and out of the vehicle, as well as the fact that they need more space than other passengers. If their service is about optimising profit, then people with a physical disability would jeopardise their chances of a good turnover. Infrastructure, terrains and buildings are not always accessible to people with a disability. A bumpy, gravel road in an informal settlement makes it difficult for a person in a wheelchair to be mobile and get to their destination without damaging their wheelchair or even being injured themselves. Most of the church leaders who participated in this study conceded that their buildings are barely or not at all accessible to people who make use of devices such as a wheelchair or walking frame. Structural accessibility of buildings is essential in order for persons with a disability to be able to participate. The impact of finances is a further factor that impedes the full participation of people with a disability and their families. With the high unemployment rate of people with disability and their reliance mostly on small grants from the government, they simply cannot afford to participate in activities or make use of the available services. This includes the activities and services of faith communities. In terms of an action oriented practical theology, strategies should be devised to include children and youth with a disability and their families in the active life of their faith communities. With a positive attitude of congregants and their willingness to help to execute such strategies, these problems can be solved. Where there is a will to render service, transport can be arranged, a ramp can be built at the entrance of the church building, and other such practical solutions can contribute to changing the lived experiences of children and youth with a disability.

An inclusive congregational approach to youth ministry can facilitate the optimal inclusion of children and youth with a disability in South African faith communities. Although this approach was not designed with this specific group of individuals in mind, the approach can be fruitfully applied to the matter of children and youth living

with a disability and can contribute to their full inclusion in the life and activities of the faith community.

This study was limited to four disabilities, namely Cerebral Palsy, Autism, Deafness and Down's Syndrome, the four most common disabilities in South Africa. However, there are many other disabilities, each with its own unique challenges, effect and impact on the lives of the people themselves, their communities and their faith communities. Though there are many commonalities across the various disabilities, be it mental, physical or psychiatric, it is necessary to delve more deeply into the unique circumstances surrounding specific disabilities that are encountered in the life of faith communities. Most of the children and youth on whom this study focused, are only minimally affected physically. Physical limitations caused by disabilities have the most significant impact on individuals' participation in the life and activities of faith communities. They are excluded because of a lack of access. For people with a mental disability, the problem is that their behavioural traits that deviate from generally acceptable social conduct, are misunderstood, which results in judgement and social exclusion. Further investigation with regard to exclusion of both physical and mental disabilities in faith communities is needed. In the case of severe physical ability where even the best efforts of the faith community to provide access are not sufficient, the community should reach out to the persons where they are safe and comfortable, be it at their home or in an institution. Further investigation into "bringing the church to the people" in cases where the people cannot come to the church building, is needed.

7.4 Let there be no more walls

In an ethnically diverse country such as South Africa, traditional beliefs and approaches with regard to disability differ vastly. Culture-specific investigations into this topic will expand on the existing knowledge base and can contribute to faith communities better understanding their calling to include all people, and governments formulating and executing more effective policies with regard to people affected by disability. These investigations will be most fruitful if done in collaboration, with shared knowledge and insights people in a great variety of fields of specialisation can work together to the maximum benefit of people who live with disability.

This investigation focused on children and youth living with a disability in South Africa and their families, in order to gain insight into the situation of their inclusion or exclusion in faith communities. Mr. H's statement that it is not about building ramps, but about breaking down the walls, is an apt summary of the gist of this study. All the parents who participated in the study indicated some form of exclusion of their child from their faith community, directly or indirectly. The investigation has shown that the exclusion was mostly not intentional and that the "walls" had not been erected on purpose. This gives some measure of hope for the future. From a theological perspective, Christian believers generally agree that people with a disability should be treated with respect for their human dignity like all God's other children. The main problem that has been identified is a lack of awareness and knowledge, which result in the exclusion of children and youth with a disability. As faith communities become aware of the "walls", they are generally motivated to break them down and make a concerted effort to design and implement measures to increase accessibility and inclusion. The study has shown that the exclusion of children and youth with a disability from faith communities, and especially in the community's youth ministry, is largely the result of a communication gap between the disability sector and the Christian church. With a greater awareness, more knowledge and the motivation of their calling to include all people in the kingdom of God, faith communities aspire to there being "no more walls", as befits the household of God. This study aimed to contribute to a dialogue that, if ongoing, can lead to the optimal care, support and inclusion of children and youth living with a disability and their families in faith communities in South Africa and elsewhere in the world. Let there be "no more walls".

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