

**A supportive care model for mothers of children with intellectual disabilities in
selected health institutions of Limpopo Province, South Africa**

by

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DECLARATION

I, **Ndidzulafhi Selina Raliphaswa**, declare that the thesis on “**A supportive care model formothers of children with intellectual disabilities in selected health institutions of Limpopo Province, South Africa**” is my own work, that all sources that I have used or quoted have been indicated and acknowledged by means of complete references, and that this work has not been submitted previously for a degree at any other institution.

Signed (Student).....

Date.....

DEDICATION

This thesis is dedicated to:

- ★ My late mother, Munzhedzi Alugumi Nemarude, and my father, Nthambeleni Thomas Nemarude.
- ★ Special gratitude is due to my loving husband, Mukondeleli Thomas Raliphaswa.
- ★ My two daughters, Tendani and Fhatuwani, and my lovely son, Phindulo Rotondwa Prince Raliphaswa, who supported me throughout this study.

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ABSTRACT

Disability is the most painful experience for the mother and relatives when a child is born. This is because every parent expects a normal child once a woman conceives. For a mother to be able to cope with their children they need to be supported emotionally, psychologically and physically by the family members, community, and health care professionals and other support service providers. The overall purpose of the study was to develop a model to support mothers of children with intellectual disabilities in selected institutions of Limpopo Province. An exploratory sequential mixed method was employed which includes both qualitative and quantitative approaches to guide the study. Population was all mothers of children with intellectual disabilities and health care professionals from the selected institutions where the research was conducted. Health care professionals were purposively selected whereas mothers were conveniently selected. The study was carried out in two phases i.e Phase 1(a & b) and Phase 2. Qualitative results were used to build a subsequent quantitative phase. In Phase 1a, a qualitative approach was employed using descriptive and exploratory designs. Qualitative data was collected through individual interviews. Data analyses were done utilising Tesch's open coding method. In Phase 1b was quantitative approach wherein a cross-sectional descriptive design was used. Questionnaires were developed and data were collected from the health care professionals in the selected study areas. Data analyses were done using the Statistical Package for the Social Sciences (SPSS) version 24 and the level of statistical difference being set at $p < 0,05$. In Phase 2, concept analysis, model development and validation of the model were performed. Themes and sub- themes were identified from the analysed data. Current study revealed that some mothers were fully supported and some were not supported at all by both the family, friends, relatives, community members and health care professionals. Hence continuous support was seen to be very crucial to them. The study recommendations include: open communication, social, psychological and emotional support, combined available support services, access to special schools and formulation of support groups.

Keywords: child, model, mother, health care professionals, intellectual disability, supportive care

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LIST OF ACRONYMS

ACDF	- African Child Policy Forum
AD	- Advisory Committee
ADHD	- Attention Deficit Hyperactivity Disorders
ANC	- Antenatal Clinic
CP	- Cerebral Palsy
CSS	-Central Statistical Service
DENOSA	- Democratic Nurses Organisation of South Africa
DICAG	- Disabled Children Action Group
DoH	- Department of Health
DS	- Down Syndrome
ECD	- Early Childhood Development
FASD	- Fetal Alcohol Spectrum Disorder
IQ	- Intelligence Quotient
ID	- Intellectual Disability
OPD	- Out Patient Department
OT	- Occupational Therapy
RAM	- Roy's Adaptation Model
RSA	- Republic of South Africa
SPSS-	Statistical Package of Social Science
UK	- United Kingdom
USA	- United States of America
UNDP	- United Nations Development Programme
UNICEF	-United Nations International Child Emergency Fund
WHO	- World Health Organisation

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CHAPTER 1

OVERVIEW OF THE STUDY

1.1 INTRODUCTION AND BACKGROUND OF THE STUDY

The birth of a child with a disability is seen as a tragedy for the family, especially the mother (Dardas & Ahmad 2015:8). Children with intellectual disabilities and intellectual developmental disorder, place a heavy burden on mothers in terms of support and care. Mothers of children with intellectual disabilities face many challenges in terms of feeding, bathing, dressing, undressing and assistance with elimination. According to Ergün and Ertem 2012:214), disability leads to shock, anger, guilt, social exclusion and stigmatisation. Mothers of children with intellectual disabilities (ID) need to be supported emotionally, psychologically, physically, socially and financially, so that they are able to continue with their daily life without considering their children as being “burdens”.

According to the World Health Organisation (WHO: 2001), intellectual disability means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development. The term intellectual disability and mental retardation can be used interchangeably as these children behave more or less the same way. Children with intellectual disabilities also form part of the community and the country as a whole. Therefore, it is important that they receive full support from their parents, especially the mother, siblings, relatives, community and the government (Ergün & Ertem 2012:219). The Disability Policy Guideline 2009 strives to economically empower persons with disabilities. This intends to entrench the rights and dignity of persons with disabilities. The primary objective of the policy was to move from policy to practice (Department of Public Works 2009:15).

The number of people with disability by types in 1996 indicated the following: visual impairment 7%, hearing impairment 4%, intellectual disability 74% and morbidity 15%

(United Nations International Child Emergency Fund (UNICEF 2002)). Severity of intellectual disability is categorised by the International Classification of diseases (ICD) 11 as mild, moderate severe and profound.

Daily care for children with intellectual disabilities (ID) is different from that of "normal" children without disabilities. This is because of the special care that needs to be provided. Some or all of the children with intellectual disabilities, including their daily living activities, are dependent on someone else. This situation may cause families of children with intellectual disabilities to experience difficulties with the children's care. (Barr, Govender & Rencken 2016:931).

Support needed for intellectual disability children is also to be seen at schools, as well as the community. Mothers of children with intellectual disability experience problems raising these children, leading to maternal stress (Ergün & Ertem 2012:216). This is mostly associated with child behaviour difficulties. The severity of the disorder and continuous support play significant roles in family quality of life. Disability can be due to congenital, disease-induced or unknown cause. Disability can occur as physical, emotional or cognitive impairments (UNICEF 2002). Hearing, visual, speech and language problems, neurological and behavioural problems are some of the disabilities encountered by mothers. In light of the above, the researcher focuses on intellectual disability. This is because mothers of children with intellectual disabilities are seen as having more challenges than those with other types of disabilities, which they are unable to handle. Hence, the researcher developed a model to support mothers of children with intellectual disabilities using different types of research methods.

South Asian families with an individual with an intellectual disability require considerable support. Existing United Kingdom (UK) research has consistently found that the formal and informal support received by families are not sufficient to meet the needs of the person with an intellectual disability, nor the family; although support from partners or other children within the household is important. South Asian families of people with this type of disability receive less support from extended family networks

and the community or faith agencies (Hatton, Akram, Robertson, Shah & Emerson 2002:181).

The study done in Turkey by Ergün and Ertem 2012:213), revealed that the most common disability in that country is mental retardation. Intellectual disability is a general term used to describe children who develop and learn slower than children without the disability. Hence, they struggle to survive in their personal and social lives without any support. Children need good care and education in order to take their place in society. These needs are provided primarily by the family, especially the mothers. Therefore, it is important to determine or know the supportive care that mothers need during the education and care of a child with intellectual disability (Ergün & Ertem 2012:216).

Mothers of children with an intellectual disability give up other social roles in society, like less social life activities due to increased responsibility for child care. Mothers of children with intellectual disability need support, particularly from the family and relatives. Support from the society plays an important role in sharing the values and feelings and helps to fulfil social roles leading to acceptance. Adequate social support influences the behaviours and development of children and families in various ways. It also improves their functionality through education. Parents who share their responsibilities with others and are supported by society are less likely to feel isolated as people around them play a vital role (Ergün & Ertem 2012:214).

In Australia, Mohay and Reid 2012:1, revealed that child care services include private and community-based full-day care centres, family day care schemes, outside school hours and vacation care services as well as occasional care services. However, there are problems identified at these child care centres. Problems include lack of sufficient admission availability, limited access to resources and equipment, inadequate staff support, poor staff-to-child ratios, inadequate staff training and experience in working with disabled children. Hence, mothers were not well supported by skilled personnel who knew how to care for mentally disabled children. The Queensland Child Care Strategic Plan 2000 – 2005 acknowledged the difficulties frequently experienced by

families of children with a disability in accessing appropriate child care programmes, and designated the inclusion of such children in child care as a high priority area (Mohay & Reid 2006:38). Moreover, the WHO mental health programme has not given similar attention to child and adolescent psychiatry as compared to adults and the elderly (Ambikile & Outwater 2012:2). This means that adults and the elderly were more highly considered and included in the mental health programmes.

In Hong Kong, a study conducted by Lam and Mackenzie 2002:30, indicated that Chinese mothers share their experiences of parenting a child with an intellectual disability. The type of stressors changed over time according to the child's age and coping strategies varied accordingly. Cuskelly, Hauser-Cram and Van Riper 2007:117, indicated that a child with an intellectual disability has certain effects on the family. Some effects relate to the likelihood that a child will display the cognitive and behavioural phenotypes considered to be typical of children with intellectual disabilities. These include specific patterns of strengths and weaknesses in information processing, social interaction, expressive language, receptive skills, motor skills and motivation.

A study done in Ireland by Redmond and Richardson 2003:206, revealed that one of the most pressing issues for the mothers was a lack of comprehensive information available to them to help them with potentially useful and essential services. Information sources used by mothers ranged from hospital to medical services such as nurses, medical staff, social workers and paramedics staff. Mothers reported a distinct lack of clear, correct and comprehensive information relating to available services for children with intellectual disabilities. Giallo and Gavidia-Payne 2006:938, explored a life source model of family care giving, and noted that the experiences of families of young children with a disability may well shape their views of the prospects for social inclusion for their children and themselves in the long- term. There was also a particular lack of provision of needed services to these young children because of their age. The mothers felt that the children needed certain services at a much earlier age, to help them experience a reasonable quality of life.

In the UK, Sheerin, Keenan and Lawler 2013:194, found that professional service providers tend to consider family carers as experts when a problem arises, but social and health care services do not always listen to parents when they try to be advocates for their children's care. According to Ray 2003:3, many families have said that professionals fail to inform them or value their opinions. This causes many families to experience difficulties in adaptation.

In Africa, there is a general expectation that children 'bring happiness to a marriage' and that womanhood is proven by giving birth to a 'normal' child (Chilwalo 2010:19). Having a child can save an unhappy marriage, solve emotional problems and to have a baby is a romantic experience. These high expectations often turn into some level of disappointment if the child born has impairments (Bayat 2014:34)).

In South Africa there is lack of reliable information on the nature and prevalence of disabilities. Study done in Limpop Province by Mudhovozi, Maphula & Mashamba 2012:154, indicated in their study that, mothers encountered family challenges, emotional problems, school-related problems, social problems and financial problems in caring for children with intellectual disabilities. They also struggled to give care to their children with intellectual disabilities and manage their families. Resources were lacking and qualified professionals were scarce. The mothers need emotional support from members of their families, friends and members of the community. This is because in the past, disability issues were viewed chiefly within a health and welfare framework. According to Census 2011:10, a profile of persons with disabilities in South Africa showed that about 3.2% of intellectual disabilities reported having mild difficulties and 1% having severe difficulties. Provincial variations show that the Free State and Eastern Cape Provinces had the highest proportion of persons with difficulties in concentrating or remembering (6.8% and 6.4%) respectively, while Western Cape and Gauteng Provinces had the lowest proportions of persons who reported having severe difficulty concentrating or remembering (2.4% and 2.7% respectively). These naturally led to failure of integrating disability into mainstream government statistical processes (White Paper on Integrated National Disability Strategy 1997).

Some useful statistics are available from the United Nations Development Programme (UNDP) and the Central Statistical Service (CSS). These provide some guidance for estimation of disability prevalence in South Africa. According to the Statistics South Africa 2005 the UNDP estimates that in 1990, 5.2% of the world population was experiencing moderate to severe disability. This ranged from 7.7% in so-called developed countries to 4.5% in less developed areas. The highest was among the black population with 5.2%, followed by whites with 4.5%, coloured with 4.2% and Indians with 3.7%. In South Africa, disability is more prevalent amongst females to males by a ratio of 8.3% to 6.5% respectively. Females also experience the highest percentage of mild to severe difficulties across all types except for communication. The proportion of persons with disabilities increases with age (Statistics South Africa 2011).

In South Africa people in wheelchairs have become the popular representation of people with disabilities. This ignores the diversity of disability and the variety of needs experienced by people with different types of disabilities such as intellectual disability. In general, families of children with disabilities, regardless of the type of disability, experience higher expenditure than other families (Resch, Mireles, Benz, Grenwelge, Peterson & Zhang 2010). The majority of people with mentally handicapped children, however, receive no grant at all. Parents had problems with applications for social financial security funds therefore this prevented them from purchasing clothing, food, and other basic needs for the mentally handicapped children (Kgole & Molepo 2014). In addition, women who bear children with intellectual disabilities sometimes face rejection, and even scorn. Such women, especially in poverty-stricken areas, also often find themselves excluded from social and economic activities due to the additional attention required by, and lack of facilities for, their children with intellectual disabilities. Thus the stigma of intellectual disability, its myths and fears are likely to increase women's social isolation in society. Children with ID living in rural areas often have a low life expectancy, due to lack of care, support and access to even the most basic services. Their mothers cannot meet the additional financial burden of regular visits to hospitals, additional expenses for equipment and assistive devices, and other necessities (Benson 2015:44; Taderera & Hall 2017:283).

The Disabled Children Action Group (DICAG) estimates that 98% of mothers of children with intellectual disabilities living in rural areas are unemployed, semi-illiterate or functionally illiterate single women and men. According to Matsebula, Schneider and Watermeyer (2006:85), adopted from Integrated National Disability Strategy: White Paper, the Office of the Premier (1997), indicated that mothers of children with intellectual disabilities are deserted by husbands and lovers, often socially excluded by their communities, banished into isolation by their extended families and tend to withdraw into a world of their own. Hence, the researcher will concentrate on intellectual disability. There is lack of information and services for children with intellectual disability in South Africa, especially Limpopo Province. The Constitution of the Republic of South Africa (RSA) guarantees all children the right to education wherein the government emphasises the importance of children accessing Early Childhood Development (ECD). The South African Schools Act makes it compulsory for all 7-16 year olds to be enrolled in a registered education programme (Act, No. 15 of 2011, as amended).

1.2 PROBLEM STATEMENT

Mothers play a crucial role in the upbringing of children, especially those with intellectual disabilities (Kgole & Molepo 2014). As at the time the study was conceptualized, the researcher was a nurse working in one of the public hospitals in Paediatric ward.

Paediatric units of a particular hospital admitted a total number of children of about 200 per month in 2014/15. About 20% of these children had intellectual disabilities, ranging from Attention Deficit Hyperactivity Disorders (ADHD), Down's Syndrome (DS), Autism, Cerebral Palsy (CP) and Epilepsy. Mothers of these children seemed to have problems coping with their children as their children were also not coping well in public schools. Mothers expressed their concern about children's rejection to attend public schools with other normal children because of the learning disabilities they were experiencing.

Most mothers had younger children at home who also needed the care of their mothers. This seemed frustrating to them. Most of the working mothers also appeared

to be experiencing problems with their employers due to the number of days that they are absent from work when they need to accompany their children to the hospital. Some of these children were seen to be neglected and malnourished. Mothers appeared to be emotional, reserved and isolated when their children were admitted.

The contact with mothers of children with intellectual disability raised questions about the ways of caring for the children which clearly unveiled the need for the researcher to search for new ways and opportunities to provide support to mothers of children with intellectual disability. It is in this light that the researcher felt the need to develop a model to support these mothers in order for them to understand their children with intellectual disabilities.

1.3 PURPOSE OF THE STUDY

The purpose of the study was to develop a supportive care model for mothers of children with intellectual disabilities in selected health institutions of Limpopo Province, South Africa.

1.4 RESEARCH OBJECTIVES

The research objectives which this study seeks to answer were arranged as follows:

Phase 1a: Qualitative

1. To explore and describe experiences of mothers of children with intellectual disabilities in selected health institutions in Limpopo Province, South Africa.
2. To assess the cultural practices and beliefs of mothers of children with intellectual disabilities in selected health institutions in Limpopo Province, South Africa.

Phase 1b: Quantitative

3. To describe the views of health care professionals about supportive care to mothers of children with intellectual disabilities in selected health institutions of Limpopo Province, South Africa
4. To determine the supportive care services available to mothers of children with intellectual disabilities in selected health institutions of Limpopo Province, South Africa

Phase 2:

5. To analyse concepts and develop a model to support mothers of children with intellectual disabilities in selected health institutions in Limpopo Province, South Africa.
6. To validate the model's feasibility pertaining to the supportive care of mothers of children with intellectual disability in selected health institutions in Limpopo Province, South Africa.

1.5 RESEARCH QUESTIONS

Research questions which guided the study were the following:

1. What are the challenges experienced by mothers of children with intellectual disabilities?
2. What are the cultural practices and beliefs of mothers of children with intellectual disabilities?
3. What are the views of health care professionals about the supportive care to mothers of children with intellectual disabilities?
4. What are the support care services given to mothers of children with intellectual disabilities in selected health institutions in Limpopo Province, South Africa?.
5. What are the concepts analysis and how to develop a model to support mothers of children with intellectual disability in Limpopo Province, South Africa.

6. How can a model to support mothers of children with intellectual disabilities be validated?.

1.6 SIGNIFICANCE OF THE STUDY

The results of this study may assist mothers to share their experiences and difficulties in the care of their children with intellectual disabilities. They will also be empowered based on the assessment of their children's needs. Mothers will be actively involved in decision making regarding the available services.

Children with intellectual disabilities may also benefit as they might get full care, support and love from their mothers.

Health care professionals may apply the knowledge obtained through this study by providing relevant services, address different types of family needs and coordinate with the mothers.

The community may also gain a better understanding on how to interact with mothers raising their children with intellectual disability. Children with intellectual disabilities may be treated like any other children in the community. In other words the community will be knowledgeable about how to interact with ID children and their families. Based on the findings, policy makers might coordinate the point of delivery across health, social services and education. The findings might also serve as useful guidance when making recommendations in this field of study.

Hospitals may also benefit as mothers will be equipped to adapt to the life-style of their children which might lessen unnecessary hospital admissions. Treatment and follow-up visits might be considered.

The Province and the District may also benefit as the mothers, family members, community and health care professionals will be empowered to work together in support of mothers of children with intellectual disabilities.

1.7 THEORETICAL FRAMEWORK

A theoretical framework is the overall conceptual underpinning of a study and it allows the researcher to knit together observations and fact into an orderly scheme. The

theoretical framework was based on propositional statements resulting from an existing theory. The framework interrelates concepts which created a specific way of looking into a particular phenomenon (Brink 2012:26). The researcher used Roy's Adaptation Model (RAM). RAM is a useful and applicable model to nursing processes as it addresses the physical and psychological dimensions for chronic diseases. It assesses behaviours affected by stimuli, maladaptive behaviours are determined, then interventions that promote positive adaptation are developed (McEwen & Willis 2011:15). RAM is a representative of a grand nursing theory whose conceptual framework focused on interconnected, holistic individuals and their interaction with the environment. From other theories, such as Orem's theory of self-care and the family system's theory, the RAM model was chosen as it was very relevant to the study because mothers of children with intellectual disability need to adapt to the behaviours of their children. Health care professionals also help mothers to adapt as they act as a continuous support system to regulate the stimuli in order to enhance adaptation for the mothers of children with intellectual disabilities. This theory was discussed in detail in Section 2.6.

1.8 DEFINITION OF TERMS

- **Child** – refers to a young human being below the age of 18 years (Children's Act 38 of 2005).

In this study a child is any person who is under 12 years with an intellectual disability at the selected institutions in Limpopo Province.

- **Model** – refers to a symbolic depiction of reality. It provides a schematic representation of a certain relationship among phenomena, and it uses symbols or diagrams to represent an idea (Brink, van der Walt and van Rensburg 2012:26).

In this study, model is an adaptation system that will assist mothers of children with intellectual disabilities in order to attain adaptation modes.

- **Supportive care** - is a way of providing strength, encouragement or emotional help to someone and an action which promotes the well-being of oneself and others (Nilsson, Ejlertsson, Anderson & Blomqvist 2015: 55).

In this study supportive care is the care received from the family members, society, department or government and health care professionals for the mothers of intellectually disabled children

- **Intellectual Disability** - is a generalized neurodevelopmental disorder characterised by significantly impaired intellectual and adaptive functioning. It is defined by an Intellectual Quotient (IQ) score below 70 in addition to deficits in two or more adaptive behaviours that affect everyday general living (Van der Schuit, Peeters, Segers, Van Balkom & Verhoeven 2009:1030).

It is a mental impairment that substantially limits a person in some major life activity, such as walking, talking, hearing, working or a record of such impairment (Jagoe 2000:5).

In this study intellectual disability refers to an instance where a child is unable to perform or adapt to the intellectual skills relevant for his or her age e.g. ADHD, CP, DS and should be between 6 and 12 years of age.

1.9 ORGANISATION OF THE CHAPTERS

Chapter 1: Overview of the Study

Chapter 2: Literature Review

Chapter 3: Research Methodology

Chapter 4: Results and discussion of qualitative and quantitative studies

Chapter 5: Concept analysis and conceptual framework for model development

Chapter 6: Conclusions, Recommendations and Limitations of the Study

1.10 SUMMARY

This chapter detailed the overview of the study which included introduction, background, problem statement, significance of the study, purpose of the study, research objectives and theoretical framework. The next chapter discusses the literature review.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

The literature is an important step in the research process. It provides the researcher with sources for research ideas and orientates the researcher to what is already known about the topic. (Brink, van der Walt and van Rensburg 2012:70). The literature review in this study looked at the support care given to mothers with intellectually disabled children.

The researcher identified the topic and the purpose of the study, a systematic search of the literature to find out what is known about the topic was conducted. A literature review refers to the sources that are effective in providing in-depth knowledge that the researcher needs to study in the the selected study areas. The literature search and review is a crucial element of the research process. It is a systematic search to find out precisely what is known about the topic (Brink et al, 2012:70).

According to Burns and Grove (2005:93), a literature review is an organised written presentation of what has been published on a topic by scholars. The purpose of the review was to convey to the reader what is currently known regarding the support given to MOCWID. The literature review identified the research problem with the work of other authors and aims to avoid duplication of the study (Hofstee 2006:91). In this study the literature review abounds with previous studies pertaining to the supportive care model of mothers of children with intellectual disabilities. The review includes journals, books, and internet reports. The literature review was discussed under the following headings:

- Experiences of mothers of children with intellectual disabilities.
- Cultural beliefs and practices of mothers having children with intellectual disabilities.
- Views of health care professionals regarding mothers of children with intellectual disabilities.

- The supportive care services given to mothers of children with intellectual disabilities in Limpopo Province.
- Roy's model of adaptation.

2.2. EXPERIENCES OF MOTHERS OF CHILDREN WITH INTELLECTUAL DISABILITIES

Raising a child with a disability can cause more daily stress and ongoing health problems than parenting a child without disabilities (Boyd 2002:208). A study done in the United States by Fautleroy (2009:6) indicated that parents have responded to items about their experience concerning time use, daily stress, positive events and physical symptoms. Researchers compared these parents to a similar group of parents of children without disabilities. They reported having at least one stressor on 50% of the study days compared to 40% among other parents. Parents of children with disabilities also reported experiencing a greater number of physical health problems.

Seitzer, Orsmond & Esbensen (2009:59), revealed that parents of children with disabilities are in need of support services like respite services. The study indicated that respite services are critical for family wellness. Unfortunately, they are often unavailable due to funding. Respite care is the provision of short-term accommodation in a facility outside the home in which a loved one may be placed. This provides temporary relief to those who are caring for family members, who might require permanent placement in a facility outside home. (Reynolds, Zupanick and Dombeck 2013:262) added that respite is very helpful and refreshing for family members to take some time off. Most respite programmes are provided through national organisations. Hence, the researcher views a need for such services as essential and there is a gap to be filled in order to support the mothers.

2.2.1 Psychological and Emotional challenges

A study done by Ambikile and Outwater (2011:4), indicated that the MOCWID experienced disturbed thoughts about living with intellectually disabled children. They reported experiencing stress caused by the behaviours of their children. These behaviours caused problems not only to their parents but also to people around them, such as neighbours. Behaviours that were of concern to mothers were aggressive and destructive behaviours as well as hyperactivity and lack of proper eating skills. Mothers seem to be worried about the future life of their children due to the children's inability to accomplish personal and social needs, such as self-care and education. This caused mothers to be unable to understand the child, especially when he or she had problems or was sick. Varying degrees of emotional distress were experienced, including feelings of sadness and inner pain or bitterness. According to Boyd (2002:208), parents of children with an intellectual disability commonly experience a gamut of emotions over the years, especially the mother. They also struggle with guilt feelings. One or both parents may feel as though they somehow caused the child to be disabled, whether from genetics, alcohol use, stress, or other logical or illogical reasons. This guilt can harm the parents' emotional health if it is not dealt with. Some parents struggle with "why" their children are intellectually disabled and experience a spiritual crisis or blame the other parent. Mothers feel disappointment that their children will not be a president, a physician, an actor or whatever they had in mind. Occasionally parents feel ashamed or embarrassed that their child is mentally disabled.

2.2.2 Physical exhaustion and stress

Physical exhaustion can take a toll on the parents of an intellectually challenged child. This also depends on the care needed by the child. Feeding, bathing, moving, clothing and diapering an infant is much easier physically than doing the same tasks for someone who weighs about 50kg. This is more so because this has to be done every day. Their child may have many more physician and other health care appointments than a typical child and may need close medical monitoring. The child may also need to be watched to avoid self-harm such as falling down the stairs or walking into the

street. All these additional responsibilities can lead to exhaustion. Therefore, it is important for mothers to be supported as they cannot meet all the needs of these children, including the needs of other normal siblings, if any. The researcher is interested in exploring the support of mothers of children with intellectually disability (Boyd 2002:209).

2.2.3 Social challenges

Caring for children with intellectual disabilities was found to be associated with many social challenges, including social services, stigma, lack of public awareness, social support and social life. In the study conducted by Horton and Wallander (2001:385) they found that families with more social support available to them showed lower levels of distress than families with less external support. Mothers were sometimes held responsible for the child's behaviour. They were thought to be spoiling their children by not being strict enough when the child was behaving strangely. Some indicated that they were told that they had caused the child to become mentally ill as a means of getting rich and becoming successful in life. The burden of the intellectually disabled child was found to be mainly borne by the mother. They indicated that some were only supporting the child financially and others did not care at all. The mothers expressed their concern about not receiving the needed support from neighbours and people in the community. According to Greeff and Loubser (2008:289), social support also provides families with a sense of worth and integration. The social life of mothers was found to be disrupted by the presence of the intellectually disabled child in the family. This is because sometimes parents avoided going out with the child to social gatherings such as to church, due to the child's disturbing behaviour. Findings by Cabtree (2007:50) and Sari, Baser and Turan (2006:31) found that mothers feel socially isolated because their children were not accepted by their community. Mothers also experienced conflicts in the community and sometimes were even accused when the child destroyed somebody's property. This resulted in a lack of peace, especially with the neighbours. These children were reported to be at risk of being physically and sexually abused, for example being burned and raped (Ambikile & Outwater 2011:7).

2.2.4 Economic Challenges

Families caring for a child with an intellectual disability such as CP, experience an added financial burden. A financial burden refers to the negative impact of caring on the mother's economic status (Wolstenholme, Fenn, Keene, Jacoby and Hope, 2002:84). In South Africa, McKenzie and Muller (2006:102) found that mothers of children with intellectual disabilities experience extra strain in terms of the money needed for therapeutic interventions for their children. This strain includes the cost of professional help, external services and institutionalization. Most parents reside far from their Health Care Services Centres (Mobarak Khan, Munir, Zaman & Conachie 2000:429). Hence, mothers of children with ID are unable to meet certain important needs of the intellectually disabled children due to poverty. Some depended on their partners and those who did not have partners depended on other people for help, especially relatives. They could not buy drugs for their children if they did not get them at the hospital. They also could not afford bus fare to go to the clinic with their children on appointment days (Ambikile & Outwater 2011:8).

2.2.5 School related issues

The mother of a child with developmental disabilities may have to deal with complex issues related to education. Families that are involved in their child's school have opportunities to learn more about their child. They are also more supportive and confident of their parenting and are able to help their children learn. Either a private education must be sought or an adequate public education must be available. Parents often have to advocate for their child to receive a quality educational experience that will enrich him/her. This often requires close parental contact with the school systems. This could mean that mothers should also be familiar with or be taught the systems in order for them to continue helping the child at home. Transportation to and from school may require a specialized bus or van and children with a severe disability may need to be schooled at home (Boyd 2002:209).

2.2.6 Professional support

Blackford, Richardson and Grippe (2000:898) describe the mother's interaction with a variety of health professionals. This can be focused on findings specific to nurses who provide pre-natal education. Mothers reported that they received insufficient, inappropriate information, especially about their pregnancies and chronic illnesses. The mothers believed that nurses doubted the ability of women to raise children with some degree of intellectual disability. Many mothers experience more stress related to their interaction with professionals than in interactions with their children (Lloyd & Rosman 2005:188). In the study done by Poston, Turnbull, Park, Mannan, Marquis and Wang (2003:314) participants mentioned negative interactions that they had experienced with professionals, particularly physicians, spending too little time with the doctor, out of stock medications, lack of speech therapists and lack of proper facilities. Families felt victimized in how it was reported to them that their child was born with a disability. They were given the most distressing prognosis at a time and in a place that offered them no support upon hearing this news. Therefore, the researcher saw a need for professionals to get proper training in order for them to give appropriate and sufficient information to the family affected, especially the mother.

2.2.7. Challenges in relation to education and training

With regard to education, emphasis is on inclusion with the mainstream setting, although special schools still exist. Inclusive education refers to the practice of including every learner, irrespective of talent, disability, socio-economic background or cultural origin, in supportive mainstream schools and classrooms and meeting the child's particular needs (Akinbola 2010:462). Intellectually disabled children need assistance to attend school, which is often provided by parents and teachers. According to Stalker and Connors (2003:30), policy is regarded as rules and regulations that give any organisation the direction to achieve its objectives. A policy has been developed to make sure that intellectually disabled people including children, have the right to access the same services available. Inclusion promotes the interaction and acceptance of differences among children. Children with different abilities will accept their peers and know them better than when they are separated

and not attending one school. Education Scotland Act of 2000 indicated that education must be provided to all children regardless of their ability or age.

2.2.8 Spiritual support

Disability and spirituality are inter-related (Feiffer 2003:30). For the four big main religions (Islamic, Christianity, Jewish & Buddhist), disability has a whole different role. According to all these four religions, disability is not simply a punishment for mistakes or bad behaviour. From the beginning, Christianity tried to integrate disabled people into society as creatures of God. According to Walsh (2003:48) religious background and beliefs are significantly related to greater acceptance, positive adaptation, less stress, and devise better coping strategies for caring for a disabled child. According to Vandsburger, Harrigan and Biggerstaff (2008:120), it is indicated that religion provides guidance and inspiration regarding the changes necessary to overcome hardship.

2.3. CULTURAL BELIEFS AND PRACTICES OF MOTHERS WITH INTELLECTUAL DISABILITY

Social perceptions of disabilities arising from cultural beliefs and practices in communities were used to rationalise the aspects of daily life as part of God's plan (Gona, Hartley & Newton 2006:3) According to Groce (1998:756), cultural beliefs about disabilities are strongly influenced by religion, socio-economic status and educational background. These beliefs affect how people with disabilities are treated in each country. In a study by El Sharkawy (2002:50), looking at the existing practices underlying attitudes towards children with epilepsy in Kilifi, Kenya, it was found that cultural beliefs and perceptions towards people with epilepsy affected treatment and social acceptance.

A study done in Namibia by Haihambo and Lightfoot (2010:78) outlined the cultural beliefs regarding people with disabilities. Namibia is a country that achieved independence from South Africa in 1990. It has a population of 1,9 million people.

According to the 2001 Population and Housing Census, approximately 5% of Namibians have a disability.

According to the World Health Organisation (2005), approximately 10% of the world's population has a disability. In response to this, many countries have developed policies related to education, employment, income support and policies, intended to improve the position of people with disabilities. For the policies and programmes to be effective, it is important that they take into account the cultural beliefs about disability that exist within their populations. Cultural myths and beliefs of Namibians about disability are one aspect for consideration in the slow implementation of these policies. Cultures differ in regards to people's social beliefs and will also have different views of disability. Research of myths and beliefs about disability in sub-Saharan Africa revealed varying myths about the causes and nature of disability.

Haihambo (2010:77) found the following myths about the causes of disability common among some African ethnic groups:

1. The mother slept with multiple partners during pregnancy;
2. The family tried to get rich by using traditional doctors, but failed to carry out the traditional doctor's instructions to the letter;
3. Disability is contagious;
4. If twins of the same sex are born to the same mother, one has to be killed, otherwise misfortune such as disability or death will befall the family;
5. A jealous rival who wanted the husband of the expectant mother bewitched the family;
6. A specific family has a child with a disability because they do not go to church;
7. Fathers desert the family when a child with a disability has been born because in their family history there is no-one with a disability;
8. The child was bewitched while in the womb;
9. If a child with albinism is born she has to be killed and offered to the ancestors to remove the curse.

A study done by Haihambo and Lightfoot (2010:15) revealed that beliefs and myths regarding the causes of disability and the community's response and interventions regarding people with disabilities were similar across regions. Supernatural causes of

disability such as witchcraft, curses of ancestors or bad omens, gift from God or punishment from God were outlined. The above findings are similar to studies done in other sub-Saharan nations such as Kenya, Zimbabwe, Botswana and South Africa.

South Africa is a multiracial and multilingual nation with many different values, traditions and cultural practices. Different belief systems may give rise to different attitudes and practices relating to disability. Lack of awareness of the diverse cultural beliefs and attitudes may hinder the outcome of rehabilitation, leading to misunderstandings between professionals and clients due to differing points of view (Masassa & Irwin-Carruthers 2005:40). Cultural beliefs also affect utilisation of rehabilitation services which in turn affects recovery and outcomes of individuals with intellectual disabilities (Wegner & Rhoda 2015; Singogo, Mweshi & Rhoda 2015). An understanding of different cultures can help health care professionals to understand how and why families make decisions concerning health care and rehabilitation.

2.4. VIEWS OF HEALTH CARE PROFESSIONALS REGARDING MOTHERS OF CHILDREN WITH INTELLECTUAL DISABILITIES

It is important for professionals to ensure that a child with a disability receives the best course of care with the most empirically sound treatment. Professionals must also be sensitive and respectful of parent's needs and desires for their child (Ravindran & Myers 2012:315). Parents of children with intellectual disabilities have an increased risk for parenting stress and psychological distress, especially the mothers (Kobayashi, Inagaki & Kaga 2012:1). This may be due to the multiple roles they play in caring for their children. Professional caregivers sometimes experience difficulties in keeping good relations or communicating with the parents. Ravindran and Myers (2012:315) indicated that cultural factors influence the relationship between parents and the professionals who provide interventions for their children. A study done in Japan revealed that professional training of more professionals who can properly deal with the parents' mental health needs was seen to be an urgent matter (Kobayashi, Inagaki & Kaga 2012:3).

Current psychiatric services in Japan are not adequate to meet the complex mental health needs. A major portion of resources have been directed to the treatment of and services connected with the children and not the mother. The health care providers noticed that the difficulties seemed to be increasing as other family members such as grandparents and siblings were involved. It has been found that when a mother suffered from signs of mental disturbance, children experienced maltreatment. Physical and medical care neglect made the utilization of medical and welfare support impossible. The demand for more specialists, especially psychologists who can support the mental health needs of both the children and their parents was a priority (Kobayashi et al. 2012:4).

2.5. THE SUPPORTIVE CARE SERVICES GIVEN/AVAILABLE TO MOTHERS OF CHILDREN WITH INTELLECTUAL DISABILITIES

According to the literature in Limpopo Province, services available were mostly for the intellectually disabled children wherein the mother is not included. Services that are mostly available in countries like Japan and USA are not available in South Africa, especially Limpopo Province. These services include respite care, out-of-school activities and community nursing. In South Africa caregivers are the primary persons for the provision of care and support to individuals with intellectual disabilities. According to Statistics South Africa (2005), the availability of resources for people with a disability and their families is limited in South Africa. Parents support their children themselves and also bear the cost of any professional services needed. Families from previously disadvantaged ethnic groups, in particular, have been found to have limited external resources and facilities available to them, according to Statistics South Africa (2005). This became more prominent following the establishment of the primary health care approach (PHC), a transformation of the Health Service in South Africa (Mavundla, Toth & Maphelane 2009:358). In Limpopo, caregivers and the cared-for have access to community-based PHC clinics for supportive counselling and prescribed medication. However, nurses are hardly trained in the provision of psychosocial care, and so the care they provide remains largely biomedical in nature.

They are often described as “mini-doctors” with the remit of offering education and training as well as diagnosing and treating common illnesses (Mavundla et al. 2009:344).

It is a known fact that stresses of mothers can arise from the behaviours presented by children in their care. Therefore, mothers need to work with health care professionals and have access to information about available services and treatment of the intellectually disabled children. However, there is no literature on mothers’ experiences and support available in South Africa and South African researchers rely on studies done in the West. The researcher therefore saw a need for the development of models that could support the mothers of children with intellectual disabilities in South Africa (Merrifield 2011:147).

2.6. THEORETICAL FRAMEWORK (ROY’S ADAPTATION MODEL)

Theoretical framework refers to the overall theory that the study is based on (Polit & Beck 2008:765). In this study Roy’s Model of Adaptation (figure 1) was used which refers to the process and outcome whereby thinking and feeling persons, as individuals or in groups, use conscious awareness and choice to create human and environmental integration (George 2011:661). The model emphasizes that human adaptive system is always challenged by internal or external stimuli. When the human adaptive system has been challenged by the stimuli the response can be reactive in order to attain adaptive mode. The model describes that a nurse is the one who will be able to regulate stimuli and assist the patient to adapt. Polit and Beck (2008: 147) affirm that the primary goal of a nurse is to assist the client to eliminate focal, contextual and residual stimuli by promoting adaptive modes. The theory was applicable to the study as the mothers need adaptation mode during the care of a child with an intellectual disability. Mothers are confronted with internal and external stimuli, for example rejection by relatives, their partners and the community as a whole. The health care professionals in paediatric wards acted as a support system to regulate the stimuli in order to enhance adaptation for the mothers of children with intellectual disability. The following four adaptive modes will be discussed in this study as shown

in Figure 1 below: Physiologic – Physical, SelfConcept – Group-Identity, Role Function and Interdependence.

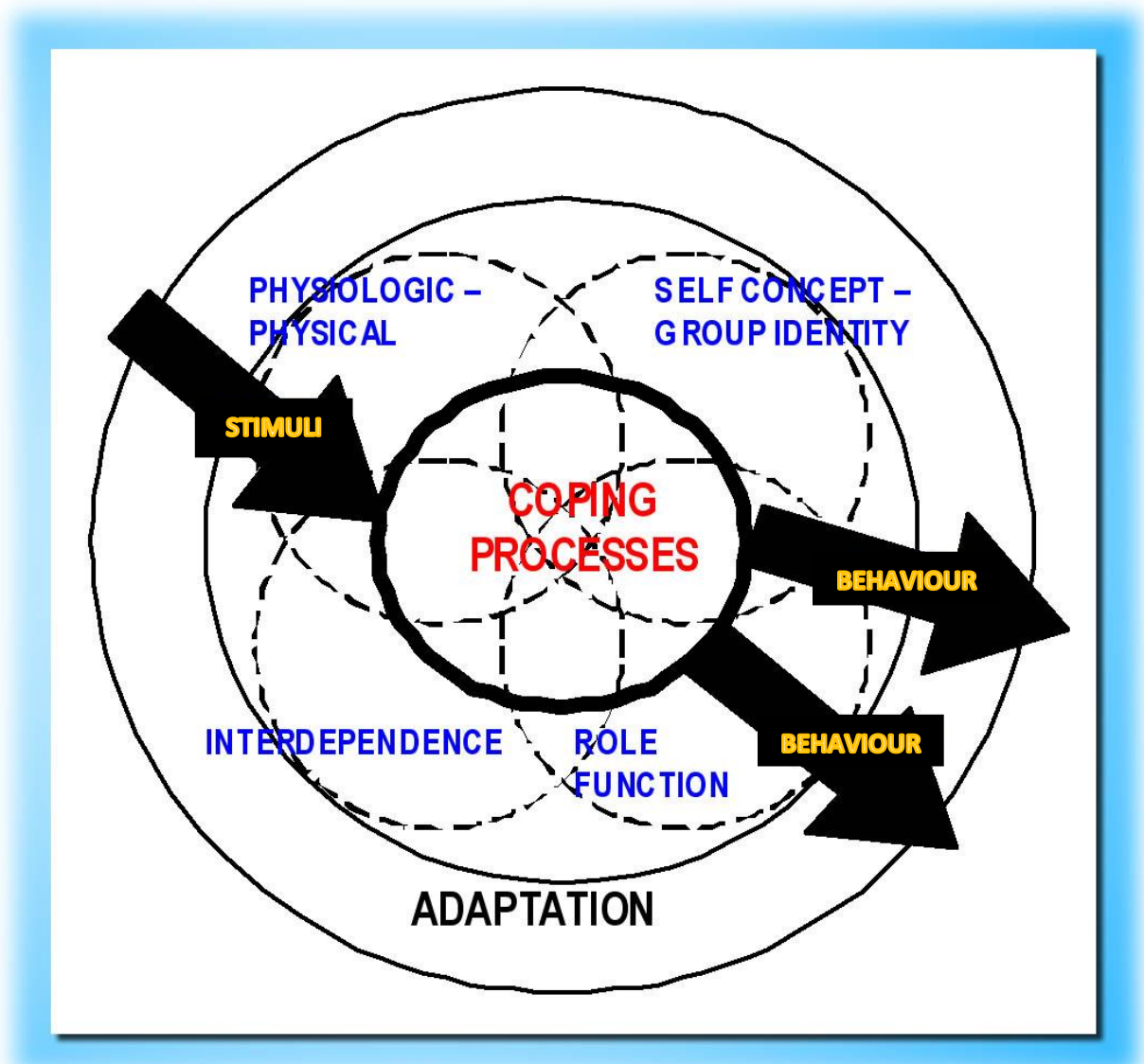


Figure 1: Four modes of Adaptation as illustrated by Roy.

2.6.1. Physiological – Physical

Physiological – physical modes refer to the human system’s physical responses and interactions with the environment (George 2011:301). In the context of individuals the underlying need of this mode is physiological integrity. In this study the researcher explored the mother’s experiences of interaction with the family, friends, relatives and the community members as a whole. This assisted the mothers to react positively to

stimuli. A mother has physiological/physical need of group identification (support systems, significant others) in order to interact well with the environment. The relatives, their partners and the community could create a therapeutic environment by giving them continuous support for the mother to feel more comfortable and accepted like any other women who gave birth to a child without intellectual disability.

2.6.2. Self Concept – Group Identity

The selfconcept – group identity relates to the basic need for psychic and spiritual integrity or a need to know the self with a sense of unity (George 2011: 302). The need underlying the group identity mode for family, group or a collective is identity integrity or interrelationships. The model is relevant to the study as the mothers have a need to identify themselves with the group of women who also gave birth to children with intellectual disability in order for them to cope well. The conflict of identity delays a mother's adaption modes if no-one would like to be identified with them (George 2011: 303) .

2.6.3. Role function

Role function refers to the category of behaviour for both individuals and groups (George 2011:302). The need underlying this mode is social integrity; that is, knowing who one is, in relation to others, so that one can act appropriately. The role of mothers needs to be clarified so that the need to give full participation in the society and full care that the child requires, can be realised despite their disabled child.

2.6.4. Interdependence

Interdependence applies to adaptive behaviour for both individual and groups. The system should give support to individuals in order to gain adaptive modes (George 2011:302). The modes based on support systems relate to identification of those who help the person meet the needs for love, respect and value. The infrastructure, context and resources are the systems that can facilitate the adaptation level. In this study the

nurses, doctors, psychologists and physiotherapists in the units act as a support system for the mothers in order to promote the adaptive modes for the care of these children. They should create the environment conducive for them to be able to verbalize their challenges.

2.7. SUMMARY

This chapter discussed the literature relevant to the support of mothers with intellectual disabilities, The literature review assisted in the identification of studies that was done on the support and challenges for mothers of children with intellectual disabilities.as well as the adopted Roy's model of adaptation that guided the study. The next chapter discusses methods and design, population, sampling of participants,data collection and analysis, measures to ensure trustworthiness and ethical considerations.

CHAPTER 3

RESEARCH METHODOLOGY

3.1. INTRODUCTION

This chapter presents a detailed description of the methods and design, population and sampling, and ethical considerations used for the purpose of this study. Research methodology refers to ways of obtaining, organising and analysing data (Burns & Grove 2003:325). There are different types of research methodology. They are categorized into either qualitative or quantitative designs. The research designs used in this study were both qualitative and quantitative designs (mixed methods) (Burns & Grove 2003:325).

3.2. RESEARCH METHODOLOGY

According to Burns and Grove (2003:187), a research design provides a plan for conducting a study that maximizes the control over factors that could interfere with the validity of findings. The research design guides the researcher in planning and implementing the study in a way that is more likely to achieve the intended goal. The research design that was used in this study is both qualitative and quantitative in nature with a descriptive and exploratory focus (Babbie & Mouton, 2006:79). A mixed methods research design is a procedure of collecting, analyzing and mixing both quantitative and qualitative research (Creswell 2012:62).

The philosophy of science in this study is pragmatism as it is typically associated with mixed methods research. Its focus is on the use of multiple methods of collecting data to inform the problem under study. Pragmatist worldview is real world practice oriented and problem centered. Hence mixed methods was used in order to provide an improved understanding of the research problem rather than individually. In other words it is used when one approach to research (qualitative or quantitative) does not adequately address the research problem or answer the research question. It is also used for practicality, multiple view-points, subjectivity and objectivity.

Building from the exploratory results from the qualitative phase, the researcher conducted a second, quantitative phase to test or generalize the initial findings (Burns & Grove 2009:219). The purpose of exploratory sequential mixed method was to test qualitative exploratory results to check if they can be generalized to a sample and a population. The research was approached in two phases as outlined in Figure 2; namely,

- Phase one - Phase 1a qualitative and Phase 1b quantitative approach.
- Phase two - concept analysis, developing the model and validating the model.

3.2.1 Layout of the research study chapter

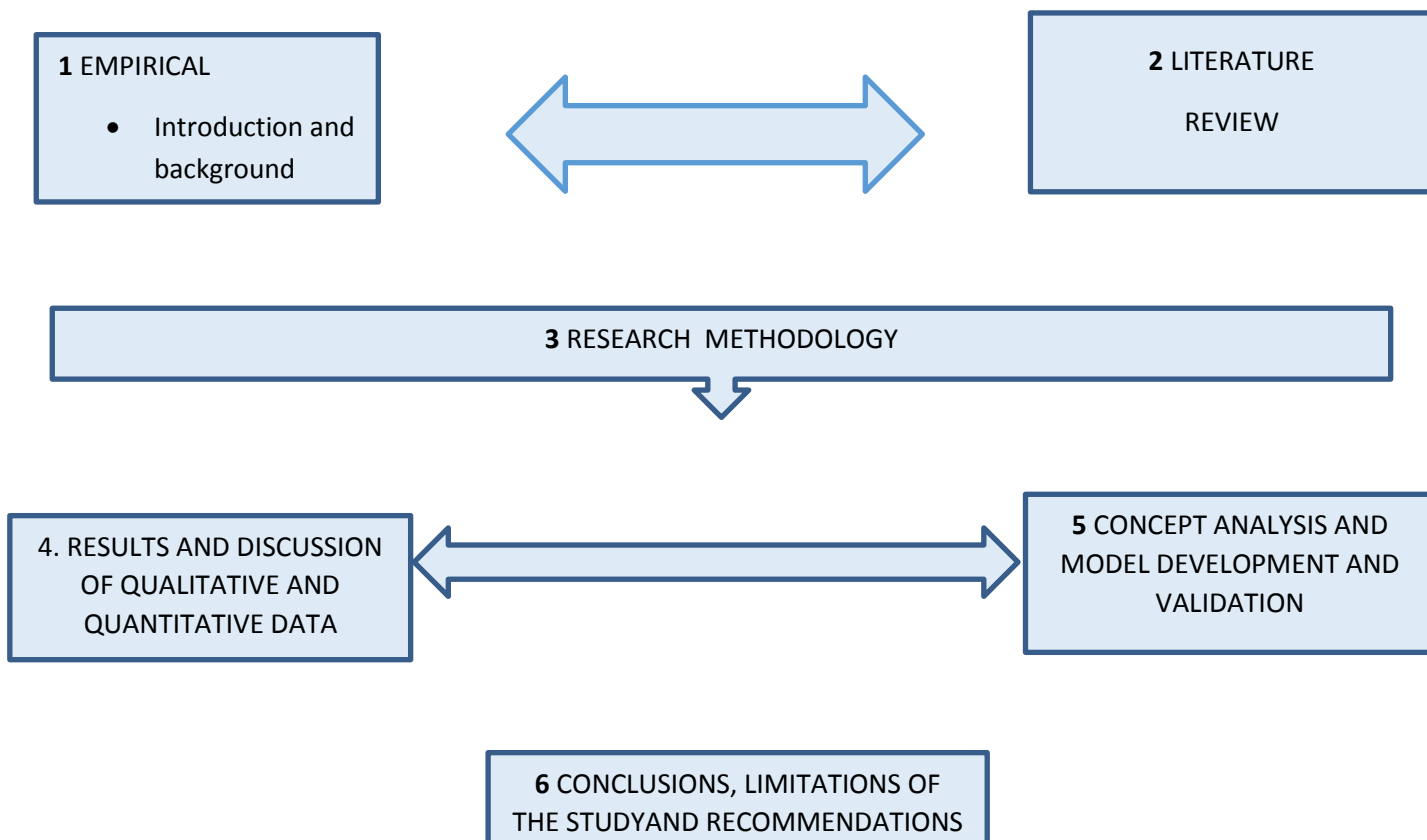


Figure 2: Flow of study

3.3 STUDY SETTING

Setting is the physical location and conditions in which data collection takes place in a study (Burns & Grove 2011:715; Brink et al. 2012:59). This study took place in a natural setting. A natural setting is an uncontrolled, real-life situation or environment. The researcher did not manipulate or change the environment in this study (Brink et al. 2012:59). The study was conducted in Limpopo Province. Limpopo Province is situated in the North Eastern corner of South Africa and shares borders with Botswana, Zimbabwe and Mozambique.

Limpopo Province has 44 hospitals located in five districts: namely Mopani, Vhembe, Greater Sekhukhune, Capricorn and Waterberg with estimated population of 5,693,564. Mopani, Vhembe, and Greater Sekhukhune are the most rural communities.

The study setting was in the Paediatric Ward and Paediatric Outpatient Department of Vhembe and Mopani Districts which are depicted in Figure 3. Vhembe District consists of four local municipalities. i.e Thulamela, Mutale, Makhado and Musina Municipalities.

There are three hospitals in Thulamela Municipality – Tshilidzini, Malamulele and Donald Fraser Hospitals; Makhado Municipality – Siloam, Elim and Louis Tritchardt Hospitals; Musina – Messina hospital, and Mutale only has a health centre.

Mopani District consists of five local municipalities: Ba-Phalaborwa, Greater Giyani, Greater-Letaba, Greater-Tzaneen and Maruleng. Greater Tzaneen has two hospitals – Letaba and Van Velden hospitals; Greater-Letaba – Dr CN Phatudi and Kgapane hospitals; Ba-Phalaborwa – M Malatji hospital; Greater-Giyani– Nkhensani Hospital; Maruleng-Sekororo hospital.

STUDY AREA

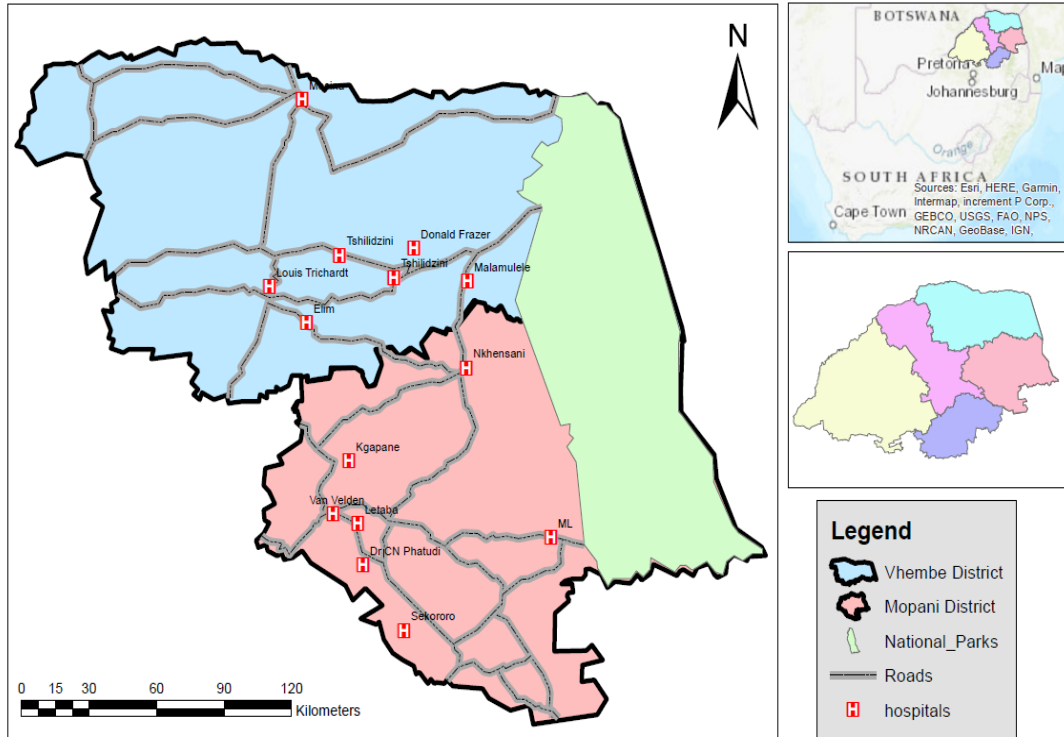


Figure 3:

Title: Geographical map showing the study area in Limpopo Province.

3.4. RESEARCH APPROACHES AND DESIGNS

3.4.1 Phase 1 (a): Qualitative study

The qualitative approach is based on a world view which involves perceptually putting pieces together to make a whole (Burns & Grove 2005:67). According to Brink (1996:13), qualitative research has few preconceived ideas and stresses the importance of people's interpretations. It does not attempt to control the context of the research, but rather attempts to capture that context in its entirety (Brink 2002:14). The qualitative method is an in-depth account as it is used to gather objective detailed information from the study group and also to freely explore their knowledge, beliefs and practices.

The qualitative research approach was chosen because the researcher wanted to describe the views and challenges experienced and assess the cultural practices and beliefs of mothers of children with intellectual disabilities in Limpopo Province. The study was conducted in a natural setting, where human behaviour and events occur. The focus of qualitative research was on participants' perceptions, attitudes and experiences (Creswell 2009:5). The objectives to be achieved were:

- Objective 1: To explore and describe experiences of mothers with intellectual disability children.
- Objective 2: To assess the cultural practices and beliefs of mothers of children with intellectual disabilities.

3.4.1.1. Descriptive research design

Descriptive studies are a means of discovering new meaning, describing what exists, determining the frequency with which something occurs and categorizing information (Burns & Grove 2005:30). According to Brink (1996:11), the descriptive research design can be used to obtain complete and accurate information about a phenomenon through observation, description, and classification. In this study, a descriptive research design was used for the conceptualization of the experiences of mothers of

children with intellectual disabilities in the selected health institutions of Vhembe and Mopani Districts in Limpopo Province.

3.4.1.2. Exploratory research design

An exploratory research design is an approach that begins with phenomenon of interest rather than simply observing and describing it, the exploratory research investigates the full nature of the phenomenon, the manner in which it is manifested, and other factors with which it is related (Polit & Beck 2012:18). According to Woods and Catanzaro (1988:150), to 'explore' means to scrutinize the unknown with the purpose of discovering and gaining insight into the phenomenon being studied. It provides more insight about the nature of the phenomenon by investigating the manner in which the phenomenon manifests itself to other related areas (Mouton & Marais 1990:133). Burns and Grove (2005:482) describe explorative research as formative research conducted to give knowledge of a phenomenon. This study is exploratory because it attempts to explore the depth, richness and complexity of the practical experience of mothers of children with intellectual disabilities admitted in the paediatric unit of two particular hospitals. The researcher probed for information about the experiences of mothers of children with intellectual disabilities in the selected health institutions of Limpopo Province by listening, discussion and analysis of characteristics or attributes and themes expressed by the participants.

3.4.1.3. Phenomenological research design

The researcher was interested in a phenomenological approach to this study. Phenomenology is a science whose purpose is to describe particular phenomena. This approach investigates subjective phenomena in which essential truths about reality are grounded. The researcher gathered lived experience according to the phenomenological school of thought. This design allows open room for personal experience to be shared subjectively. The important thing was the experience as it was presented (Polit & Beck 2006:220; Streubert & Carpenter 2009:49).

There are also three principles in the phenomenological approach in qualitative studies, namely, intuition, bracketing and making sense of data depending upon intelligibility (Wood & Haber 1994:262). Intuition is defined as the power of knowing or knowledge obtained without recourse to inference or reasoning innate knowledge. It can be used as a method of problem solving and can operate in two ways as a form of inference in which it closely shows sensory perception or extra sensory experience. It also helps in gaining a deeper understanding of reality that can be obtained by analysis of data. It depends upon some familiarity of a subject area as people do not produce intuition in a subject area in which they are ignorant (Wood & Haber 1994:370). With this approach, the participants have a deeper understanding of their experience of having a child with intellectual disability (Wood & Haber 1994:262). In this study, the researcher tried to avoid asking personal questions, but followed the central questions and more questions emanated from the discussion.

Experiences were collected in a relaxed atmosphere with sufficient time allowed to facilitate a complete description by the participant. The researcher attempted to immerse herself in the data in ways that allowed the intended meaning to emerge. Bracketing may occur when the researcher immerse herself and identifies personal biases about phenomena of interest to clarify how personal experiences and beliefs may colour what is heard and reported. The researcher set aside personal biases to bracket them when engaged with participants by avoiding to immerse herself and identify personal biases.

3.4.1.4. Research Population and sample

According to Strydom and Venter (2005:194), a population is the totality of persons, events, organisational units, case records or other sampling units with which the research problem is concerned. Populations are not restricted to humans. A population might consist of all hospital records in a particular hospital or all blood samples in a particular laboratory (Polit & Beck 2012:273). The population in this study consisted of all mothers whose children have intellectual disabilities. According to Polit and Beck (2008:338), the target population is the aggregate of cases about which the researcher would like to generalize.

The target population for this study was mothers of ages 21 to 35 years whose children were under 12 years of age and admitted in the paediatric ward at Tshilidzini and Letaba hospitals. These were mothers who were served by the selected hospitals in two districts. Burns and Groove (2005:740) define accessible population as the portion of the target population to which the researcher has reasonable access. In this study the population was all mothers whose children were admitted in the paediatric ward and those who came for follow-ups in the paediatric clinics of the selected hospitals in Limpopo Province.

- **Sampling**

Sampling is a process of selecting subjects who are representative of the population being studied (Burns & Grove 2005:41). A sample is a representative unit of a population that is to be studied (Polit & Beck 2006; De Vos, Strydom, Fouche & Delpont, 2011). A sample in any given research is very important because choosing a wrong sample size or frame can affect the results of the study (Onwuegbuzie & Leech 2007:110). Sampling is therefore the process of choosing the sample units that will represent the population to be studied (Polit & Beck 2010). Two types of sampling techniques are mainly used in research: probability and non-probability sampling. In quantitative research, the probability sampling technique is used most often while the non-probability sampling technique is used in qualitative research (Polit & Beck 2010; De Vos, Strydom, Fouche & Delpont 2011) The non- probability sampling technique that was used in this qualitative research study is known as judgment or purposive sampling, where informants are selected because of their unique characteristics (Polit & Beck 2010:275). Elements have different chances of being included in a sample (Polit & Beck 2008:291). Mothers who brought their children to the selected hospitals had a chance of being selected as participants.

- **Sampling of the districts and hospitals**

In the sampling of hospitals purposive sampling method was used which was a non-probability sampling. This means that the researcher selects information-rich cases or those cases that can provide a great deal of information about the purpose of the

study (Burns & Grove 2009:355). The researcher has purposefully chosen two hospitals in two districts. The selection was done based on their high intake of patients with intellectual disabilities as they are referral hospitals. The two districts were also the most accessible districts for the researcher. All the necessary information needed were supplied and all processes were followed in these hospitals. Paediatricians are available at these hospitals which also assists in proper diagnoses of children with intellectual disabilities.

- **Sampling of the participants**

Sampling methods for obtaining a representative sample can basically be divided into two broad classes; namely, probability and non-probability sampling. In non-probability there is no way of estimating the probability that each element has equal chance of being included in a sample, and there is no assurance that every element does have a chance to be included.

There are different types of non-probability sampling designs and each addresses a different research need (Burns & Grove 2001:374). The researcher chose a non-probability sampling method in which participants were selected based on the researcher's personal judgement about who was the most representative or informative (Polit & Beck 2012:279).

The use of purposive sampling in a qualitative study is a method of sampling in which typical cases are sought and selected for the study. The sample is usually composed of elements that contain the most characteristics, that are representative, and that demonstrate attributes of the population that serve the purpose of the study best (Polit & Beck 2012:279). The use of purposive sampling in the study allows the researcher to select participants who will give in-depth information to meet the objectives of the study.

Therefore, in this study, the researcher purposely selected mothers of children with ID under 12 years of age who were staying with their children at the study site (hospitals). They were admitted for three days and more. Those mothers who accompanied their children to OPD rather than those who came to visit their children in the ward were

also included. The researcher purposively sampled the participants based on the knowledge of the phenomenon of the study.

3.4.1.5 Inclusion criteria

This is an effort to make the sample as homogenous as possible. Sampling criteria should be based on the research problem, purpose, design and practical implications of the research topic. A good participant is one who has good knowledge and experience and is often what the research requires (Streubert & Carpenter 1999:22). The inclusion criteria entail all mothers whose children were admitted in the ward, irrespective of their colour and race, as long as they were staying with their children in the Paediatric Medical Ward, and they were the biological mothers of those children (Polit & Beck 2006:260). Mothers of children with an intellectual disability who came to OPD for follow-up visits were also included.

3.4.1.6 Exclusion criteria

Mothers whose children were admitted but were not staying with them, were excluded from the study. Baby-sitters were also excluded as they were not their mothers. Mothers of children above 12 years were not included either.

3.4.1.7 Sample size

In qualitative research, when purposive sampling is used, the researcher does not know in advance how many participants are needed. The sample size depends on data saturation (Brink 1996:141). Data were collected until no new information emerged and redundancy was achieved. The key issue was to generate enough in-depth data to illuminate the patterns, categories, and dimensions of the phenomenon under study (Polit & Beck 2008:521). In this study, 20 mothers were selected until data saturation was reached.

3.4.1.8 Research instrument

The researcher collected data through phenomenological interviews and field notes in order to describe what people experience and how they interpret those experiences or what meaning the experience hold for them. Therefore individual interviews were conducted by asking a central question.

3.4.1.9 Data Collection

According to Burns and Grove (2007:536), data collection is the process of identification of participants and the precise, systematic gathering of data relevant to the research purpose or the specific objectives, questions, or hypothesis of a study. Data collection consists of steps that are specific to a study and are dependent on the research design and methods. Decisions on what to collect evolve in the field (Polit & Beck 2008:532).

In this qualitative study the researcher was the sole data collector. The researcher did not make use of any research assistant for data collection. Communication with the participant was facilitated in one to one in-depth phenomenological interviews to encourage the participant to talk and express their experiences freely about the support regarding their children with intellectual disabilities. The researcher made observations and took field notes at the same time. Permission was sought to have a quite private room before commencing with the in-depth phenomenological interviews. In this study, data was collected from mothers of children with intellectual disabilities. The researcher collected data from the selected institutions of Limpopo Province. Data collection from mothers were conducted using one central question:

” Can you kindly tell me the experiences of having a child with intellectual disability ?”.

The researcher encouraged the participant to talk by means of the following communication techniques:

Probing: Participants were encouraged to during an interview by making vague comments that could have multiple meanings more clearer.

Paraphrasing: This is to convince and convey the message to the participant that you are with him/her and that you understand what he/she is going through. Paraphrasing also helps the researcher that he/she really understands what the participant is exactly describing by repeating what he said in a more concise manner.

Summarising: The researcher was summarising what has been said by the participants throughout the interview in order to make sure that what the researcher heard is correct.

Clarification: The purpose of clarification is to highlight participant's meaning that was not clear initially. Clarification was done throughout the interview for the things that were not clear.

Listening: This is the process of tuning in carefully to the participant's messages and responding accurately to the meaning behind the messages. The researcher listened while participants narrated the information in order to understand everything that the participants were saying (Polit & Beck 2012:336).

Semi-structured interviews were done under three phases: preparatory, interview and post interview phase.

- **Preparatory phase**

This refers to the planning of conversation between the researcher and a participant before the actual phase of the interview is conducted (De Vos, Strydom, Fouche & Delport 2005:303). Preparatory phase starts with the recruitment of the participants according to the research objectives. Sample sizes were determined based on informational needs, hence data were collected to the point at which no new information was obtained and redundancy was achieved.

- **Interview phase**

The interview phase refers to the beginning of conversation between the researcher and a participant with the specific objectives of gathering information about a topic that is being researched (Rossouw 2003:146). The researcher conducted an in-depth

phenomenological interviews in the study area. This was done in a quiet private room in paediatric ward. This was in the afternoon when the doctors were finished with the patient's assessment as mothers were expected to be there when doctors are taking rounds. This was also to avoid interference with ward routines and visiting times as relatives would want to see those mothers. At the meeting between the researcher and participant, the researcher created an environment favourable for conversation by warmly thanking the participant for her willingness to participate and stressing that she was an expert on the topic of the interview. The researcher explained the purpose of the interview to the participant and ensured that ethical measures such as guarantee of beneficence, and the participant's right to withdraw from the research may be applied (Rossouw 2003:146). During the interview the researcher made field notes on the observations (*crying, frowning, etc.*) made during the interview and the use of voice recorder was done during interview sessions with the permission of the participants. The field notes helped the researcher to remember and explore the process of the interview.

- **Post-interview phase**

Post-interview refers to the time after the actual interview between the researcher and the participants (Rossouw 2003:147). The researcher listened to the tape-recorded interviews and checked the audibility and completeness soon after the interview was completed (Polit & Beck 2010:751). All data tapes were carefully labelled, including the date in which the data were collected.

3.4.1.10. Pilot study

A pilot study is a procedure for testing and validating the instrument by administering it to a small group of participants from the intended research population (De vos, Delpont, Fouche & Strydom 2011:237). Piloting was done to 4 mothers whose children were admitted in paediatric ward and met the requirements. This was done before the actual data was collected in order to detect or address the possible flaws that might arise. The participants who participated in the pilot test were not included in the main study. Appropriate and necessary changes were made.

3.4.1.11. Data Analysis

Qualitative data is the information collected in narrative form (without using numbers/non-numeric). This is done in transcript of an unstructured interview. The analysis thereof is the organisation and interpretation of this non-numeric data for the purpose of discovering important underlying patterns of relationship. Data were analysed qualitatively according to Tesch's open-coding method (in Creswell, 2012:186).

Table 1: Tesch's eight steps of systematically analysing textual data collected through interview questions

1. Getting a sense of the whole	The researcher read through all of the transcriptions several times carefully in order to understand the information provided by participants, mothers whose children were in a paediatric medical ward. The researcher immersed into the topics in detail, to gain a sense of the interviews as a whole before breaking them down into parts. Some ideas were jotted down as they came to the researcher's mind.
2. Picking one document at a time	The researcher picked up the most interesting, shortest interviews and read through them, analyzing their underlying meanings. Thoughts were written in the margin.
3. Making a list of all topics	After reading several interview documents from participants, the researcher made a list of all topics derived from interview reports. Similar topics were clustered together, formed in columns that were arranged as major topics, unique topics and left-overs.

- 4. Taking the list of topics and going back to the data**

The researcher took a list of the topics, went back to the data, and abbreviated topics as codes and codes were written alongside the appropriate segments of the interview report.
- 5. Turning topics into categories**

Topics derived from the interview reports that related to each other were grouped. Then the researcher classified the qualitative information by looking for categories, themes or dimensions of information. General themes and sub-themes were identified. The researcher drew columns between categories to show how they were interrelated.
- 6. Making a final decision**

The researcher made a final decision and themes were made by assembling data material belonging to each category.
- 7. Assembling the data**

The data material belonging to each category were assembled in one place and preliminary analysis were performed.
- 8. Recording data, if necessary**

Re-coding of the existing data was done as the researcher found it necessary during the process of analysis. The researcher was able to generate themes, categories and sub-categories from the collected data.

[†]See Tesch (1990) and Creswell (2012)

3.4.1.12. Measures to ensure Trustworthiness

Trustworthiness is a method of establishing rigour in qualitative research without sacrificing relevance. Rigour assists the researcher in preventing errors (Lincoln & Guba 1985:216). There are four evolution criteria that were used to ensure trustworthiness (Lincoln & Guba 1985:216). According to Lincoln and Guba (1985:290), these questions are used by the researcher to establish the truth-value, consistency, applicability and neutrality of the study. These criteria were ensured through the following strategies:

- **Truth Value (Credibility)**

Credibility questions whether the researcher has established the truth of the findings for the subjects or participants and context in which the study is undertaken. Credibility refers to confidence in the truth of the data and interpretations thereof. Credibility can be demonstrated by participants when they accept that the findings are a true reflection of their experiences (Polit & Beck 2008:584).

Prolonged engagement with the mothers and health care professionals and clear descriptions of the findings were done to enhance credibility. Prolonged engagement is a technique used to achieve credibility and include remaining in the field for a long time in order to achieve good results. Prolonged engagement helps to build trust between the researcher and participant (Brink 2002:124). In addition, it increases rapport with participants through familiarity and participants are able to open up and talk about more hidden and sensitive information (Krefting 1991:217). The researcher remained in the field for a long time interacting with the participants. The researcher documented everything said by the participants in the field notes and observed everything. The researcher's thoughts, feelings, ideas and hypotheses generated through contact with participants were reflected in the field notes. The frustrations, questions and problems concerning the whole research process were written down so that the researcher could be aware of biases and preconceived assumptions. Data triangulation was ensured by using different data-collection methods e.g. the

researcher collected data through field notes and in-depth phenomenological interviews and observation of participants for non-verbal cues such as “*crying*” as they talk. Data collected by various means were compared.

- **Applicability (Transferability)**

Transferability refers to the generalizability of the data. That is, the extent to which the findings can be transferred to other settings or groups (Polit & Beck 2008:585). According to Babbie and Mouton (2006:277), thick or dense descriptions of data and purposive sampling are useful strategies for transferability in qualitative research. The researcher presented a dense description of the methodology and the results to enhance transferability to other settings (Kreftling 1991:217). The research setting was richly and thoroughly described; what transpired and the non-verbal cues were thoroughly described.

- **Consistency (Dependability)**

Dependability of qualitative data refers to the stability of data over time and over conditions (Polit & Beck 2008:585). It is a dense description of research methodology. It asks how one can determine whether the findings of an inquiry would be repeated if the inquiry is replicated with the same participants in the same contexts. Dependability refers to variability that can be ascribed to identify sources. This was ensured through conducting an enquiry audit, where a scrutiny of the data and relevant supporting documents were done by an external reviewer. The researcher used a coding and recoding procedure. For instance, after coding the data, the researcher waited for two weeks and returned to recode the same data and compare the results. The findings were also analysed by an independent coder.

- **Neutrality (Conformability)**

Neutrality is when there is freedom from bias in the research procedures and results. The researcher used the strategy of conformability to ensure neutrality. The

researcher enjoyed the same status as participants in the research (Lincoln & Guba 1985:317). In other words the researcher was as neutral as possible to avoid bias. This was ensured through listening to the tapes to verify interpretations, conclusions and recommendations. An audit trail, which is a systemic collection of documentation, in this case the field notes and voice recordings that allow an independent auditor to reach conclusions about the data was developed. Field notes were checked and compared with non-verbal cues.

3.4.2 Phase 1(b): Quantitative study

This phase involved the quantitative approach that involves measuring the magnitude, size or the extent of the phenomenon with detailed observation, describing, comparing, discovering and analysing the characteristic attributes and dimensions of a phenomenon (Akinsola 2005:66). Quantitative research is a formal, objective, systematic process in which numerical data are utilized to obtain information (Brink, Van der Walt & Van Rensburg 2009:92). This research method was used to describe variables, examine relationships among variables and determine cause-effect interactions between variables. Furthermore, quantitative research is thought to produce a 'hard' science that is based on rigor, objectivity and control (Burns & Grove 2005:326). The following objectives were achieved:

3.4.2.1. Design

The researcher adopted a cross-sectional descriptive research design. A descriptive design is also called observational because the researcher just describes the results without intervening. The design does not involve manipulation of variables and there is no attempt to establish causality (Polit & Beck 2006:22). A cross-sectional descriptive study generate insight about a phenomenon under study. Data collection took place during one data collection period from a cross-sectional sample, appropriate for the description of the phenomenon under study. Descriptive studies aimed at determining the frequency with which events occur and classify information (Polit & Beck 2012:226). The design was used in order to achieve the following objectives:

- To describe the views of health care professional about supportive care to mothers of children with intellectual disability.
- To determine the supportive care services available for mothers of children with intellectual disabilities.

3.4.2.2. Population and sample

In this phase the target population were all the 724 health care professionals in all the 14 hospitals in the two districts; namely, Vhembe and Mopani. This included nurses, doctors, psychologists, physiotherapists and occupational therapists shown in Table 2 below.

Table 2: The sample of hospitals follows in the table below:

Vhembe District Hospitals	Municipality	Number of Health care Professionals per hospital
Tshilidzini Hospital	Thulamela	84
Donald Frazer Hospital	Thulamela	53
Messina Hospital	Musina	52
LouisTrichardt Hospital	Makhado	24
Malamulele Hospital	Thulamela	40
Elim Hospital	Makhado	68
Siloam Hospital	Makhado	50
TOTAL		371

Mopani District Hospitals	Municipality	Number of Health care Professionals per hospital
Letaba Hospital	Greater Tzaneen	73
Dr CN Phatudi Hospital	Greater Letaba	50
Van Velden Hospital	Greater Tzaneen	40
M Malatji Hospital	Baphalaborwa	45
Sekororo Hospital	Maruleng	55
Kgapane Hospital	Greater Letaba	48
Nkhensani Hospital	Greater Giyani	42
TOTAL		353

- ***Sampling***

Sampling is a process of selecting subjects who are representative of the population being studied (Burns & Grove 2005:41). Probability sampling was used in this study as it ensures that every member of the population has an equal chance of inclusion in the sample. It was based on probability theory and includes the principle of equal probability (Burns & Grove 2005:43).

- ***Sampling of hospitals***

Total number of hospitals in Vhembe and Mopani Districts is 14, N = population size, n = number of sampling size, e = accepted level of error set at 0.05. From the 14 hospitals found in Vhembe and Mopani Districts, all the hospitals were included even though challenges were met in two hospitals of Mopani district i.e. Van Velden and Maphutha Malatji hospitals (Details discussed in chapter 4).

- **Sample size and Sampling of participants**

Treating each hospital as a stratum, the researcher used a stratified random sampling technique to select the participants from a total of 724 health care professionals. This process involved the proportional representation of each hospital and the random selection of the participants from each hospital (Table 3). The sampling size was determined as follows:

$n=N/(1+Ne^2)$ where N = population size, n = number of sampling size and e = accepted level of error set at 0.05. Hence the sample size is:

$$\begin{aligned}n &= \frac{N}{1+N(e)^2} \\ &= \frac{724}{1+724 \times (0.05)^2} \\ &= 725/2.81 \\ &= 258\end{aligned}$$

The selection is shown in Table 3 below:

Table 3: The sampling and samples per hospitals

Vhembe and Mopani districts	Hospitals per district	No. of Health care Professionals per hospital	Sample size selected per hospital	Percentage	Response rate
Thulamela	Tshilidzini	84	30	11.6%	10.8%
	Donald Fraser	53	18	6.4%	6%
	Malamulele	40	14	5.1%	4%
Makhado	Louis Trichardt	24	9	3%	2%
	Siloam	68	23	9%	8%
	Elim	50	18	6.5%	5.5%
Musina	Messina	52	19	7.3%	6%
Greater Tzaneen	Letaba	73	25	10%	8.5%
	Van Velden	40	13	5.5%	0%
Greater Letaba	Kgapane	50	21	9%	8.3%
	Dr CN Phatudi	48	17	7%	6.4%
Baphalaborwa	M Malatji	45	16	6.1%	0%
Maruleng	Sekororo	58	20	8%	7%
Greater Giyani	Nkhensani	42	15	5.4%	4.5%
TOTAL		724	258	100%	77%

3.4.2.3. Data collection tool

Sel- designed structured questionnaires in this study, were used as an instrument to collect data in the form of self-administered survey questionnaires with health care professionals from all the hospitals in the selected districts of Limpopo Province. In this objective, questionnaires were used as an instrument for collecting data. Burns

and Grove (2005:398) define a questionnaire as a printed self-report form designed to elicit information that can be obtained through the written response of the subject. A questionnaire is a document used to gather self-report data via self-administration of questions (Polit & Beck 2008:414). Leading questions were avoided when formulating the questions. Questions were in an affirmative rather than a negative manner. The questionnaires were presented to a statistician, a research supervisor and an expert in child health for review and critiquing. Advantages and disadvantages of questionnaires were outlined in Table 4 below.

Table 4. Advantages and disadvantages of questionnaires

Advantages/Strengths	Disadvantages/Weaknesses
1 Questionnaires are a quick way of obtaining data from a large group of people	1 Mailing of the questionnaires may be expensive as due to lack of personal contact, other means of chasing the participant's responses like telephone calls and follow up letters may be necessitated
2 They are less expensive in terms of time and money and they provides a high proportion of useable responses	2 Questionnaires often provide low response rate (return rates)
3 They are one of the easiest research instruments to test for reliability and validity	3 Respondents may provide socially acceptable answers
4 Participants feel a greater sense of anonymity and are more likely to provide honest answers	4 Respondents may fail to answer some of the questions
5 The format is standard for all participants and is not dependant on the mood of the researcher	5 There is no opportunity to clarify any questions that may be misunderstood by the participant
6 Questionnaires facilitate the collection of vast amounts of data with minimal efforts	6 Participants must be literate
	7 The participants who respond may not be the representative of the population

3.4.2.4 Data collection

Data collection involves the process of gathering data from the studied participants (Brink, 2006; Burns & Grove 2012). Data were collected from the health care professionals through the administration of the self-designed survey questionnaire. The questionnaires were developed by examining questions that would answer the objectives of the study, as indicated in the literature. The questionnaires consist of a total of ninety-five (95) test items arranged in three sections (A-C) as follows:

- SECTION A demographic data.
- SECTION B views of health care professionals on supportive care to mothers of children with intellectual disabilities.
- SECTION C the supportive care services available for mothers of children with ID.

The attitudes of respondents towards continuous support were assessed using a Likert scale (strongly agree, agree, disagree, strongly disagree).

Questionnaires were used because they ensure complete anonymity as no names were attached to it. In relation to this study, an instrument was developed based on the findings from the qualitative research.

Close-ended and open-ended questions were included in the questionnaire to address all research questions.

3.4.2.5 Pre-testing of the instrument

A pre-test is a trial run to determine whether the instrument is clearly worded and free from major biases and whether it solicits the type of information imagined (Polit & Beck 2012:496). It is also done to investigate for possible flaws in the instruments (Brink et al. 2012:175). Pre-testing was done at two hospitals to determine whether the instrument or the tool is feasible. Only five health care professionals from each hospital were included and they were from each category of health care professionals. Participants in the pre-test were excluded from participation in the actual study.

This was done in order to address unforeseen problems that can arise in the course of the project. A pre-test study might also bring about changes before the actual data collection commences (Brink et al. 2012:57).

3.4.2.6 Measures to ensure reliability and validity in quantitative approach

- **Validity of the research tool**

Validity refers to the degree to which an instrument measures what it was designed to measure (Speziale & Caperter 2007:460). Polit and Beck (2008:540) define validity as the degree to which an instrument measures what is intended to measure. According to Burns and Grove (2005:376) validity refers to the extent to which the instrument actually reflects the abstract construct being examined. It entails both internal and external validity. Internal validity refers to the ability of the research tool to measure what is supposed to be measured, whereas external validity relates to the generalisation of the study findings to the whole with that problem (Polit & Beck 2012:496).

- ✓ **Internal validity**

Internal validity is crucial to experimental research design. Polit and Beck (2012:200) believes that the internal validity of the study is the extent to which its design allows the researcher to draw accurate conclusions about the cause and effect relationships. In this study, internal validity was ensured by pre-testing of the research instrument. Ten participants completed questionnaires prior to the actual study to detect any flaws in the tool. Moreover, the questionnaires were also checked by the promoters and the statistician to check the logical flow of the questions.

- ✓ **External validity**

For the research to use sample results to make generalisations about the larger population, the sample must be representative. A representation sample is one that is similar to the larger population from which the sample was drawn (Polit and Beck 2012:264). In this study, probability sampling was used believing that the sample might be representative and would enhance the generalisation of the results.

✓ **Measurement validities**

Neuman 2011:211, describes measurement validity as how well an empirical indicator and the conceptual definition of the construct that the indicator is supposed to measure fit together. There are several types of validity, face and content, concurrent and predictive validity and construct validity. In this study the validity of the instrument was ensured by using the following classifications:

✓ **Content validity**

Content validity refers to representativeness or sampling adequacy of the content of an instrument (De Vos 2005:160). According to Polit and Beck (2008:459) content validity is the degree in which an instrument has an appropriate sample of items for the construct being measured and adequately covers the construct domain. In this study questionnaires covered the objectives stated in the research study and were able to give all the information necessary in the research. Those who are experts in the instrument development and those who are knowledgeable about intellectual disabilities and the support needed, were given the questionnaires to judge if the tool has truly covered the research objectives and the questions.

✓ **Face validity**

Face validity refers to whether the instrument looks as though it is measuring the appropriate construct (Polit & Beck 2008: 459). According to De Vos (2005:160) face validity refers to the desirable characteristic of a measuring instrument. The questionnaires will be readable, concise and appealing to the participants. This was ensured by giving the expert and the supervisor the questions to re-check if they would be truly readable, concise and appealing to the participants.

- **Reliability of the research tool**

Reliability refers to the consistency with which the instrument measures the attributes (Polit 2001:305). According to De Vos (2005:162) and Mouton (2002:144), reliability

is the requirement that the application of a valid measuring instrument to different groups under different sets of circumstances should lead to the same observations. In this study reliability was assessed in three key aspects; namely stability, internal consistency and equivalence. This means that someone should be able to obtain similar findings using the same method in the same circumstances (Polit & Beck 2006:340).

✓ **Stability**

The stability of an instrument is the extent to which similar results are obtained on two separate occasions (Polit & Beck 2008:453). This was done by conducting a pre-test study which is a small scale, trial run of an actual research study. The data were collected from 10 participants to check if it will give the same results.

✓ **Internal consistency**

Internal consistency refers to the degree to which the items of an instrument are all measuring the same attribute or dimension, as a measure of the instruments` reliability (Polit & Beck 2008:454). The researcher appointed a person with expertise on the topic to check the items of the instrument and if after the discussion the findings will yield the same results.

✓ **Equivalence**

Equivalence in the context of reliability assessment primarily concerns the degree to which two or more independent observers or coders agree about the scoring on an instrument. In this study an independent coder assisted with data analysis and after discussion a consensus was reached between the researcher and the co-coder.

3.42.6. Data analysis

In quantitative approach, data was analysed and synthesised using descriptive statistics. Data analysis was done using Statistical Package for the Social Sciences

(SPSS) version 24.0. Descriptive statistics refers to summary statistics that allow the researcher to organise the data in ways that give meaning and facilitate insight, such as frequency distributions and measures of central tendency and dispersion (Burns & Grove 2005:43). Microsoft Excel was used to produce figures and graphs.

3.4.3. Ethical considerations

The term 'ethics' means conforming to the standards of conduct of a given profession or group (Babbie & Mouton 2002:250). Ethics is defined as a set of accepted moral principles that offer rules for behavioural expectations of experimental subjects and respondents. Researchers are bound by ethical morals and rules when conducting the research (De Vos et al. 2005:69). In this study, ethical considerations were the core principle because credibility and trustworthiness were ensured. The ethical considerations were in accordance with statutory ethical standards and principles (Democratic Nurses Organisation of South Africa (DENOSA) 1998:15; Burns & Grove 2005:99).

Explanation of the research processes was done at the level of the participant's understanding. This included their level of education, knowledge, experience and language. Participants gave informed consent that they are willing to participate in the study.

- Permission to conduct the study

3.4.3.1 Ethical clearance

Ethical clearance was obtained from, University of Venda Higher Degree Committee, Department of Health Limpopo Province, Research committee, the Chief Executive Officers of the Hospitals, District Managers of the district hospitals, Nurse Managers of the hospitals. For ethical purposes, participants were assured that participation in the study is voluntarily and that no remuneration or reward of any kind will be awarded. Furthermore, participants were assured that their consent will not be disclosed and that confidentiality, anonymity and fairness will be observed. Ethical principles were

adhered to throughout the study. Ethical measures were strictly followed in order to protect the participants from harm.

3.4.3.2 Informed Consent

Obtaining informed consent from human subjects is essential for the conduct of ethical research. Informing is that transmission of essential ideas and consent is the prospective subject's agreement to participate in a study as a subject, which is reached after assimilation of essential information (Burns & Grove 2005:209). Informed consent means that participants have adequate information regarding the research, comprehend the information and have the power of free choice, enabling them to consent voluntarily to participate in the research or decline participation. The participants were allowed to make informed decisions regarding participation in the study. The researcher explained the purpose of the study, the procedures that will be involved, how confidentiality will be maintained and the right to withdraw from participations. The researcher considered the participants' comprehension during the explanation sessions (Polit & Beck 2006:93).

3.4.3.3 Rights of Participants

The rights of participants can be protection from either physical or psychological harm. The participants were informed that the research will be conducted humanely, that the researcher will not probe for any information that could harm them, and that she will leave sensitive questions for a later stage as the researcher will have a prolonged interaction with them to gain their trust and understanding (Brink 2006:74). The researcher provided a therapeutic session for the participants in which they talked freely without being judged. Possible pain, discomfort, stress and loss of dignity that accompanied the research process were discussed with the participants. Privacy, confidentiality and anonymity were maintained (Burns & Grove 2005:203).

3.4.3.4 Selection of Participants and Explanation of Procedures

Participants were informed about the rationale behind their selection. The researcher explained to the participants the setting, data collection method and the fact that data will be analyzed at a later stage, that there will be no financial or other rewards for participating in the study and they were allowed to state their opinions, experiences and attitudes regarding the topic (Democratic Nurses Organisation of South Africa (DENOSA) 1998:5).

3.4.3.5 Right to Privacy

The researcher ensured privacy by conducting interviews in the isolation cubicle which was not utilized by the staff. Privacy information of participants was not shared without the participants' knowledge or against their will. Participants were assured that they have the right to expect that any information they provide will be kept in the strictest confidence (Polit & Beck 2008:156).

3.4.3.6 Confidentiality and Anonymity

Confidentiality and anonymity refer to the researcher's obligation to keep data secure and protected. Participants were assured that any information they provide will not be published or reported in a manner that might identify them. The researcher undertook to refrain from sharing the information without the authorization of the participants. No one had access to the raw data of the study without authorization (Burns & Grove 2005:99).

Participants were told that field notes will be limited to the superiors only, to decrease the threat to loss of confidentiality, and that their names and addresses shall be withheld from the publication of any information obtained from the study. Each participant was provided with a number or code to ensure anonymity.

3.4.3.7 Right to Withdraw and Withhold Information

Participants were told that even after consenting they still have the right to withdraw from the study and refuse to provide any further information (Pilot & Beck 2008:158).

3.4.3.8 Right to Maintain Self-Respect

Self-respect is a feeling of confidence and pride in your own ability and worth. It is the esteem or regard for the dignity of the individual's character (Pilot & Beck 2012:154). The researcher was not judgemental of the participants and accepted what they were saying as the truth. The researcher asked probing questions and responded humanely towards the participants' emotions.

3.5. CONCEPT ANALYSIS

Objective 5: To analyse the concepts and develop a model to support mothers of children with intellectual disabilities in selected health institutions of Limpopo Province, South Africa.

Concept analysis was guided by eight steps as outlined by Walker and Avant (2005), whereas development of model was discussed within the six areas of (Dickoff & James 1968:243) the framework.

Concept analysis refers to clarification and analysis of the lay concepts in the study and the way in which one's research is integrated into the body of existing theory and research (Mouton 2002:119). Concept analysis was used to clarify meaning and to promote mutual understanding of the readers. In this study, Walker and Avant's (2005) method was used in concept analysis and eight steps, which are listed below were followed:

3.5.1. Select a concept– concept selection should reflect the topic or area of greatest interest.

3.5.2. Determine the aims or purpose of analysis– it is used to clarify the meaning, and develop an operational definition. The method also intended to distinguish between normal, ordinary, and scientific language usage of the concept.

3.5.3. Identify all uses of the concept – the search was done in the dictionary, thesauruses, hospitals, journals, articles, books and literature. The search was limited to mothers and professional literature.

3.5.4. Determine the defining attributes – on examining the different concepts, taking notes on the characteristics that appear over and over again. These characteristics become the critical or defining attributes of the concept.

3.5.5. Construct a model case – these will be construct borderline, related, contrary, invented, and illegitimate cases:

- Borderline case – contains some of the critical attributes but not all of them. A concept is used in a different context. Once a concept is well accepted it gives a centralconceptual meaning
- Related case – it represents instances that represent a different but similar concept. It is related to the concept but does not contain critical attributes. They usually share several criteria with the concept of interest.
- Contrary case – not related to the concept and it is totally different from the concept you are considering. It often reveal important aspect of the exemplar case that are hidden in assumptions that you may be making about the concept.
- Invented cases – constructed, not existent in real life.
- illegitimate cases – the concept is not used properly.

3.5.6. Identify antecedents and consequences

- Antecedents – events that must occur prior to the occurrence of the concept. It implies prediction within a linear time frame. It can also be placed in a causal relationships with those that follow.
- Consequences – events that occur as a result of the occurrence of the concept.

3.5.7. Define empirical referents – classes or categories of actual phenomenon that by their existence or presence demonstrated the occurrence of the concept.

3.6 MODEL DEVELOPMENT

Model development forms part of phase two (2). The objective to be achieved was as follows:

A model that will enhance the continuous support for mothers of children with intellectual disability was developed. Dickoff and James's (1968:200) framework was used in this study and the six areas mentioned below were followed:

- **Agent** – an agent is a person or any other person/thing who contributes towards realisation of the goal (Dickoff & James 1968:200). In this study the agents were the health care professionals.
- **Recipients** – these are persons who receive action from an agent and this activity contributes to a certain goal (Dickoff & James 1968:200). In this study recipients are mothers of children with ID, their families, friends and relatives.
- **Context** – The context is viewed from the aspect of the matrix of activity. In this study the activity occurred within the legal framework of health institution and government and rules and regulations governing employees.
- **Dynamics**– these are the power sources for the activity which can be chemical, physical, biological and psychological for a person or thing to function as agent, patient or part of the framework in realising the goal (Dickoff & James 1968:200).
- **Procedure**– refers to how the activity took place.
- **Terminus**– to treat activity from the aspect of terminus is to view activity from perspective of the end point or accomplishment of activity (Dickoff & James 1968:200). In this study the terminus were the outcome of how mothers will be supported in caring for their children with intellectual disabilities.

3.7. VALIDATION OF MODEL

Objective 6: To validate the model's feasibility pertaining to the support given to mothers of children with intellectual disability in Limpopo Province, South Africa.

The developed model was validated for its effectiveness during the implementation process according to Chinn & Kramer (2008:99). Evaluation of the study was done against its purpose and objectives as set out in Chapter 1.

3.8 SUMMARY

An introduction or brief overview about a supportive care model for mothers of children with intellectual disabilities in Limpopo Province was given in the research proposal. The study may assist the mothers to gain psychological, financial and physical support from relatives and the community. The background to the research, research problem statement, research questions, objectives, and significance of the study were introduced. The definition of concepts, preliminary literature review and the research method were outlined. Measures to ensure trustworthiness and ethical considerations were also indicated.

CHAPTER 4

RESULTS AND DISCUSSION OF QUALITATIVE AND QUANTITATIVE DATA

4.1 INTRODUCTION

The previous chapter discussed the methodology that was used to conduct this study. In this chapter results and discussion of data collected from individual interviews were dealt with. It consisted of the results and discussions of the qualitative study which were followed by quantitative results and discussion.

4.2 PHASE 1a: QUALITATIVE DATA

The analysis and interpretations of qualitative data were guided by Roy's Model of Adaptation. The researcher provided quotes from the participants who gave their views. Conclusions were also drawn according to Roy's Model of Adaptation. The analysis and interpretations of qualitative results were discussed based on the findings of the semi-structured interviews. The chapter aims to analyse, interpret and describe the data collected through individual interviews with mothers of children with intellectual disabilities. Literature control was done to validate the findings.

Unstructured interviews followed by probing questions were conducted with 20 mothers of children with intellectual disabilities. The demographic profiles of the mothers recruited to this study are shown in Table 5. One central question was asked during the interview followed by a probing question, '**Can you tell me your experiences of having an intellectual disability child in the family?**' The interview sessions lasted for 20-30 minutes with individual mothers in order to generate an understanding about the problem studied. Data collection from the sample was determined by data saturation (Brink 1996:134). The interview sessions were captured by means of a tape recorder and written field notes which, therefore, did not contain any of the researcher's bias. The central question (De Vos et al. 2006:344) became apparent and reflected that participants experienced the same challenges. The

findings, that is the participant's challenges are presented as direct italicised quotations.

4.2.1 Demographic profiles of the participants

Data were collected in Vhembe and Mopani districts, Limpopo Province. Data was collected from 20 participants and their children's ages were below 12 years. Data saturated at the twentieth participant. Four participants were employed and able to support themselves and their children financially. Eleven participants were not employed and depend on child's grant for everything. Two participants were self-employed and selling food and clothes to augment the child's grant they are getting. Three participants were financially supported by their husbands. Three mothers had obtained primary level of education, 10 secondary education, and 7 had obtained tertiary education. Participants were interviewed in Tshivenda and Xi-tsonga as it was their mother tongue, and then translated verbatim into English by the researcher. From the total number of participants, 9 spoke Xi-tsonga and 11 spoke Tshivenda as illustrated by the Table 5 below.

Table 5: Demographic profiles of the participants

Mother's age(years)	Child's age (years)	Number of children	Language	Educational level	Support System
27	10	2	Tshivenda	Secondary	Child's grant
26	6	1	Tshivenda	Tertiary	Child's grant
30	8	2	Tshivenda	Secondary	Self
26	7	2	Tshivenda	Secondary	Husband
26	10	1	Tshivenda	Secondary	Husband
28	12	1	Tshivenda	Primary	Child's grant
29	9	1	Tsonga	Secondary	Child's grant
26	6	2	Tsonga	Tertiary	Child's grant
32	6	3	Tshivenda	Tertiary	Self
27	8	2	Tsonga	Secondary	Child's grant
31	7	1	Tshivenda	Primary	Child's grant
30	9	1	Tsonga	Secondary	Self
27	7	2	Tshivenda	Secondary	Child's grant
29	12	2	Tsonga	Secondary	Husband
28	8	3	Tsonga	Tertiary	Self employed
30	10	1	Tshivenda	Tertiary	Child's grant
33	7	1	Tsonga	Tertiary	Child's grant
26	8	2	Tshivenda	Secondary	Self employed
34	9	3	Tsonga	Tertiary	Self
28	12	2	Tsonga	Primary	Child's grant

The independent coder and the researcher used open coding according to Tesch's inductive, descriptive coding technique (Creswell 2011:185) quoted in Botman, Greeff, Mulaudzi and Wright (2010:223) for data analysis. The steps considered during qualitative data analysis were fully discussed in Chapter 3. Raw data was forwarded to a qualitative analyst to allocate the themes and subthemes. Thereafter a meeting was held between the qualitative analyst and the researcher and supervisors. A consensus on the themes and subthemes was reached. The findings were discussed in relation to the themes and relevant responses from participants emanating from the interviews.

4.2.2. Presentation of themes and sub-themes

Four themes emerged during data analysis using Tesch's open-coding technique as outlined in Chapter 3, Table 3. Themes were categorised and clustered according to their identified relationships. The identified themes and subthemes are presented in Table 6. substantiated by appropriate quotations from the raw data and contextualized by a literature control.

Table 6. Themes and sub-themes reflecting mother's experiences and challenges of having a child with intellectual disability in Vhembe and Mopani District, Limpopo Province

Main themes	Sub-themes
1. Experiences related to parenting a child with intellectual disabilities	1.1 Fear, anger, blaming oneself, guilt, stigma, social rejection and embarrassment 1.2 Experiences regarding awareness of diagnosis of the child 1.3 Acceptance versus lack of acceptance of parenting intellectually disabled child
2. Challenges experienced by Mothers of children with intellectual disability	2.1 Problematic appointment dates at the health service 2.2 Lack of special schools for disabled children 2.3 Lack of support groups for parents with disabled children 2.4 Inadequate assistance at health care facilities
3. Knowledge deficit related to children with intellectual disability	3.1 Lack of knowledge regarding origin of disability by mothers and family members 3.2 Disclosure of child's disability is made known to parents by health care professionals and relatives.
4. Cultural beliefs and practices	4.1 Rituals 4.2 Traditional healers 4.3 Believing in God

4.2.2.1. Theme 1: Experiences related to parenting intellectually challenged child

Theme 1 was divided into 3 sub-themes namely: Fear, anger, blaming oneself, guilt, stigma, social rejection and embarrassment; experiences regarding awareness of diagnosis and acceptance versus lack of acceptance of parenting a child with intellectual disability.

Sub-Theme: 4.2.2.1.1 Fear, anger, blaming oneself, guilt, stigma, social rejection and embarrassment

In this study, some mothers of children with intellectual disability displayed some feelings of fear, anger, blaming oneself and embarrassment. This was due to giving birth of unexpected intellectually challenged child. They experienced social rejection attached to the weakness and helplessness of the child.

Participant A confirmed this by saying that: *“I am having fear that no men will ever marry me again because they are afraid of my child with intellectual disability. I am just alone with my child at home since my husband divorced me when the child was 1-year-old now my relationships with men no longer last or exist.”*

Mothers also showed experiences of anger when people display strange behaviours towards their children:

Participant B said: *“Sometimes I become very angry and confused not knowing what to do, because my in-laws do not have good relationship with my child and I as well. They sometimes speak words that hurt me a lot. That is very stressing especially on my side.”*

Embarrassment was also experienced by mothers due to the fact that their children are grown-ups and too heavy for them to carry or pick up, especially during napkin changing. An 11-year-old child is expected to be independent to a certain extent, like controlling his/her bladder or using the toilet. When a child fails to perform such tasks, it becomes a burden and tiring to a mother for the rest of her life. This was supported by a mother with an 11-year-old child with intellectual disability (participant J) who said:

“Ok, my child still behaves like a small child. I can say like a two-year-old. As you can see, she is always drooling saliva. She cannot control her saliva. She is still messing herself up. The way she plays also, she takes everything from hand to mouth. I need to do everything for her, until when? (crying). She also treats everything like it is a car and making sounds like a moving car that is embarrassing.” Through probing she said: *“These days she is even very stubborn. When you rebuke her of something, she does it intentionally like you did not say anything. It is also tiring when she moves around the streets. Once she goes out of the yard and you did not notice that it is very difficult to find her. It is very bad as this days, the world is not like, some years back. There are lots of bad things happening in our area. I am afraid she might be raped.”*

This was also confirmed by participant H who said:

“Some children she plays with bully her sometimes and when this happens, I feel more embarrassed and guilty. When I am walking in the village with her everybody will look at us as she will be screaming in the manner that takes everybody’s attention.” She added: *“I mean that the child will go and play and before I knew it, she will be out of the yard and people will just call me to come and take her and tell me to guard against her. Some will just tell that we saw your child in such a place and they will say “take care of her.” These people know that I cannot guard against her because she is a hyperactive child and to take care of her is very difficult.’* Wanting to cry, *“When I am in the house I will think that the child is at home whereas she has gone out.”*

In this study, guilt and blaming oneself was found to be another common feeling of emotional distress due to having an intellectually disabled child. Participants felt that falling pregnant again would lead to another child with intellectual disability or another type of disability. This was due to the burden and trauma they were presently facing.

“I feel guilty, my child is mentally disabled because of me, I really regret to be born in the family with a history of mental retardation (shaking her head).” She continued and said *“...I accepted that I have a mentally retarded child but each time I see my child, I really grieve because I am suffering a lot about this child.”* (Participant F)

“I don’t know because the other doctor said she is suspecting Autism but she said she is not sure, she is still checking.” She continued by saying: *“It is too hard for me as I*

am in darkness. She is six years and I cannot even think of having another child as I cannot afford to have two disabled infants as this one is also an infant who needs all my attention (crying). I was telling my husband as he was forcing me to have another child but I cannot and he is angry with me about that. What must I do then (crying)?”
(Participant A)

Mothers show feelings of social rejection by the community as they are mostly excluded from community activities such as community gatherings in the village. Their children were also rejected by other children during play. This was confirmed by the following participants:

Participant K said, “People in the community treats me badly, when there are meetings of mothers here in the village, they don’t invite me, as if I’m not a mother, even at school when I sell at the market with other workers, their stalls are erected away from me and most children avoiding to buy from me.”

Another participant M said, “My neighbours have a 4-year-old child whom my child like to play with but her parents would not allow them to play together. The only time they play together is when I am around and I can see her, other than that playing is not possible. This was also witnessed by my other neighbour who warned me not to allow my child to play with that child again as my child was not allowed to touch anything there. She gives her dog’s carpet to my child to sit on as if she is also a dog.”

She further explained in a very sad mood by saying, “Having a disabled child is a very painful experience as the child is like an animal not human being. it feels like a punishment from God, a gift He gave me, I cannot kill her.”

Participant C said, “Another neighbour has a disabled child at a special school I think we share the same sentiments. A neighbourhood relative to my husband is very mean to us. Eeh.....”, she said “in this area we will open a school called “Fulufhelo” (special school for intellectual disabled children who are regarded as ‘mad’ by other people in Vhembe District, Limpopo). She was trying to laugh at us and make us feel very bad.”

This study revealed that parents, especially young mothers of low educational level expressed feelings of social rejection and isolation implying lack of knowledge and information by community members regarding people with disabilities as a whole within the communities in the villages. However, social interaction was seen to be of importance according to Roy's theory. Such rejection instills more fears, especially to mothers who are always at the child's side with husbands and spouses running away from them to avoid disappointment and embarrassment because of the birth of such children in the families. This study concurs with that of Gona, Mung'ala-Odera, Newton and Hartley (2006:178) that fear, anger and embarrassment are experienced by parents, especially of children who showed signs such as behavioural or physical disorders. On the other hand, Hoffmann, Windham and Anderson (2014:945) is also of the opinion that mothers of children with Autism Spectrum Disorders (ASD) have fewer subsequent children due to fear of having another child with an ASD.

Furthermore, mothers of children with intellectual disabilities struggled with guilt of being responsible for their children's condition, blaming themselves that they are the cause of the disability. This was also noted by Boyd (2011:50) that parents of mentally handicapped children often struggle with guilt. The findings of this study also concur with that of Chang and McConkey (2008:38), wherein mothers expressed a sense of sorrow about their children. Talking about the birth of the handicapped child reminded many mothers of the tragic events they experienced and the pains they felt as well as the implications it had for their lives including divorce. Mothers spoke of the child they had hoped for and the sadness of what their son or daughter will never be able to do. However, Baker, Blacher, Crnic and Edelbrock (2002:436) indicated that the characteristics related to the child with an intellectual disability may also be important predictors of parental divorce. Studies of children with intellectual disabilities indicate that parental stress and marital dissatisfaction are more strongly associated with the child's behaviour problems than his or her intellectual disadvantage. These also include factors such as low-income, rural housing, low education level, and young parents, which are presented as factors related to divorce. This is in relation to this study where some mothers were divorced by their spouses due to the presence of their children with intellectual disability in the family. This implies that parents, especially mothers tend to suffer more as they are divorced and left to face the

challenges of parenting an intellectual disability child alone. Both parents require prenatal counselling in order to accept the child with intellectual disability.

Chang and McConkey (2008:38) furthermore, have a contrary implication wherein parents indicated that their marital relationship became stronger and the other children without disability impacted in multiple ways. Couples were working together towards caring for a child with an intellectual disability which was not the case in the communities of this study.

Furthermore, people's attitudes and public reactions coupled with the intellectually disabled child's uncontrolled behaviours hurt mothers more, causing anger in them. However, studies based on Roy's theory showed that support in nursing care assist the patient's adaptive responses to improve (Allgood 2010:205). The Collins English Dictionary defines anger as the strong emotion that is felt when someone behaves in an unfair, cruel, or unacceptable way. The study findings imply more and regular health education to families and communities regarding issues of children with intellectual disabilities.

Sub-Theme 4.2.2.1.2 Experiences regarding awareness of diagnosis of the child

The current study revealed that a number of children were diagnosed after the age of 12 months whilst mothers remained in the dark for that long. Majority of mothers experienced shock and confusion after diagnosis of their children was revealed to them. There were also no clear directions as what to do next with such a disability. This was confirmed by a participant A mother when she said:

"I was shocked and confused when I became aware of his diagnosis when he was 1,5 years (18 months). I was told by the doctor who was treating my child after I have asked exactly what the problem with the child was because time and again I was told to bring the child for check-up though it was not clear which service my child was coming for, why and for how long."

Another participant O expressed her feelings by saying: *"The challenge is that I was only told when he was 18 months that he is having Down Syndrome. He is always fitting and mentally not stable. The diagnosis made me feel bad I think I was supposed*

to be told long ago. It is now as if I am the one who is wrong and it always bring guilt and anger in my face.” Through probing she continued to say: “He stopped fitting for some time 3 or 6 months and now it started again daily.”

Furthermore, lack of proper communication and full explanation about the child’s condition was experienced by majority of mothers when still at the hospital.

Another mother D also verbalised this: *“It was so bad. More especially when I realized that it is like the problem starts earlier, but nothing was said to me. I think that was not fair at all and it was so traumatizing. Eish, I couldn’t believe that.”*

This was supported by participant E who said, *“The way it was communicated to me it was like something that is not serious and does not matter. I felt very bad and it was painful but I thought it was just something that will continue for a moment.”*

A 26-year-old mother C said: *“I was not satisfied and ask myself, how come. In fact, I had a problem the day I gave birth to him. This was because some kids will cry and mine did not cry. In my mind because I always hear people saying that if a child does not cry during birth, it means that he is dead. Nothing was explained to me. Later on, the other nurse came and said, ‘This is your child. You are not going to stay with him. We are taking him to Nursery’. So, I suspected that something was not right but there was no further explanation. I was only happy when my child was discharged.”*

The other participant G confirmed this by saying, *“I think the doctor who was explaining did not have time. He was in a hurry. He just said “mom, you can see what the child is doing, you must take care of him”. I just looked at him and he left. I did not know what it meant as I was not given time to ask anything.”*

From the above quotations it is clear that mothers are not given full explanation about their child’s diagnosis from birth. They remain in darkness until such time as things become complicated. This means that mothers left the hospitals not knowing as to what the child was suffering from and how to care for the child, including the risks the child might encounter. Some mothers complained that they were not told about the

diagnosis of a child immediately and were never given the opportunity to ask questions while still in the hospital. They indicated that initial awareness was very important to them. This could have brought a better understanding to mothers as to what to expect from their children. Every parent expects a healthy normal child when the child is born. The birth of an intellectually disabled child brings shock and shame to parents, especially the mother. It is very important for the health care professionals to break the news to parents once the diagnosis is made after a thorough assessment and investigation. According to RAM, nurse's role is to manipulate stimuli by removing, decreasing, increasing or altering stimuli using six-step nursing process. Therefore, accurate and systematic assessment followed by planning according to the needs, implementation and evaluation processes should be done for mothers and the family as a whole as majority of mothers indicated that they were never offered counselling after their children's diagnosis.

This study is of the opinion that timeous, accurate and appropriate information should be provided to parents as soon as a diagnosis has been made that something is wrong, and proper confirmation is done to avoid shock to parents. Furthermore, the study revealed that health care professionals lacked patience, support and enough time to explain the diagnosis to parents. They did not bother about the parents' feelings or give them time to ask questions or talk about their feelings as a whole. This could be due to shortages of manpower or lack of counselling skills on the part of health care professionals at that time. On the other hand, the institutions lack counselling staff and lack referrals to appropriate health institutions.

However, previous studies by Ergün and Ertem (2012:217), indicated that mothers became very frustrated after their children's diagnosis was revealed due to lack of direction and support from health care professionals. Because of lack of real direction mothers did not know what to pursue and when. In contrast, Brogan and Knussen (2003:33) argue that parents appear to be more satisfied with the diagnostic process if they are given information about the syndrome at the time of diagnosis. Receiving information early in the diagnostic process would prepare mothers and enable them to ask any questions they may want to ask, when their children receive a diagnosis.

Nissenbaum, Tollefson and Reese (2002:34), supported the study by highlighting that parents who are aware that professionals suspected developmental disability were less likely to be shocked at the time of diagnosis. Stoner, Bock, Thompson, Angell, Heyl and Browley (2005:41), in Martinović and Stričević (2016:20), highlighted that the first reaction of parents faced with symptoms of any illness or disorder of their child is to seek information to better understand the condition and enhance the knowledge about their child's illness. The parents' first reaction following a diagnosis is to look for information and practical advice. This is in support of the current studies wherein mothers were just transferred from one hospital to another without the mothers having any idea of what the reason was. No explanations were done in most instances.

Furthermore, an accurate diagnosis made in a timely manner, affords patients or parents of patients, the opportunity for a positive health outcome because clinical decision making depends on a correct understanding of the patient's health problem (Martinović & Stričević 2016). If parents do not have accurate and appropriate information, they will not know how to tackle the condition of their children. A lack of adequate health information contributes to parental stress. Providing parents with effective and timely health information can reduce the anxiety imposed by their child's illness and facilitate parental empowerment and control.

Sub-Theme 4.2.2.1.3 Acceptance versus lack of acceptance of having a child with intellectual disability

Accepting a child with an intellectual disability has been problematic to some mothers who participated in this study. This was because they never expected to give birth to a child with an intellectual disability. To most of them, from birth the child looked fine and they did not suspect anything until developmental milestones were delayed, as exemplified by a mother M who said:

“Yes, what I can say is that having a child with intellectual disability you ought to accept this because who do you think deserve to have an intellectual disability child. At first I thought I will never have another child again but I just realise that I can still have a

child without intellectual disability. At home there is no intellectual disabled child but God gave me this child and I am proud of her.”

Another mother E, indicated that, *“My relatives, sisters, aunt used to say, this things also happens in other families, you are not the only one with CP child. They were really behind me until such time, I was able to accept and God gave me strength to accept things I cannot change. That’s how I strengthen myself and start coping.”*

Mothers and families with a Christian background were seen to accept their children and displayed coping skills easier.

This was confirmed by a mother who said, *“From the day we knew about the condition of my child, it was difficult to accept and to live with her. It was very hurting, but we console ourselves by what is in the bible that ‘everything comes from the Lord.’ It gave me a courage to thank the Lord rather than questioning Him. This was because there are many people without children but God gave me this child. So, I had to believe that I will live with my child by faith, even in pain like this. Having the child with intellectual disability means to make sure that you guard or you take care of each step or movement which is very difficult. I am also working and it is not easy to always get a leave from work to accompany her to the hospital. As she is taking treatment I think we are able to do the best we can for her.”*

She added a statement that shows acceptance, *“Some people gave birth to children who can’t even walk. So people must not be surprised as if I am the cause of my child’s condition or I did something to her. Others are trying to have children, but they are not able to conceive and nobody knows why. I teach them that they are not supposed to look at my child like it is the first person to have intellectual disability who behaves the way she behaves.”*

Mothers who were not supported by their relatives and neighbours were frustrated and had some difficulties in accepting their children. This was supported by a mother who said,

"...and visit the child every weekend but to me it was not easy. I had this guilt feeling of saying 'why me' more especially that my husband left me also depresses me, but as I was going there time and again bit by bit I tried to accept."

"If you happen to come across challenges in life and nobody supports you and people are saying this is just a 'spoiled child', you feel frustrated. When you come to the hospital, doctors will say that the child is sick and when you go home you will be accused of spoiling a child, it confuses and you feel very bad. As a mother you don't know what to do to make your child to be like others. Of course I am to blame."

A study done by Ryan and Cole (2009:46) supports the current study by indicating that reactions from the public gave parents the opportunities to advocate about their children with autism. This was supported by the mothers who were also not happy about how people reacted to them and their children. One participant said, *"I feel hurt and embarrassed because of the way they look at us, but sometimes I take that chance to help those people who look surprised by explaining to them God's will that nobody knows what will happen to your child when you are pregnant."*

The level of support received from different people and structures also contributed to their coping. Some parents were able to accept the child's diagnosis whereas others could not. Mothers who accepted their children's diagnosis easily, were those getting support from in-laws, partners, parents and neighbours. This was supported by the study done by Home (2002:90) that the disability of a child is not a challenge per se but lack of support from family, community and professionals was said to be the most challenging for many mothers. Support from the extended family showed that they accepted their children and gave emotional support.

The study done by Taanila, Syrjälä, Kokkonen and Järvelin (2002:75), revealed that the family is strengthened and copes well when members are united, working together and understanding each other. Thus bringing family cohesion and a sense of belonging amongst family members. The researcher concluded that family support is very essential and must be encouraged by teaching family members what to expect from the child with intellectual disability and how to deal with challenges. This brings a positive feeling to mothers knowing that they do not face challenges or carry the burden alone if the family is involved.

4.2.2.2 Theme 2. Challenges experienced by parents with intellectually disabled children

Sub-Theme 4.2.2.2.1. Problematic appointment dates at the health services

Chronic conditions or diseases need constant follow-up in order to maintain the health status of a patient. Appointments depends on the severity of illness and the services needed by a child. These can be a doctor, physiotherapy, occupational therapy or psychology services (Adams 2010:450).

In this study some mothers experienced problematic scheduled appointments that made it difficult to consult well with the paediatrician and this was expressed angrily by participant G, *“It is a challenge because I come here for different clinics on different days. The clinics must also be put on the same date. If I am bringing the child to a Paediatrician today, I must not be given another date like tomorrow for occupational therapist (OT) because it becomes very expensive for me.”*

Mothers were also not happy due to the fact that some appointments were not fruitful or were delayed. Participant P expressed her feelings and experience when coming for a check-up and she said,

“Sometimes I would come at 06 o’clock in the morning and go home at 19H00 without the child’s treatment. It is so unfortunate because without the treatment, my child cannot cope. When I try to say it out, I will be told to keep quiet and sit down. The following morning I must come again using money I do not have because I will be worried about my child’s medication, like today, I came at 06H30 and I only got my file now at 12H00 which is not fair. It is like we mothers with intellectual disability children are not treated well, we are taken for granted.”

Participant F from one of the hospitals also indicated that the services are too slow which is worsened by the process of getting a file.

“The service is very slow, if you come here in the morning, you must be ready to go home late in the evening. The process of taking the file and the collection of medication is worse and very poor. The services which must be utilised by children with intellectual disability are not centralised. You walk a long distance from one service to the other

like from Occupational therapist to the Physiotherapists. Eish.., this is tiring, more especially when you are having a child who is weighing more than 30kg on your back.”

Participant H also verbalizes the same experience and said, *“Hey, it depends on who is helping you. Some staff members are very helpful whereas others are not. The process of getting a file also, is time wasting and the file are also missing. The file that I am having now for my child is a new file. The old file is lost and it was having a lot of information. Now the new one is very empty. The problem is when you meet new doctor who does not know the child and he will ask me some questions I will not be able to answer as it was written in the file. The other time my child was given a wrong medication and unfortunately I only discovered that when I was at home and I had to go back to the hospital the following day which was very costly to me.”*

The supportive statement was made by participant I who said,

“The treatment/support is not right because sometimes I come here for the check-up of my child but returned home without being seen by the doctor because the file will be missing.”

The findings of this study also revealed that during check-ups, mothers returned home with their children without being reviewed. This was because the doctors were not available or the file was not found (missing).

Participants verbalised that the process of taking the file from Outpatient Department (OPD) were very slow. Some files were found to be missing which is a serious challenge because the therapists and doctors will not be able to link the progress of a child, more especially if the therapist is assessing the child for the first time. It causes delay to the progress of the child.

Continuity of care is important and very helpful to certain children with intellectual disabilities. This is best achieved when children are seen by the same relevant professional each time they visit. Mothers and their children with an intellectual disability may experience less distress if they are dealing with a member of staff that they know and who know the child better, rather than changing the health care professionals each time. Appointments can also be weekly, fortnightly, monthly or when necessary depending on the need and the progress of the child. Each service is rendered on its own without compromising the health of a child. Mothers raised a

concern regarding the scheduled appointments. This was because the doctor will need to see a child on a particular day and the occupational therapists on another. Sometimes the dates are in the same week. This causes a lot of travelling there and back which is very costly. The health care professionals are perceived by the parents as being better at preventing and dealing with challenging behaviours of a child (Wallander, Dekker & Koot 2003:101).

The present study concurs with the previous study which indicated that poor continuity of care such as inadequate follow-up and being reviewed by a different doctor each time, may lead to the prescription of incorrect medication and to unnecessary investigations (Ali, Sicora, Ratti, Strydom, King & Hassiotis 2013:1371).

Sub-Theme 4.2.2.2 Lack of special schools for intellectually disabled children

All children, including those with disabilities, have a right to free and compulsory primary education, and to secondary education and further education or training. The South African government in 2015, declared that it had reached a universal enrolment for primary education and achieved the United Nations Millenium Development Goals on education (Lomazzi, Borisch & Laaser 2014:8).

Participant C had this to say; *“In some schools they said he is not fit and in other school, they said they are full. I could see that the reason stated is not valid. I think the government must have its own school or day care centre where they will be able to accept all the intellectual disabled children without any discrimination because we are suffering.”* She continued after probing by saying: *“The other thing which is very important, is to have a school that will cater for children from infancy to toddler wherein instead of taking our children to the crèche, we take our children to that school. The staff there will be trained and know how to take care of our children by feeding the right way, bathing and play with them to stimulate them.”*

Another mother C also said *“I want my child to go to school. So that she can be able to do something for herself because I will not live for her and live forever. I want her to be independent. I still believe that she can still learn something or do handwork and make money out of it.”*

Mothers in the present study denied it when told that their children were not coping in a normal school, meaning that they must be transferred to a special school. *Participant E angrily said, "Hmm, Ok. The first time they call me, it was when she was in grade R, and I was told to take my child to the special school. To be honest with you, it was a mountain to me. I couldn't believe and understand what was happening. I was much stressed. The following morning, I washed her and take her to school again (same school)."*

Participant B showed a sign of being relieved when a school is found for the child. She verbalized that it is difficult for them to get admission from a day care center or a special school. Once they get that opportunity they feel very relieved because the child will be playing with other children. The mother will also be resting for those few hours. This is what has been explained by mothers who were disappointed by not finding a school for their children and: *".....the only thing that was worrying me is when she could not get a school to be with other children, but now I am very happy that finally I got a school for her. Like today as you can hear her crying, she can feel that she is missing other children to play with."*

"I am not working. I only have grade 12 but I was still struggling to get a school for her. Since my child is now in the day care center if I can get a job, I can work. Previously, it was difficult for me to work as there was nobody to take care of her."

The results of this study found that the South African government has not yet reached universal education since it has left out over half a million of children with intellectual disability from education (Connor 2006). Poopedi (2012:65) indicated that extremely high levels of unemployment amongst people with a mental handicap could be attributed to inadequate education, as well as inaccessible provision for vocational rehabilitation and training. Mothers of children with intellectual disability were also facing a challenge of placing their children in relevant schools. Some of them were not even convinced or aware that their children need a special placement regarding school matters. The study indicated the shortage of schools from the crèche level to the higher grades in Limpopo Province. The criteria for admission to those few special schools available for intellectual disability children are not clear. Mother J was also surprised to be told that her child does not qualify to be in one of those schools.

This study is contrary to the study done by Chomba, Mukuria, Kariuki, Tumuti and Bunyasi (2014) in Kenya, who revealed that learners with intellectual disabilities were equipped with adequate skills that will enable them to pursue either post-secondary education or employment after high school. Since all schools use the same curriculum in all grades, the emphasis in the education system is academic oriented and does not train learners in technical skills that may lead to self-employment.

Sub-Theme 4.2.2.2.3 Lack of support groups for mothers of children with intellectual disability

Mothers of children with intellectual disability needed continuous support from different groups in order for them to cope better.

Mothers indicated a need for knowledgeable personnel who will explain everything concerning the condition of their children. This is what participant Q said, *“This is very helpful. To be counselled by someone with experience and having the same problem with you is a medicine by itself as the person is not talking about what he/ she read from the book, but lived experience. It also helps to know that what you are going through, some parents have also experienced and are coping well. There are mothers who are facing a serious problems and they do not know what to do. So support group of mothers is very important.”*

Mother J said, *“Support group is also necessary. Wherein an expert can come and address our issues as we have different knowledge on the care of our children. Once we are empowered with knowledge we will be able to go out and teach others who do not have that knowledge or those who have relatives with the same problems and those mothers or parents who hide their children due to some disability of any kind can be assisted.”*

Participant G supported by saying, *“It can be very useful because some of us do not have information about our children and we cannot help others. Children are still hidden by their mothers because they feel ashamed and embarrassed about their*

children's condition, but if we can meet and talk about our children's conditions like how to feed them, what are the future expectations, what to do when challenges comes our way and just to share our experiences because we do not meet same challenges every day. I think it can also relieve one's pain just to see that I am not alone and I am the first person to have a CP child."

Information sharing amongst mothers of children with intellectual disability has been a source of strength and empowerment. This was shared by a mother who said, *"No, I don't know, but we do meet coincidentally with other mothers when coming for check-ups but it will depend on how those mothers want to open up. I have helped so many women I came across by sharing my experiences and how I overcome challenges. Some women love the grant for their children without love for their children. So, it is important for us mothers to sometimes be together in order to share information rather than isolating ourselves because we learn through other's experience."*

"It is very helpful and relieving because you tend to know that you are not alone. Some might share some painful experience that is even worse than what you are experiencing and then how they overcome it and could be good for us."

She further indicated that, *"....I think many children are still hidden by their parents. So, there is a need to get a person who can teach us on the care of our children. Where I am staying there was a number of children who were not taken to school but because I took mine to special school, others have followed him."*

The present study found that in Limpopo Province there is a lack of resources and services like support groups and respite care which are important services that mothers of intellectually disabled children are desperately in need of. Previous studies indicated a need for different services and interventions for mothers of children with an intellectual disability. Thus, continuous support can be from the family and also outside the family. Present studies have found that some mothers were not supported by families and friends. These services include support groups of which most mothers were involved in as it was very helpful to them. Support groups were seen to be of importance to mothers as they are able to meet with other mothers with the same challenges and experiences. Counselling and advice is more effective when taught by

somebody who has personally experienced the same. Hence, support groups comprise of people with the same experiences and challenges. They cry with the same voice and speak the same language. So, it is easy to understand and believe one another. This will help mothers to understand their children and take care of them better (Wyman, Clarke, McKenzie & Gilbert 2008:101).

Sub-Theme 4.2.2.2.4 Inadequate assistance by health care professionals at health care facilities

Health care professionals attend to various patients who may be admitted or are out-patients at the health care facilities. Among other duties they are to assist these patients irrespective of age, gender, disability or creed. In this study some mothers became dissatisfied by the services rendered by the health care professionals where the study was conducted.

This was supported by one mother who said, *“When you report something to them, they do not take it serious. It is like they are saying ‘which hope do you have for your child?’. I thought maybe when I report something to them, they will react or respond the same way as they do with other children without intellectual disability.”*

Participant L said *“Some nurses would say I will come and help you I am still busy” and never come back. Some do not even listen. It is difficult sometimes and you feel frustrated as your hope is on them.”*

Some nurses were not supportive of the mothers whose children were admitted in the ward. This was seen during feeding times wherein mothers will be called to come and feed their children. During admission of a child, mothers were hoping to be relieved by nurses during feeding times as they are well-trained to care for the intellectual disabled children.

Participant C was not happy about this practice and she said, *“Like when it is time to come and feed the child, I will be called to come and feed him or when he has messed himself up, I will be called to come and change his napkin.”*

This is what participant S experienced. *“I was referred to the psychologists for counselling and it took a month to see him because I had to wait for an appointment which was scheduled a month later. That was very bad for me because I should have undergone a counselling session immediately.”*

“Support is not good though people are not the same. Some health care professionals like nurses and doctors are good but had negative attitude.” She added by saying, *“.....I mean they do not communicate well with me, it is like they blame me. They do not have time to sit with me to know how the child is doing and just to know the challenges I am facing as a mother, what they do is to give treatments and go.”*

Participant M expressed a feeling of dissatisfaction about the health care professionals and said, *“Things did not go well at all because she was discharged prematurely from physiotherapy department. It is true she crawl and sit on time but her left hand was still in need of a great support from the specialists. May be it was going to help her and be able to use this hand because now she is using one hand and it worsens his condition. The worst painful thing is when I was told that the physiotherapist team will visit her at home every month from that time of discharge. But unfortunately until today I have not seen anyone visiting us at home. It was just a false promise.”*

She further explained that *“She was discharged when she was 4 years old and now she is 8 years nobody came to visit her and is very traumatize to me because this hand is now affecting the whole side and when I try to stretch it she cries of pain and who knows, maybe I am exercising it wrongly and now I no longer touch it and the bone on the wrist is protruding.”*

Mothers whose children were admitted in the ward verbalised always being anxious. This was aggravated by doctors and nurses who often come and discuss issues about their children without saying anything to them. This is what one mother said,

“Most of them will just come and stand next to my child without saying anything. Some will just come and seem to be very surprised and leave my room. It was like I was in a show room. I did not like their attitude. In other words, they were not supportive at

all. Doctors will also come being many and write on the child's file and go after writing. When he is fitting and I call them they do not come."

From the above quotations, it is clear that the health care professionals, especially nurses, were not involving themselves in the care of the child with an intellectual disability. Mothers felt neglected and they were on their own as if they were at home. Health care professionals are expected to give all necessary support and assistance to patients and clients. Mothers of children with an intellectual disability faced a challenge of not receiving support from health care professionals. This was seen to be a challenge as mothers were relying on them for any assistance. Mothers were ignored when reporting the condition of their children to the health care professionals, especially nurses.

After the delivery of a child with an intellectual disability, mothers need counselling if it was not done prior delivery. If counselling was done, continuous counselling is important until the mother is able to cope and is responsible enough for the care of her child. This enables mothers to see their children as a child rather than as a burden or a curse. The way in which the mother receives counselling will also determine how the child will be accepted and treated. Unfortunately, mothers had a bad experience when it comes to the counselling they were supposed to receive. The health care professionals, such as social workers and psychologists must take full responsibility to help clients and patients depending on their need.

Health care professionals displayed lack of knowledge about the health needs of people with an intellectual disability. This leads to delay in diagnosing and treatment of the patients. Inadequate discharge arrangements were done (Ward, Nicholas & Freedman 2010:284). According to Roy's theory, full and accurate assessment assist an individual to address the maladaptive behaviour and be able to stand, to take his role and function accordingly. They also displayed negative attitudes and behaviour towards children with intellectual disabilities and their mothers (Dinsmore 2012:207). Clinical decisions were not shared with mothers and this was seen to be aggravating anxiety as they cannot question those decisions. Mothers' concerns were not taken into consideration which further delayed diagnosing the child; and mothers become

reluctant to approach health services for assistance (Ali, Scior, Ratti, Strydom, King & Hassiotis 2013:1371). In a study by Mudhovozi, Maphula and Mashamba (2012:451), it was found that some participants reported that there was a lack of resources in hospitals to treat their children and owing to the shortage of professionals, programmes that were supposed to be run on a weekly basis were happening monthly only.

4.2.2.3 Theme 3. Knowledge deficit related to intellectual disability

Knowledge regarding intellectual disability is very important to parents, especially mothers. This knowledge can be obtained from different sources including media, health education from the health care facilities and from friends and relatives. Mothers who are suspected of having a child with developmental disorders or intellectual disability need counselling for them to understand the causes, symptoms, diagnosis and the prognosis of the child. It is also important to know the behaviour of an intellectually disabled child and the related care needed.

Findings of the current study were that mothers displayed different knowledge related to care, diagnosis and behaviour of an intellectually disabled child. Therefore, different reactions were expressed related to those aspects which also caused hurt feelings.

Sub-Theme 4.2.2.3.1 Lack of knowledge about origin of disability by mothers and family members

Knowledge is power for everyone. Findings of this study evidenced that mothers and family members did not understand their children. They indicated that they were not told what could have caused the disability of their children. This was verbalised by a mother:

Participant N with a Down Syndrome child who said, *“Eish, I do not understand my child and nobody is willing to give me information as to what is going on with my child. Once I am empowered with knowledge I will understand my child and be ready to go*

out and teach others who do not have that knowledge or those who have relatives with the same problem and those mothers or parents who hide their children due to some disability of any kind can be assisted.”

Participant D who was looking very sad indicated that, *“That is one thing I do not understand because my child was not like this. He was very normal. This disease just came when she was 3 months (crying) and I wonder why this is happening to me. It is so frustrating. I do not even want people to talk about my child. It breaks my heart.”*

Participant F said (laughing): I do not know, but it can be the works of the people....it can be some witchcraft...”

The parents' suspicions about witchcraft occurs when full and accurate information is not given to the parents and family as a whole. Parents and families who know the origin of disability will refer them to health care professionals to better serve them earlier with higher quality of care.

It is important for parents and family members to know the cause or origin and how to care for the child with an intellectual disability. This knowledge can reduce the fear and help parents to understand the child better.

Parents revealed that they do not have knowledge about the child and on how to care for their children. The skills and knowledge can greatly affect positive change in their lives. From the above quotation, mothers verbalised a need to know what the child is suffering from at the earliest stage of the child's diagnosis to enhance their growth and proper development.

Knowledge about the cause and originality of intellectual disability can reduce the suspicious behaviours that parents and families have. Intellectual disability is found in both the low, middle and high class countries (WHO 2011). From the African countries like South Africa, Tanzania and Uganda, intellectual disability is associated with witchcraft or spirituality and beliefs (Mathye & Eksteen 2016:591). Intellectual disability is usually diagnosed before the age of 18 years and is manifested by physical, mental, sensory and intellectual impairment.

Sub-Theme 4.2.2.3.2 Disclosure of child's disability is made known to parents by health care professionals and relatives.

Health care professionals are the most important figures to health care. Clients and patients rely mostly on them for better health. Hence, if nothing is said with sensitivity by health care professionals, it leaves parents in the dark as some are more illiterate than others. Mother I had this to say,

“It was discovered by his grandmother because the child couldn't talk and she said “the other children of his age are talking, what is wrong with your child?’ Then I said maybe he is just keeping quiet. But the child has been going to the well-baby clinic since birth. Then I took the child to the clinic and I was given a letter to go to Tshilidzini hospital (local clinic). Later on I was transferred to Polokwane hospital (Provincial hospital). But nobody was explaining to me what the problem with the child was.”

Mothers who had good relationships with their neighbours were assisted in seeking medical help. This was supported by a mother who was advised by a neighbour to take the child to the health care providers and she said,

“My neighbour came and was surprised to see my child not sitting by herself and always supported by blankets for her to sit up which was also difficult. She advised me to go to the clinic of which I did. Nurses transferred me to the hospital and she was seen by a doctor but they did not tell me anything. I was only told to come back after a month. I even went to the physiotherapy as she was not able to sit.”

From the above quotations it is clear that lack of knowledge by mothers and family members about intellectual disability can cause more harm to the patient, as parents will not see a need to seek medical help for a child who needs a thorough assessment for a diagnostic purpose.

Some mothers did not show any knowledge of how a child with an intellectual disability manifests. Mothers spend some time taking care of the child without seeking any medical assistance due to lack of knowledge and information about intellectual disability. Family members with some experience of how infants react to certain stimuli, especially the grannies who can recognize an intellectual disability in a child,

were able to assist mothers in seeking medical advice. Some neighbours were able to support mothers of children with an intellectual disability throughout their lives. Neighbours who were seen to be supportive to these mothers, brought some joy and hope to mothers as it is the support they most appreciated receiving from them. This implies that mothers feel some sense of belonging and acceptance. Hence caring and disclosure of the intellectually disabled children will be easier for them as some children are still hidden at home.

Some doctors were able to disclose the child's condition after several follow-ups whereas others were unkind to those mothers. This was confirmed by below quotations from mothers,

"I was told by the doctor who was treating my child after I have asked exactly what the problem with the child is because time and time I was told to bring the child for check-up".

"The doctor who saw my child for the first time was in human because he said he cannot give me another date to come back because the child is having a permanent disability which cannot be reversed."

The stress that mothers of children with an intellectual disability encountered, is lessened by the positive social support they receive from their kin and neighbours (Cranford 2004:25). Roy's theory is in support of social support as the interdependence mode is achieved with effective communication. In other words, the more they are supported, the less stressed they become. The stresses of having a child with a disability are greatly reduced when families have many supportive relatives living in the same community, or families with a strong network of neighbours and friends. When parents are isolated or when friends and family are uncomfortable with the child, the parents will likely experience far more difficulties.

4.2.2.4 Theme 4. Cultural beliefs and practices

Every person has the right to culture, including the right to enjoy and develop cultural life and identity. However cultural rights are not boundless. They become limited at the

point where they infringe upon other human rights. Harmful beliefs and false perceptions made matters difficult for mothers of children with intellectual disabilities as they just accept and believe in those perceptions without looking into their consequences.

Sub-theme 4.2.2.4.1 Rituals

When people are faced with difficult situations they may indulge in some form of ritualized activity rather than facing the situation just as is. Most families or mothers living with a child with an intellectual disability performed rituals as a cure for intellectual disability.

Participant F said, *“When we first realise that he`s not like other kids, we did a ceremony, bought a goat, killed it and cook the intestines first and feed him the soup, but it didn`t work, we thought that it will work because we`ve never had a child in this family like this one.”*

Participant Q said, *“We went to the river with my mother-in-law, my child, and my husband before he divorced me. My husband and I got into the river and wash our faces, hands and feet, we then took our child and wash the whole body in the river and then gave her water from the river to drink, but nothing changed even today.”*

The mothers in this study, showed to perform rituals in every manner they could, but no good came out of it, as they`ve said, *“it didn`t work and nothing changed even today”*.

Rituals can be in the form of killing, burning, eating, dancing, or use of special dresses. This study found that most parents refuse to believe that there`s no cure for this condition when they are told, that is where performing rituals arose. This means that their culture influences them as most of them believe in traditional practices.

Culture influences how people live and behave. All the beliefs, religion, social habits, languages, may have influence on children with intellectual disabilities. Although all

societies have a cultural heritage which transmitted from one generation to the next, the particular style varies from one to another. Where contrast is marked, it is possible to speak of different cultures (Milbank 2005:2). Van Niekerk (2012:105) states that the fact that a large proportion of the population believes in and follows traditional cultural activities confirms that they are a much-valued component of people's life experiences. They are part of people's significant truths that occupy the brain's limbic system where our fears, feelings, and beliefs are situated. Cultural healers share powerful influences on the way in which humans are primed by nature or nurtured to respond. Hence religions and cultural beliefs may also share rituals that are similar (Van Niekerk 2012:105).

Sub- theme 4.2.2.4.2 Traditional healers

Traditional healers or doctors are highly respected in our African countries. They are believed to be people who know everything and can predict the future of people. Whatever they say is not supposed to be challenged by anyone. Any misfortune in the family is believed to can be handled by the traditional doctors. This was evidenced by the following participants who said:

Participant F said, *"The way my child was, made me to go for traditional advices, to know what might be the possible cause of this condition. Some people also influenced me saying that if you go to so and so, your child will be fine and no longer have this problem. Because I so wanted my child to be relieved from this condition, I was forced to go there but that was before I was born again Christian. After accepting God, I turned up my mind to say that God is the only one to put my trust on. I spend a lot money going to the traditional healers but realized I was wasting my time and money."*

Participant D said, *"Yes, when we found out about the condition my grandmothers took the baby to traditional healers believing that my child was bewitched and we tried to give medication from the tradition healer for many years but the condition was not corrected."*

Participant H supported by saying, *“When we realized that the child is different from the other children, we tried traditional healers thinking that maybe he will be okay, we spend a lot of money on traditional healers but nothing came out of it, we then decided to accept the child as he is.”*

In this study, mothers show that their first action was to consult traditional healers to cure intellectual disability, and none of them seemed to have worked for them. Van Niekerk (2012:105), concurs with the current study and emphasized that traditional healers are the first to be called upon for help by the majority of Africans when illness strikes.

Methods used by traditional healers include the use of roots, fetish dolls, voodoo dolls, and the smoking out of a possessing spirit or spell. Van Niekerk (2012:105) states that traditional healers are the first to be called for help when illness strikes by the majority of South Africans. Their communities have faith in their ability to cure or alleviate conditions managed by doctors, and much more. When visiting them, they promise help, providing more power, love, security or money, protection from evil people and spirits.

This study found that, mothers who are living with intellectually disabled children focused more on traditional healers or sangomas, or are mostly intrigued to consult on sangomas but coming out with no good results. They get the message through verbal evidence instead of seeing the results of their work. Traditional health care systems are used in cases where the medical problems are believed to require the attention of a traditional healer. Studies conducted in Nairobi show that traditional healers receive a high number of patients with priority mental illnesses, particularly depression (Mbwayo, Ndetei, Mutiso & Khasakhala 2013:136). This was because the traditional healers were believed to be providing holistic care that involves social and psychological integration with the community (Mhame, Busia & Kasilo 2010).

People mostly in our African countries believe in traditional healers for their sicknesses. In some parts of Africa, like Ghana, patients who visit a traditional healer, delay their visits to a mental health unit. Traditional healers' knowledge on recognition of common mental illnesses is imperative for early intervention and referral, hence improper training and support. (Kurihara, Kato, Reverger & Tirta 2006:1441). Study

conducted in South Africa on the treatment of mental disorders found that the consultation time for traditional healers was longer than those of the health care professionals. Sorsdahl, Stein, Grimsrud, Seedat, Flisher, Williams & Myer 2009:436), indicate that traditional healers had more time to talk with the patients during consultation than the health care professionals. This means that the health care professionals, unlike the traditional healers are not putting more effort to their patients during assessment and consultation. Hence they are missing some important information for a proper diagnosis. Lack of knowledge, training and skills are the most contributing factors.

Traditional medicine may be codified, regulated, taught openly and practiced widely and systematically, and benefit from thousands of years of experience (WHO 2002). Conversely, it may be highly secretive, mystical, and extremely localized, with knowledge of its practices passed on orally.

Sub-theme 4.2.2.4.3 Believing in God

In South Africa, major religions such as Christianity, Hinduism, Judaism and Islamic religion are not regulated by the government councils. People have freedom of religion. Unfortunately the government only reacts to the effects of these religions when the unexpected happens to certain individuals in the community. This is evidenced by the current situations wherein people are instructed to eat snakes , drinking petrol and being sprayed by dangerous chemicals under the pretext that they would receive divine healing.

In this study, there were mothers who believed in God. They kept on praying to God as they believe that God is in charge of every human life. Most mothers were in denial after realising that their children are intellectually disabled. Their religious influence helped them to cope, accept and understand their children's disability. This was confirmed by the participants who verbalised by saying: Participant E said: *"We as a family, went to church to pray, even today we never stop praying, we never didn't go*

to witch doctors or performing any rituals because we believe that if God wanted it to happen this way, no human being can change that.”

Participant H said: *“As for my belief, there is nothing we do for this child as a family, we prefer going to hospital seeking for medication. But on my first child who passed away we took her to church tried to pray for her but I finally realized that this was God’s doing and cannot be corrected by anybody. So, to this child it was no longer a surprise.”*

Participant P said: *“...there are none that I know of. All I do is to go for physicians and keep praying to God and thank him for this situation, because if it didn’t happen to me, to whom was it supposed to happen?”*

Mothers show to be having faith in God as they never stop praying to God believing that one day he will make changes, as the participant K said, *“we went to church to pray, even today we never stop praying”* which emphasized that they never stopped praying, only because they believe in God.

Although all societies have a cultural heritage which transmitted from one generation to the next, the particular style varies from one to another. Where contrast is marked, it is possible to speak of different cultures. Van Niekerk (2012:105), states that the fact that a large proportion of the population believes in and follows traditional cultural activities confirms that they are a much-valued component of people’s life experiences. They are part of people’s significant truths that occupy the brain’s limbic system where our fears, feelings, and beliefs are situated. Faith in religions or cultural healers shares powerful influences on the way in which humans are primed by nature or nurtured to respond, religions and cultural beliefs may also share rituals that are similar (Van Niekerk 2012:105).

4.2.2.5 Summary

In this chapter, the challenges faced by mothers of children with intellectual disability were presented, analysed, interpreted and discussed. The researcher used the results from phase 1a to design a research tool for conducting phase 1b with health care professionals from different hospitals where the research study was conducted.

4.3 PHASE 1b: QUANTITATIVE STUDY

RESULTS AND DISCUSSION OF QUANTITATIVE DATA

This part of chapter 4 presents the results of the quantitative study under the following headings: Section 1: A socio-demographic data; Section 2: Views of health care professionals on supportive care to mothers of children with an intellectual disability; Section 3: Supportive care services available to mothers of children with intellectual disabilities. The purpose of this section was to present the information obtained from the quantitative aspects of the questionnaires. This was interpreted and discussed as guided by the objectives of the study as well as support of mothers of children with an intellectual disability.

The questionnaire used to collect quantitative data was developed and administered by the researcher. The researcher visited 14 hospitals in Vhembe district (7) and Mopani district (7). Challenges were met in two hospitals of Mopani district i.e. Maphutha Malatji and Van Velden hospitals as participants were not cooperating. In other hospitals participants were cooperating, except for the doctors who were usually not ready to complete questionnaires due to the shortage of staff. This happens despite several appointments made with them. In this study, 258 questionnaires were initially distributed to potential respondents to complete with the promise of coming back to collect on a certain agreed date and venue. The researcher checked each questionnaire for completeness and accuracy. Out of 258 questionnaire forms issued to the respondents, only 200 were duly completed and accurate. Respondents whose data were collected, analysed and interpreted gave a total of 74%. Only 20 questionnaires were incomplete and inaccurate and were spoiled, 30 were not returned at all for reasons not known by the researcher as it was not the focus of the study. The response rate was 77% and non-response rate was 23%.

4.3.1 SECTION 1: SOCIO-DEMOGRAPHIC DATA

The personal profile of the respondents reported in this section was based on information obtained from section A of the questionnaires. This includes age, occupation and working experience.

4.3.1.1 Age

Figure 4 shows the demographic distribution of the participants. Of the 200 respondents, 57.5% were above 35 years and 42.5% were below 35 years with the 11% minority of less than 25 years of age. This shows that many employees were from the active working population and mature enough to understand nursing and how to interact with the patients.

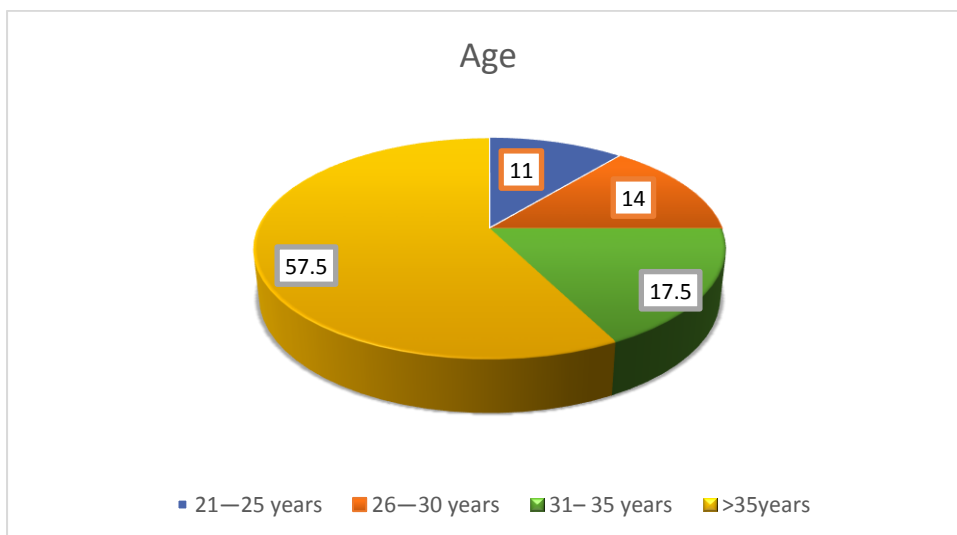


Figure 4: Pie chart to represent Age groups (n=200)

4.3.1.2 Occupation

The distribution according to the occupation (Figure 5) shows that 67% were nurses, 1% doctors, 17% physiotherapists, 13% occupational therapists and 2% psychologists. Nurses were in a majority and were females whereas doctors were in a minority of 1%, hence a shortage of doctors in the medical field. Male nurses were in a minority since the beginning of nursing. This is due to the fact that nursing was pre-dominantly a women’s profession in the earlier years.

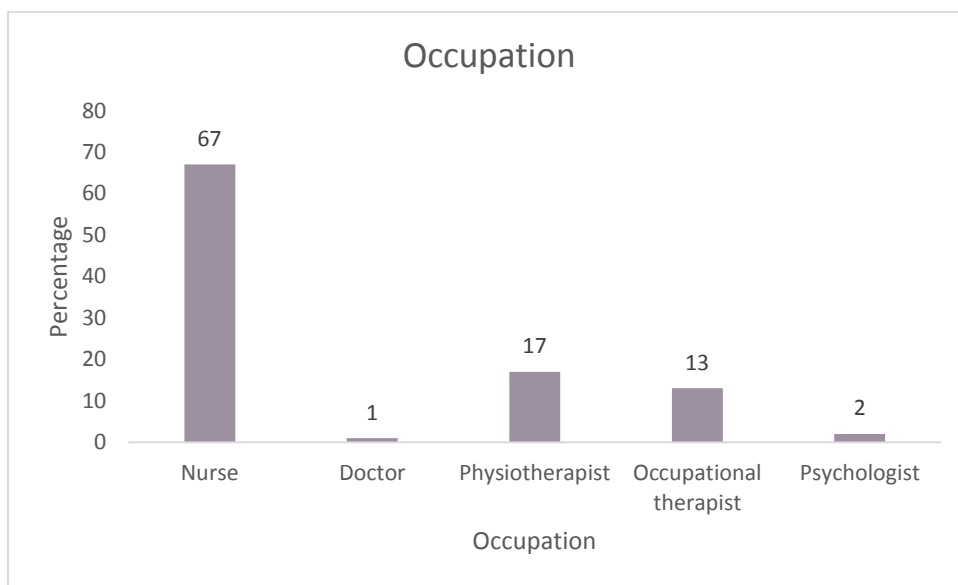


Figure 5: Bar chart representing occupation

4.3.1.3 Number of years working with intellectually disabled children

Table 7 of this study below, shows that 32% of the respondents had more than 10 years’ experience of working with intellectually disabled children whereas 28.5% had less than 3 years’ experience. The working experience distribution of the respondents was as follows: working experience less than 3 years was 28.5%, working experience less than 5 years was 20.5% and working experience less than 10 years was 18.0%.

Little or no experience by the health care professionals had a negative impact on mothers as they lacked continuous support they deserved from them. This means that the institutions management must consider spending their time and money in preventing service failures by training and developing the staff. The more the health care professionals become competent and self-assured, the more committed they are to the institution and the patients becomes happy and satisfied (Booyens 2008:211).

Table 7: No. of years working with intellectual disability children (working experience)

		Frequency	Percent	Valid Percent
Valid	0-3	57	28.5	28.8
	4-5	41	20.5	20.7
	6-10	36	18.0	18.2
	>10	64	32.0	32.3
Total		200	100.0	

4.3.1.4 Distribution of the participants by age and the number of years working with intellectual disability children

Table 8: Cross tabulation for the relationship between age and the number of years working with intellectual disability children

Count

		No of years working with intellectually disabled children				Total
		0-3	4-5	6-10	>10	
age	21—25 years	18	2	2	0	22
	26—30 years	14	11	3	0	28
	31– 35 years	6	9	8	12	35
	>35years	19	19	23	52	113
Total		57	41	36	64	198

Table 9: Chi-Square Tests relationship between age and the number of years working with intellectual disability children

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	65.828 ^a	9	.000
Likelihood Ratio	74.246	9	.000
Linear-by-Linear Association	50.934	1	.000
N of Valid Cases	198		

a. 2 cells (12.5%) have expected count less than 5. The minimum expected count is 4.00.

Tables 8 and 9 above represent the results with regards to age and the number of years working with intellectual disability children or the working experience. Majority

of participants were above 35 year of age with more than 10 years of working experience. The responses were also cross-tabulated. $P=0.000$ and since $P<0.05$, therefore the null hypothesis was rejected and the conclusion was made that the age and the working experience are not independent. There is an association or relationship between the two variables.

4.3.1.5 Age of children with intellectual disability

Most of children with an intellectual disability who were in the majority were of 6-9 years of age (70.9%) and 12.1% were above 12 years (Table 10). From the qualitative findings of this study, mothers revealed that the more the child is growing, the more the pain and therefore continuous support is needed.

Table 10: Age of most of the children with intellectual disabilities

Age of children		Frequency (n)	Percentage (%)
Valid	6- 9 years	134	70.9
	10-12 years	36	19.0
	>12 years	19	10.1
	Total	189	100.0

4.3.1.6 Occupation of mothers

The results of this study from the respondents revealed that more than 80% of mothers of children with ID were not employed whereas less than 14% were employed. Most of them encountered financial constraints as their children demand a lot and there is no other means of financial support. Some mothers miss medical appointments due

to lack of money despite the fact that their children are getting a disability grant. When mothers fail to adhere to the child's appointment, the child suffers the consequences. So, some children were found not to be getting the grant as expected and moreover, parents are not working or are getting too little to survive on. The educational level of mothers of children with an intellectual disability were secondary education being 74.0% and tertiary education of 2.5%, of which 81.5% were not employed, 13% were employed and 2% self-employed. The findings from a qualitative study indicated that majority of mothers with intellectual disability children experienced a financial burden which concurs with the quantitative study as more than 80% of mothers were not working. Below is the bar graph to indicate their occupation rate as discussed above.

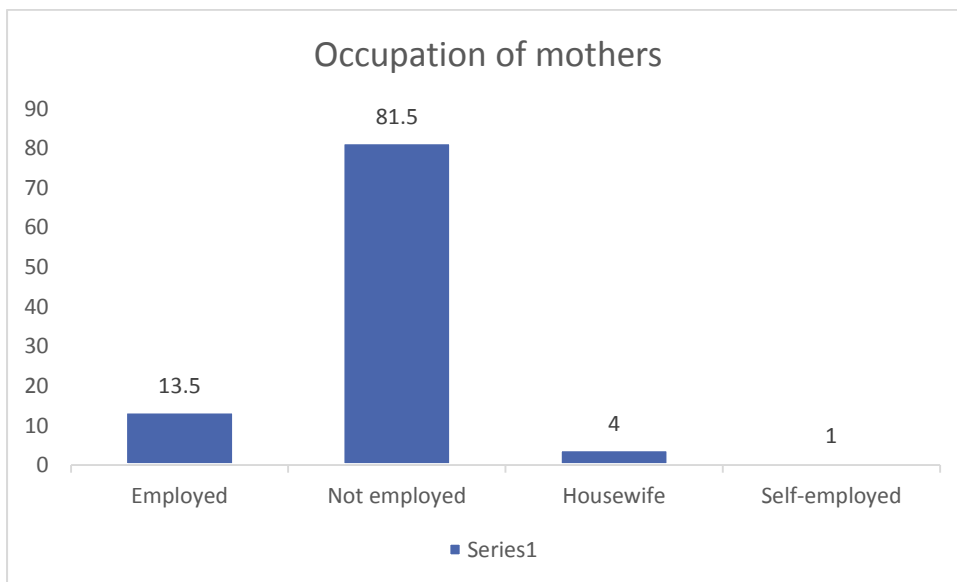


Figure 6: bar graph to represent occupation of mothers

4.3.1.7 Child's main type of disability

The health care professionals revealed that the main type of disability they mostly see and attend to in their health care facilities were in the majority of Down Syndrome 75(38.3%), followed by Epilepsy 49(25.0%) and Cerebral palsy 66(33.7%) as shown in Figure 7. ADHD and profound intellectual disability were in the minority according to the health care professionals' report. However, the majority of mothers interviewed

had children with Down syndrome followed by ADHD, CP, Epilepsy and Profound type of disability. Previous studies indicated that the most common syndromes associated with disability is Autism, Down Syndrome, Fragile X syndrome and Fetal Alcohol Spectrum Disorders (FASD).

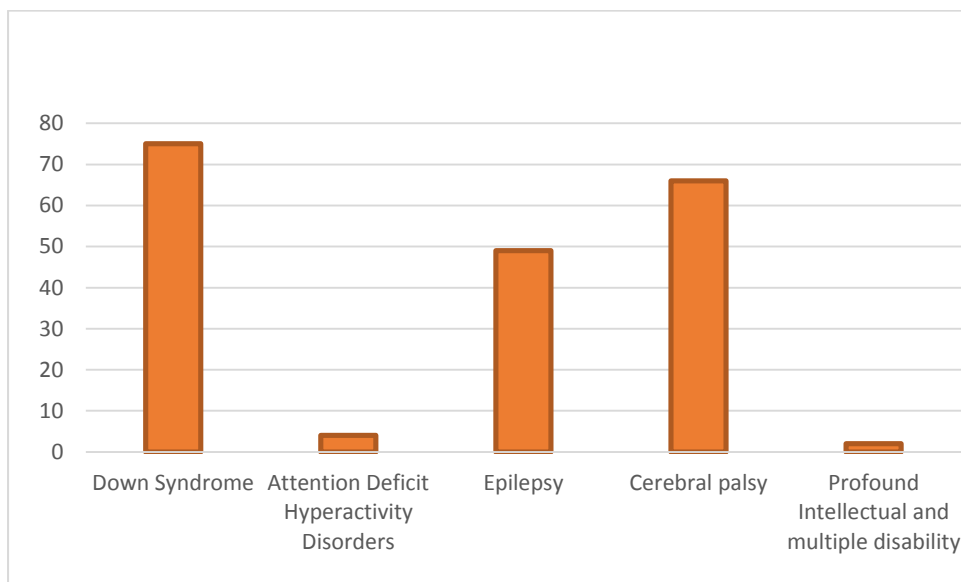


Figure 7: Bar graph to represent child's main disability

SECTION 2: VIEWS OF HEALTH CARE PROFESSIONALS

4.3.2. Introduction

In this study, questions were asked to determine the views of health care professionals on supportive care to mothers of children with an intellectual disability. This was done in two districts of Limpopo Province (Vhembe and Mopani Districts' hospitals).

4.3.2.1 Mothers of children with ID's need continuous support from the health care professionals

Respondents were asked a question to determine if there is a need for continuous support to mothers of children with intellectual disabilities. Health care professionals

indicated that there is a need for them to support mothers of children with intellectual disabilities continuously as shown in Table 11. They strongly agree with 113(60.4%) and agree with 67(35.8%). They also indicated that they experienced some distress from the parents due to lack of support. This means that there was poor communication as mothers were frustrated and do not know what to do. This concurs with the findings from the qualitative results wherein the participants indicated that there was no support and clear communication from the health care professionals. This was expressed by one mother from the qualitative results who said, “*Most of them will come and stand next to my child without saying anything. Some will come and seem to be very surprised and leave my room. It was like I was in a show room. I did not like their attitude. In other words, they were not supportive at all. Doctor will also come being many and write on the child’s file and go after writing.*”

This shows that there is a gap of communication between mothers and health care professionals. Improper communication hinders the child’s progress as mothers were anxious about the child’s condition and they could not provide proper care to their children. This was triggered by lack of knowledge displayed by mothers. Lack of continuous support by the health care professionals created an unpleasant environment for mothers as they did not know what is going on with their children.

Table 11: Need for support from the health care professionals

		Frequency (n)	Percentage (%)
Valid	Strongly disagree	2	1.1
	Disagree	5	2.7
	Agree	67	35.8
	Strongly agree	113	60.4
	Total	187	100

4.3.2.2 Training of more professionals who can properly deal with parents' mental health needs is important

The findings of this study as indicated in Table 12, shows that there is a need to train more professionals since there is a shortage of staff. The qualitative findings of this study also revealed the need for more professionals to be trained. This was confirmed by one mother who indicated that it took her a month to see a psychologist since there were many patients waiting on the list to see the psychologist. This study findings concur with the study done by Mathibe, Hendricks and Bergh (2015:5), who indicated that shortage of staff is related with difficulties in providing quality services. These services include full examination or assessment to exclude any abnormalities, which can be through proper history information. It is important to assess the parent's mental health needs to see if she is coping or not. If the mental status of a mother is disturbed, it will also affect the child in a negative way. Hence continuous support is needed.

Table 12: Represents the need for training of more professionals

		Frequency (n)	Percentage (%)
Valid	Strongly disagree	5	2.5
	Disagree	4	2.0
	Agree	64	32.3
	Strongly agree	125	63.1
	Total	198	100.0

4.3.2.3 Specialists especially psychologists are in demand to continuously support the mental health needs of both children and the mothers

Children with intellectual disabilities need a multidisciplinary team to review them. This is because they face more challenges than any other type of disability. Table 13 below

indicated that 73(36.5%) respondents agreed whereas 115(57.5%) strongly agreed that psychologists are in demand to support the mental health needs of both parents and the children. Rodriguez, Cavaleri, Bannon & McKay 2008:907, showed similar results with the findings of this study, which revealed that engaging children and their family is an important factor to families of children with intellectual disabilities. Many families discontinue the therapy due to time on a waiting list, expectation for therapy and the belief about the therapeutic processes which seem not to be helpful to them (Gopalan, Goldstein, Klingenstein, Sicher, Blake & McKay 2010:185). Ongoing counselling and continuous support by the psychologist plays a vital role in the mental health of a mother, including the family. Engaging families in mental health treatment remains a serious challenge despite ongoing advances in evidence-based treatments.

Table 13: Represents the need for psychologists to support mothers

		Frequency (n)	Percentage (%)
Valid	Strongly disagree	6	3.0
	Disagree	5	2.5
	Agree	73	36.7
	Strongly agree	115	57.8
	Total	199	100.0

4.3.2.4 Mothers of children with intellectual disability are at an increased risk of parental stress and psychological distress.

Table 14 below illustrates the respondent's findings of mothers who are at an increased risk for parental stress and psychological distress. Ninety(45.0 %) of the respondents agree and 98(49.0%) strongly agree that mothers are at an increased risk of parenting stress and psychological distress. The qualitative findings of this

study revealed that most mothers were stressed about the condition of their children as they were not expecting to have a child with any type of disability. Sources of stress also include the behaviour and daily living skills of the child. Findings of this study concur with the study done by Schieve, Boulet, Kogan, Yeargin-Allsopp, Boyle, Visser, Blumberg and Rice (2011:143) on the issue that parents of children with ASD and developmental delays (DD) demonstrated an increased parenting-related stress compared to parents of typically developing children. Continuous support is needed in order to improve a child's functioning and decrease parenting-related stress as they are faced with numerous potential challenges. The study further indicated that parents of younger children experience higher levels of stress than parents of older children with an intellectual disability. This suggests that parents' stress and psychological distress in the toddler years may set the stage for later parent adjustment and be a critical period for parents of children with intellectual disabilities (Carter, Martínez-Pedraza & Gray 2009:1271).

Table 14: Increased risk for parental stress and psychological distress

		Frequency (n)	Percentage (%)
Valid	Strongly disagree	5	2.5
	Disagree	6	3.0
	Agree	90	45.2
	Strongly agree	98	49.2
	Total	199	100.0

4.3.2.5 Mothers' participation in family support groups

Table 15 below illustrates mothers' participation in family support groups. 71(35.5) of the respondents agree whereas 26(13.0) strongly agree that mothers are participating in family support groups. These findings are in contrary to the qualitative findings as

most mothers verbalised that they need support groups to be initiated for them. Meaning that they are not participating and never heard about it. It is the responsibility of the health care professionals such as occupational therapists and nurses to encourage support groups (Wyman, Clarke, McKenzie & Gilbert 2008:101).

Table 15: Need for support groups

		Frequency (n)	Percentage (%)
Valid	Strongly disagree	26	13.5
	Disagree	65	33.7
	Agree	71	36.8
	Strongly agree	31	16.1
	Total	193	100.0

4.3.2.6 The ratio of nurses to patient is inadequate

Respondents were asked questions on whether the ratio of nurses to patient is adequate or not. Table 16 below indicated that about 63(31.5) of the respondents strongly agree whereas 74(37.0) agree that the ratio of nurses to patient is inadequate. This means that there are too few nurses at the hospitals as compared to the total number of children admitted and those coming for follow-up visits at the hospital. This contributes to mismanagement of children and misdiagnoses during assessment as a result of fatigue and overworking. Hence, this practice adds more discomfort to their mothers as they do not know what the real problems with their children are. In most health facilities, children with intellectual disabilities are admitted with their mothers despite their age so that they can take care of them. This is due to the shortage of staff as children with intellectual disabilities need more attention than those without a

disability. Booyens (2008:211), highlighted that the health care facility is challenged to provide the type of quality care expected by the patients or clients due to the number of nursing and other health care staff to the expected workload. Hence health care services become a public concern Mothers on the other hand were seen not to be happy about that as to them, it was a relief when the child is admitted. These findings concur with the findings from the qualitative findings of this study as mothers revealed that they were not happy when they were called to change the child's napkin or to feed him, as they were relying on nurses for assistance and for them to be relieved by experienced personnel. Unavailability of qualified, skilled, competent and knowledgeable health care professionals contributes to work overload, fatigue, mismanagement of patients and death (Clarke & Donaldson 2008:95). Proper staffing protects both the public and the nursing profession as quality care will be provided and there will be no litigation against the health care professionals.

Table 16: Ratio of nurses to patient

		Frequency (n)	Percentage (%)
Valid	Strongly disagree	15	8.0
	Disagree	36	19.1
	Agree	74	39.4
	Strongly agree	63	33.5
	Total	188	100

4.3.2.7 Distribution of the participants by district and the ratio of nurses to patient

Table 17: Cross tabulation of the participants by district and the ratio of nurses to patient

Count

		The ratio of nurses to patient is inadequate				Total
		Strongly disagree	disagree	Agree	Strongly agree	
District	Vhembe	10	21	48	38	117
	Mopani	5	15	26	25	71
Total		15	36	74	63	188

Table 18: Chi-Square Tests of the participants by district and the ratio of nurses to patient

	Value	Df	Asymptotic Significance (2-sided)
Pearson Chi-Square	.675 ^a	3	.879
Likelihood Ratio	.676	3	.879
Linear-by-Linear Association	.034	1	.853
N of Valid Cases	188		

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 5.66.

Table 17 and 18 above represent the results of the two districts and the ratio of nurses to patient. The respondents who strongly agree that the ratio of nurses to patient is inadequate were from Vhembe district. The response were cross-tabulated. $P=0.899$

and since is $P > 0.05$, therefore the null hypothesis was not rejected. The results indicated that the two variables are independent. There is no association or relationship between the two variables.

4.3.2.8 Professionals' views on cultural practices and beliefs for mothers of children with ID

The findings of this study indicated that professionals' assessment on cultural practices and beliefs of mothers of children with ID during consultation, revealed that 56(28.1%) strongly agree in supernatural causes of disability such as witchcraft of which 31(66.1%) agree that disability is a curse from ancestors as depicted in Table 19.

Notably, 88(44.9%) of the professionals' assessments strongly disagree that a disabled child must be killed and offered to the ancestors. 24(12.0%) agree and 7(12.6%) strongly agree that a disabled child must be killed and offered to the ancestors, making a total of 31(15.6%). Field studies done in Cameroon, Ethiopia, Senegal, Uganda and Zambia, reports that common beliefs about the causes of childhood disability include an ancestral curse or demonic possession (African Child Policy Forum (ACPF), 2011). There are a number of factors that can contribute to the formation of negative beliefs about disability, including lack of understanding and awareness of disability and reinforcement of prejudice and fears through law and policies that may affirm harmful beliefs about disability. Negative beliefs are detrimental to the health care of intellectually disabled children because at first, parents do not view seeking medical help as important to them. They only consider medical advice when they fail to get help from their sangomas or traditional healers. It is the duty of health care professionals to overcome such challenges (Wegner & Rhoda 2015:128).

Table 19: Professional views on cultural beliefs and practices

Professional assessment on cultural practices and beliefs of MOCWD	SD	D	A	SA	TOTAL
Believe in supernatural causes of disability such as witchcraft	34 17	25 12.6	84 42.2	56 28.1	199
Believe that disability is punishment from God	46 23.2	69 34.5	57 28.8	26 13.1	198
Believe that disability is a curse from ancestors	48 24.4	64 32.5	57 28.9	28 14.2	197
Believe that a disabled child must be killed and offered to the ancestors	88 44.9	77 38.5	24 12.0	7 3.6	196
Believe that disability is caused by disobedience of ancestors	64 33.5	67 35.1	46 24.1	14 7.3%	191

4.3.2.9 Health care professionals' need to know and understand the cultural beliefs and practices of mothers

Culture plays an important role in disabilities in the community and the country at large as people are expected to behave according to what their culture expects of them. Table 20 shows that 92(46.0%) agree whereas 95(47.5%) strongly agree that health care professionals need to know and understand the cultural beliefs and practices of mothers of children with intellectual disability. Knowing the culture and beliefs of mothers will help the professionals to assist mothers on how to overcome the consequences of harmful beliefs regarding disability. Lack of community support was also reported to be a challenge in qualitative study as pointed out by one of the participants who said, "We went to Sangoma and they said somebody who died long ago is complaining through her and some rituals need to be performed". The health care professionals must be able to guide mothers in a professional way because children with intellectual disabilities also have the right to education for them to learn, based on their capacity to learn. Beliefs also vary based on how the disability was acquired whether a person was born with a disability or was acquired later in life e.g.

by accident. Socio-economic issues can also affect attitudes of disability, such as those from economically disadvantaged background may face more stigma than those from a wealthier background. Every person has the right to culture but culture cannot be utilised to justify torture, murder, discrimination and any fundamental freedom established in international law. This study's findings are similar to the study conducted in Cameroon, Ethiopia, Senegal, Uganda and Zambia by Eskay, Onu, Igbo, Obiyo & Ugwuanyi (2012:475), which disclosed that children with intellectual disabilities are not allowed to attend school due to some misguided belief. This had a negative impact as children are deprived of their rights. Therefore it is important that mothers are supported in this regard and are shown what can benefit their children (Wegner & Rhoda 2015:128).

Table 20: Need for health care professionals to know cultural beliefs and practices of mothers

		Frequency (n)	Percentage (%)
Valid	Strongly disagree	2	1.0
	Disagree	9	4.5
	Agree	92	46.5
	Strongly agree	95	48.0
	Total	198	100.0

4.3.2.10 Supportive care services available to mothers of children with intellectual disabilities

Table 21 below illustrates the services available to support mothers of children with intellectual disabilities. Respondents revealed that there is an effective collaboration with other organisations to support mothers of such children. This includes those who provide resources, services and support. They agreed by 108 (57.1%) and disagree by 81(42.9%). Other services that the respondents indicated are available includes: home support, speech and language therapy, occupational therapy visits,

paediatrician, social work visits, nutrition services and psychiatric services. The respondents indicated by 94(51.6%) that there is no respite care service or short-term break whereas 88(48.4%) indicated that there are respite care services. Respite care services are ways of relieving the family caregivers of their daily responsibility of caring for a sick person. mothers of children with ID also need some time off to relax or take care of other responsibilities, then it becomes helpful to them. Respite care services can be once a week, thrice a week or fortnightly depending on the need of your loved ones. The mother or a caregiver would then get time to rest or attend to certain other appointments she could not do without this type of service. The findings of this study also revealed in the table below by 98(49.0%) that child minding is not available in Limpopo Province. Child minding was seen to be essential as most mothers who are employed reported having a challenge of not finding a reliable person to take care of their children. Lack of services like community support, educational, psychological visits including advocacy and legal support depresses the mother as these services might change the mindset of affected mothers. Services that are said to be available to the mothers by the respondents, are not utilised due to lack of awareness. In Limpopo Province, there is a lack of support services to mothers of children with an intellectual disability as most services are directed to children and not to the mothers (Adnams 2010:439).

Table 21. Services available to support mothers

Professional/service support	YES	NO	TOTAL
There is effective collaboration with other organisations	108 57.1	81 42.9	189
Home support	139 73.9	49 26.1	188
Respite care/short-term break	88 48.4	94 51.6	182
Speech and language therapy	164 87.7	23 12.3	187
Occupational therapist visit	169 90.4	18 9.6	187
Social worker visits	170 93.4	12 6.6	182
Clinical psychologist visits	139 75.1	46 24.9	185
Paeditrician	101 54.9	83 41.5	184

Child minding	86 46.7	98 49.0	184
Holiday provision	57 31.5	124 68.5	181
Psychiatrist	93 50.8	90 49.2	183
Befriending scheme	56 31.5	122 68.5	178
Community support	89 49.7	90 50.3	179
Family therapy and support groups	106 58.2	76 41.8	182
Advocacy and legal support	79 43.9	101 56.1	180
Nutrition services	146 81.1	34 18.9	180
Home-based nursing	129 72.1	50 27.9	179

4.4 Summary

From the findings of this study, health care professionals evidenced that mothers of children with intellectual disability are not getting enough support from relatives, friends, neighbours and the community as a whole, including a multidisciplinary team due to insufficient staff, particularly in terms of staff training, lack of family support groups and unavailability of important supportive care services. Furthermore, about 28.5% of health care professionals had less than 3 years experience working in a paediatric unit. When mothers are not well supported, children suffer as they become the victims of frustrations.

CHAPTER 5

CONCEPT ANALYSIS AND MODEL DEVELOPMENT

5.1 INTRODUCTION

Based on the reviewed literatures (Chapter 2) and methodologies that followed, chapter three, chapter four presented data analysis about the need for continuous support for mothers of children with intellectual disabilities. Chapter five analysis the concept based on the data collected. The empirical perspectives of the study laid the foundation for this chapter and led to the syntheses and identification of the core theme. The findings of this study revealed that most of the mothers with intellectual disability children were lacking support from their families, friends, relatives and community including the health care professionals. Those who seemed to be getting support was not adequate according to them as they still meet challenges on daily basis in their lives. The core theme known as CONTINUOUS SUPPORT was identified by the researcher. Concept analysis of continuous support was conducted using Walker and Avant (1995:39) in order to analyse and generate descriptions, definitions and further explored the meaning of this concept in the context of the support of mothers of children with an intellectual disability. The concept analysis together with the empirical perspective of the study and six aspects of Dickoff, James and Wiedenbach (1968:422), facilitated the development of a model to continuously support mothers of children with an intellectual disability in Vhembe and Mopani District of Limpopo Province, South Africa.

5.2 CONCEPT ANALYSIS

Conceptual analysis is used to identify concepts in the data and to clarify, define, give meaning and make sense of concepts and relationship between them within a specific context (Garcia-Dia, DiNapoli, Garcia-Ona, Jakubowski & O'Flaherty 2013:266). The

researcher explored continuous support in relation to the supportive care needs of mothers with intellectually disabled children. The purpose of concept analysis was to distinguish between the defining attributes of continuous support and its relevant structure and is used to clarify overuse of a vague concept. In this study, the concept continuous support was clarified; this concept was selected and evaluated using the analysis method described by Walker and Avant (2005:80).

5.3 METHOD OF CONCEPT ANALYSIS

The method for concept analysis to describe the meaning of continuous support to mothers of children with intellectual disability was done using Walker and Avant's method of concept analysis. This method has the following steps:

- Step 1: Select the concept of interest
- Step 2: Determine the aims or purpose of the analysis
- Step 3: Identify all uses of the concept
- Step 4: Determine the defining attributes
- Step 5: Identify cases studies: model cases, borderline cases, illegitimate cases
- Step 6: Identify antecedents and consequences
- Step 7: Define empirical references

5.3.1 Select the concept of interest

Identification or selection of concept is the first step of concept analysis. It is the way of choosing the concept that best describes the participant's experiences and challenges from the study findings (Walker & Avant 2011:76). Selection of the concept communicates the idea that the researcher wishes to convey in the model. The concept should be useful and related to the model to be developed (Walker & Avant 2005:64). Continuous support was selected as the area of great interest in mothers of children with intellectual disabilities. This was based on the objective of the study as well as the needs of their children as a conceptual framework of the study. Continuous

support is necessary to assist mothers of children with an intellectual disability to cope. The current knowledge about continuous support of mothers with a child with an intellectual disability, are: availability of sufficient and well trained staff, family and social (community) support, self-efficacy, organisational support and collaboration.

5.3.1.1 Definition of concept “CONTINUOUS SUPPORT”

The *Webster English Dictionary 2010*, defined “continuous” as going on without being interrupted or break; unbroken; connected. *Continuous* is stronger than *continual*. It denotes that the continuity or union of parts is absolute and uninterrupted, as in a *continuous sheet* of ice. The concept “continuous” is also described as “continuous verb groups” that is used especially when you are focusing on a particular moment. Continuous support is achieved through encouragement, making it easier to face the future and adapt to sometimes difficult circumstances. The word continuous can also mean “endless, limitless, unbroken, without end, boundless”. It can also mean “permanent, eternal, undeviating, stable, constant, and unending”; and incessant, non-stop, interminable, never ending, everlasting, ceaseless”; also “perpetual, interrupted, undying, enduring and long lasting”.

5.3.1.2 Definition of concept “SUPPORT”

Support can mean “provision, care, financial assistance, maintenance, upkeep”. It can mean “backing, strengthen, encouragement, aid, co-operation, collaboration, to boost, to increase, enhancement, uplift, to motivate”. Support can mean “enabling someone to last out, give strength to, encourage”; also “to prop, scaffold, underpinning, pillar, buttress, foundation, base; as well as “reinforcement, maintain, sustain, to bear, tolerate, carry, advocate for, stand up for”; “give help or countenance to, speak in favour of or be actively interested in”. Support can be assisting a person by one’s presence, giving moral or psychological support (Merriam-Webster Dictionary, 2011); as well as “furtherance, persistence, prolongation, continuance”.

Taylor, Welch, Kim & Sherman (2007:824) describe support as an array of social exchanges which involves encountering support, recognizing support and a feeling of being supported. Support can also be defined as the total level of assistance or any services given (Cummings, 1996:86).

Macmillan Dictionary 2013, highlighted the distinct meaning of support as:

- ❖ Help someone and be kind to them when they are having a difficult time/situation;
- ❖ Help someone to become successful or to improve;
- ❖ Stop someone from falling/failing;
- ❖ Be able to deal with something; and
- ❖ Make the best out of something.

In the context of midwifery during childbirth, continuous support refers to the presence of a competent, skilled and expert midwife throughout labour. The results of this support shows solid evidence that these women experience shorter labour and tend to deliver normally. It also involves the availability of a preferred family member for support.

Support may also mean reinforcing the building using pillars during construction. From the above definitions “continuous support” is defined as the availability of someone to help somebody to become successful or to improve without being interrupted. Mothers of children with intellectual disability are desperately in need of such support as they feel embarrassed, isolated, discouraged and stigmatised. They also need competent and skilled health care professionals who through their skills, will be able to positively help them to use conscious awareness to create human and environmental integration for them to adapt.

5.3.2. Determine the aims or purpose of the analysis

The aim of the analysis was to clarify the meaning of continuous support to mothers of children with an intellectual disability as well as to develop its’ operational definition. Continuous support is an acknowledged phenomenon that draws the attention of the

researcher; however, a clear and universal definition is lacking. The purpose of this concept analysis was to clarify the phenomenon of continuous support and to provide a universal conceptual and operational definition for researchers and health care professionals.

5.3.3. Identify all uses of the concept

Continuous support in this study refers to the availability of a model or strategy to support mothers, physical infrastructure, material and human resources that need to be in place for the continuous support of mothers.

According to Roy Adaptation Model, as a conceptual framework for this study, there are concepts necessary to help mothers to adapt/cope with their children which include: person, environment, health and nursing. According to Roy, humans (persons) are in constant interaction with their environment. They use a system of adaptation, both innate (inborn) and acquired to respond to the environmental stimuli they experience. This can be individuals, organisations and community as a whole. Humans in this context would be mothers of intellectually disabled children. Environment is a stimulus that requires a person to adapt and this stimuli can be positive or negative. Roy categorised this stimuli as focal, contextual and residual. In this study environment is home, community and health facilities. Health was defined by Roy as the state where humans can continually adapt to stimuli. If humans continue to adapt holistically, they will be able to maintain health to reach completeness and unity within themselves, whereas their integrity can be affected negatively if they cannot adapt accordingly. The goal of nursing is the promotion of adaptation for individuals and groups. Nurses are the facilitators of adaptation. Nurses eliminate ineffective coping mechanisms leading to better outcomes. Mothers should be encouraged to adapt with their environment using their cognator (a person's mental coping mechanism). The cognator subsystem enables individuals to use their brain to cope via self-concept, interdependence and role function adaptive modes.

5.3.4. Determine the defining attributes

Walker and Avant (2005:60) described attributes or characteristics of a concept as the “heart of a concept analysis”. The goal of this stage in the concept analysis is to underscore a collection of attributes most frequently associated with the concept and that set it apart from other similar concepts.

Continuous support in this study is attributed by the availability of: paediatric team/human resource, organisational support, self-efficacy and collaboration. These characteristics appear consistently throughout data collection, data analysis and (conceptual framework of the study) concerning enabling environment and reflect the essence of the concept. These attributes are discussed as follows:

5.3.4.1 Human resources

Human resources include availability, appropriate competencies, responsiveness and productivity. Mothers of children with an intellectual disability need professionals who are always there for them, as continuous support is fulfilled by someone who provides support without being interrupted or unconnected.

5.3.4.2 Availability

Availability of sufficient and skilled health personnel, including relatives and community members is a characteristic that indicates that the environment is enabling or allowing to support mothers of children with intellectual disabilities.

5.3.4.3 Appropriate competencies

Health care professionals need to have appropriate knowledge and skills in order for them to be able to provide comprehensive services. They need to be adequately educated and equipped with the expertise to offer all the services needed by the family and community at large. This is an indication that continuous support is in place. Furthermore, competency is demanding for the continuous support as continuous counselling is important and it needs someone who is very competent with counselling skills.

The person incharge of these multidisciplinary units, should ensure that staff have the right training at the right time to provide quality basic services. Training opportunities must be provided fairly and must not interfere with service delivery, by helping the staff to gain access to training opportunities in an equitable way, promote their career development and improve motivation and morale. All family members, relatives, neighbours and friends should also show some sense of understanding on how to live with intellectually disabled children in order to enhance support of their mothers.

5.3.4.4 Responsiveness

According to Aarts, Chalker and Weiner (2014:449) responsiveness is the quality of reacting quickly and positively. The positive attitude and good working relations among staff members and mothers is considered as an important attribute to support mothers of children with an intellectual disability. Qualitative findings revealed that mothers experienced challenges when they report to the hospital what they do not understand about their children, and nurses were not responding to their problems (they ignore them). Relatives and community members are the people who should be available to mothers of children with intellectual disabilities, to support them in all possible ways as these mothers rely on them for support. Unfortunately most of them were not giving sufficient support, instead they isolated and stigmatised them for having a child with an intellectual disability.

5.3.4.5 Productivity

Productivity refers to producing the maximum effective health services and health outcomes possible given by the existing pool of health care professionals without compromising their skills. Productivity is one of the attributes of continuous support which is necessary to enhance adaptation skills for mothers. This is also achieved with effective communication.

5.3.4.6 Organisational support

Organisational support is defined as the degree to which employees perceived their organisation's concern with their health and well-being as well as with the reduction of conflict between employee's personal and professional life (Keyser, Maseko & Surujlal 2014:126). Perceived organisational support is defined as global beliefs concerning the extent to which the organisation values their contributions and cares about their well-being (Kath, Marks & Ranney 2010:646). The well-being and health of employees is very important in order for them to provide quality care to the clients and patients. Organisational support is also valuable for nurses in order to make them feel part of the organisation, to belong, to be recognised or appraised and rewarded. Zagencyk, Scott, Gibney, Murrell & Thatcher (2010:129) reported that human resource practices such as training, promotion, rewards and developmental experiences are an indication of the organisation's responsibility towards the competency of employees.

Organisational support refers to infrastructure, centralisation of services and availability of directions to a particular service. Health care professionals are also available to support mothers of children with an intellectual disability.

Continuous support is attributed by direction to the service and centralisation of the available service. The physical work environment often influences the mind-set of the service providers and their efficiency and ability to innovate in delivering quality services. A disorganised service impairs the support of mothers of children with an intellectual disability.

5.3.4.7 Collaboration

Collaboration between the multidisciplinary teams attribute to a continuous support in community and paediatric setting which may also result in successful coping skills for mothers of children with intellectual disabilities.

5.3.4.8 Self-efficacy

Self-efficacy is defined as people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives. Mothers of children with an intellectual disability need to have a positive attitude that can influence them to accept their children. Perceived self-efficacy is the optimistic self-belief or perceived competences (Greenglass 2007:222). Self-efficacy reflects confidence in the ability to exert control over one's own motivation, behaviour, and social environment (Bandura 2002:14).

5.3.4.9 Social support

Social support was seen to be an important need of mothers of children with intellectual disabilities as they are not living on an island. Social support is the perception or experience that one is cared about by others, esteemed and valued, and is part of a social network of mutual assistance and obligations (Taylor 2008: 161). Social support may come from a partner, relatives, friends, and social or community ties. Social support can also be received or provided. Social support is acknowledged by many authors as a critical resource for managing stressful occurrences. Social support can be provision of emotional (loving and caring), instrumental support (e.g. practical/provision, financial help), and informational support (e.g. advice). Hence mothers of intellectually disabled children revealed that they are affected emotionally, financially and they lack information about intellectual disability of children. Social

support can also arise from members of the social networks to which an individual belongs, though the existence of such networks does not guarantee the provision of social support. The most important thing is the willingness to provide support rather than the number of people in a network. This can be formal (government or agencies), or informal (friends, spouse). In the workplace social support occurs through social interactions with co-workers and supervisors who provides continuous support to mothers (Taylor 2008:267).

5.3.5. Construct model case

Walker and Avant (2005:62) describe a model case as something which enables one to distinguish the essential from the non-essential features. Model cases can be drawn from literature, art or film or any other context in which the concept is accurately symbolised. A model case for this study was developed to reflect the real life situation.

The following is an example of continuous support as it demonstrates all the defining attributes of the concept:

“My sisters were very supportive and my elder sister took a child for a year and she stayed with her that is when I was doing grade 10.”

“I was referred to the psychologists for counselling and it took a month to see him because to I had to make an appointment which was scheduled a month later. That was very bad for me because I should have undergone a counselling session immediately.”

“Aah!! I am supported emotionally but you must know that even if you are supported, there are things that you need to face yourself no matter what.”

“That was because of the way I was treating the child myself even though now I cannot say they are fully supporting me but it is better than before. They still insist that the child must be beaten up to make him good and I told them that beating him will worsen him because this is just his condition. Others will still say I am spoiling him and we differ.”

“Neighbours are very good, I don’t have any problems with them. Even their children plays well with my children. If my child is looking for a toy or something that other children are having they would give him and say he will be tired of that thing, let’s give him. Indeed they will give him until he becomes tired of using that toy. The neighbours are really supporting me. They are far much better than the family members.”

“I am relating very well with doctors and nurses, no problem.This is because they also advise me to bring the child even if it is not check-up day, as long as I see that there is something wrong with the child and not to wait for a check-up day.”

“Yes, they are supporting me very well, my parents and in-laws. As I am working her grandmother requested to stay with the child so that when she comes back from crèche there is somebody at home .Even our neighbours are supporting us, though there are some people who takes her somehow and ask funny questions like, how is your child like, what is happening to her, why is she like this?”

5.3.6. Identification of surrogate terms

Surrogate terms are means of expressing the concept in different ways (Rodgers & Knafl, 1993:83). Surrogate terms for the word “support” revealed during data collection were: strategies, advice, knowledge and response.

5.3.6.1 Strategies

Strategies are ways of dealing with stressors or stressful events (Shah & Thingujam, 2008:184). Many strategies were identified by mothers of children with an intellectual disability in living with stigma, isolation and acceptance of children’s diagnosis. Different strategies used were going to church, using traditional advice, giving advice to those who were laughing and mocking them and also to just ignore them. These strategies were very helpful to them as they could endure the tough times.

5.3.6.2 Advice

Advice to give an opinion or suggestion to someone about what should be done: to give advice to someone (Merriam-Webster Dictionary 2011). In this study, some mothers revealed that they were able to advise those who were displaying negative attitudes towards the behaviour of a child, showing them the right thing to do as disability is not something that one chooses and buys from the shop.

5.3.4.3 Knowledge

Knowledge is defined as the fact or condition of being aware of something (Merriam-Webster Dictionary, 2011). Mothers of children with intellectual disabilities cope better when they know and understand the diagnosis of their children. Knowing what to expect of the child and his or her limitations made mothers cope better with assistance from the health care professionals.

5.3.4.4 Response

Response is something that is done as a reaction to something else; that is when one is responding or answering what is being asked by the next person. Mothers were seen to be responding to new challenges by finding ways to cope with them. They were also responding to the health care professional's questions and able to give honest and truthful information on how they feel about the condition of their children.

5.3.7. Identify antecedents and consequences

5.3.7.1 Antecedent

Walker and Avant (2005:64) define antecedents as, “events or incidents that must occur or be in place prior to the occurrence of the concept. Continuous support was seen as the best way to assist mothers to adapt to their children with an intellectual disability. Health care professionals, especially nurses must have basic counselling skills to assist these mothers. This includes health talks during pre- and post-delivery of a child. Antecedents for mothers include the need for them to be guided by the health care professionals and to get support their families. However, a key prerequisite to successful support is the knowledge, open communication, mutual trust, community involvement and readiness to accept and adapt. Information on intellectual disability including causes, possible prevention and how to care for these children is of vital importance.

For continuous support to take place, participants must have knowledge so that they are able to learn and cope based on what they were taught. Open communication is needed from both the health care professionals and the mothers for them to understand each other. Mothers should also reveal their fears and anxiety in order to get help. Mutual trust should be developed for them to share the vision of the future. One participant said, *“I was very much disturbed and ask myself why, because he is number 3 and all other children are fine. It was so embarrassing and frustrating.”* Readiness to adapt and cope could assist them to utilize the support model effectively.

Continuous support requires an enabling environment which is attributed by adequate infrastructure, equipment and human resources capable of providing services such as OT, physiotherapy and guidelines that ensure quality assurance mechanisms. Also the availability of skilled staff to ensure sufficient adaptation and coping mechanisms to mothers of children with intellectual disabilities. The aspects that are necessary for successful continuous support includes: trained health care professionals, social support, financial and emotional support, support groups and home visits. The Roy’s

model as a conceptual framework for this study identified four factors necessary which include: human resources, organisational support, self-efficacy and collaboration. The presence of these four prerequisites results in an enabling work environment that may result in successful continuous support.

5.3.7.2 Consequences

According to Walker and Avant (2005:67) consequences are those events or incidents that can occur as a result of occurrence of a concept and that can often stimulate new ideas or avenues for research pertaining to certain concepts. Possible consequences of an enabling environment may result in successful adaptation of coping strategies or mechanisms for mothers and family members. This is generally a positive process yielding positive outcomes.

5.3.8. Identification of concepts related to the concept of interest

Related words to the concept of support may help in understanding intentions or objective of support. These are the words that express the concept in a different way. The following words were identified as concepts that were used interchangeably with the term support: Tolerate, motivate, backing and aid/help.

5.3.8.1 Tolerate

According to Webster New World Dictionary 1984, to tolerate is to endure or resist the action without serious side effects or discomfort. Mothers of children with an intellectual disability were able to bear the pain when their children were being ill-treated by neighbours and relatives. Some were abandoned by their husbands and blamed for having an intellectually disabled child.

5.3.8.2 Motivation

Motivation is an act of instilling or giving hope or support to someone. Mothers need to be motivated to give proper care to their children with intellectual disabilities. Some even sacrificed by leaving their job as they could not leave the child with people they do not trust to give proper care. They need to be praised and encouraged to continue to love their children. The health care professionals also need to be acknowledged by the managers for their care giving role. They also need to maintain good interpersonal and open communication. This can increase their job morale and commitment.

5.3.8.3 Back-up

This is additional personnel who provide assistance, auxiliary reinforcement, reserve or one that serves as a substitute or support; standing by as an alternative or auxiliary, give moral support (Complete Wordfinder Dictionary and Thesaurus 1993). Having a child with an intellectual disability is very stressful and a burden that can lead to both physical and emotional exhaustion. Intellectual disability has a negative impact on mothers and caregivers. Therefore they need back-up from relatives to relieve them, services like respite care and child minding. Some neighbours were found to be helpful as they could help working mothers by taking care of their children when they come home after school.

5.3.8.4 Aid/help/assistance

This is an act of assisting, helping, aiding in support of (Complete Wordfinder Dictionary and Thesaurus 1993). This contributes to the fulfilment of a need or furtherance of an effort or purpose. Mothers need services like counselling services, support groups, social workers' and psychologists' services to help

them overcome the problems encountered when caring for their children with intellectual disabilities.

5.3.9. Define empirical references

According to Walker and Avant (2005:73), empirical referents are measurable ways to demonstrate the occurrence of the concept; relatively the means by which you can recognize or measure the defining characteristics or attributes. Empirical referents provide extremely useful information in instrument development because they are clearly linked with observable phenomena to measure continuous support in health institutions. Furthermore empirical referents "are classes or categories of actual phenomena that by their existence or presence demonstrate the occurrence of the concept itself. [They] are extremely useful in instrument development because they are clearly linked to the theoretical base of the concept".

5.3.10. Analysis of data regarding the characteristics of the concept "continuous support"

Data drawn from the definition of the term "continuous support" was analysed for similarities and differences. The meaning of the concept was read from the literature. Common words were underlined and clustered in order to develop a theme.

Theme one describes "*awareness of child's diagnosis*". The antecedents included were: fear, denial, anger, anxiety, depression, embarrassment, guilt, self-blame. Mothers whose children were diagnosed with an intellectual disability for the first time experienced shock and denial. They were also depressed due to the fact that their hope for their children's future cannot be met. They also blamed themselves that they are the cause of the problem and that led to guilt feelings.

Theme two describes mothers' "*acceptance of child's diagnosis*" of children with an intellectual disability. The following antecedents were included; knowledge, open

communication, availability of skilled health care professionals, mutual trust and honesty. Mothers must have full information on intellectual disability. Counselling was seen to be a pillar of strength to mothers in order to accept their children with intellectual disabilities. However, availability of staff and open communication is also important for the mothers to feel comfortable in revealing their thoughts.

Theme three describes “*adaptation to the child’s diagnosis*” by mothers to the behaviours of their children, care needed for them as they differ according to the level and severity of the condition. The antecedents included were adaptation, motivation, willingness to learn and commitment. Continuous support would imply that adaptation with changes in the family life by mothers becomes evident. They should also show willingness to grow and adapt.

Theme four describes “*continuous support*” as an effort to disengage from unattainable goals. Continuous support would mean that mothers of children with intellectual disabilities should strive to attain their desired goals of overcoming challenges they face. Antecedents included are self-efficacy, self-actualisation, support group and social support. Continuous support can be achieved if mothers show self-efficacy by being able to interact with support groups and some people surrounding them.

Table 22: phases for continuous support

CHARACTERISTICS OF PHASES OF CONTINUOUS SUPPORT	THEME	SUBTHEMES
Phase 1: Awareness	Awareness of diagnosis	fear, denial, anger, anxiety, depression, embarrassment, guilt, self-blame, disbelief
Phase 2: Action	Acceptance	knowledge, open communication, availability of skilled health care professionals, mutual trust family involvement, community involvement and honesty
Phase 3: Adaptation	Adaptation to diagnosis	Adaptation, enabling environment, commitment, motivation, willingness to learn
Phase 4: Support	Continuous support	Self-efficacy, self-actualisation, support group, social support

5.4. SUMMARY

Using Walker and Avant's (2005) eight steps for concept analysis, both a clear understanding of and concise definition of continuous support were identified. After deliberation of the growing body of literature, unique attributes and antecedents were identified that will be useful for future knowledge development, research, education and decision making.

5.5 DEVELOPMENT AND DESCRIPTION OF MODEL TO SUPPORT MOTHERS OF CHILDREN WITH INTELLECTUAL DISABILITIES

5.5.1 Introduction

This chapter deals with the development and description of a model to support mothers of children with intellectual disabilities. The purpose of a model is to enhance transition of support to mothers of children with intellectual disabilities. The findings of the study revealed that most of the mothers were overwhelmed with frustrations, feelings of fear, anger and embarrassment of having a child with an intellectual disability. This was mainly due to lack of support from partners, relatives, community members and health care professionals. Lack of knowledge related to initial awareness of the diagnosis, care of the child, financial burden, lack of assistance at the health care facilities as well as lack of continuous counselling were challenges raised by certain mothers dealing with intellectual disabilities. The specific objectives to attain the study purpose were to:

- Explore and describe the experiences of mothers of children with intellectual disabilities
- Determine the views of professional health care workers about supportive care to mothers of children with intellectual disabilities
- Identify the supportive care services available to mothers of children with intellectual disabilities in Limpopo Province South Africa

5.5.2. Description of the model

The development and description of the model to support mothers of children with intellectual disabilities were done following the six elements of practice orientated by Dickoff, James and Wiedenbach (1968:203). The six elements of practice orientated theory are Agent, Recipient, Context, Dynamics, Procedure and Terminus. Practical activities identified according to Dickoff et al. (1968:426) and they were discussed as follows:

1. Who or what performs the activity? Mothers of children with intellectual disabilities and the health care professionals.
2. Who or what is the recipient of the activity? Mothers of children with intellectual disabilities, their partners, relatives or family members, neighbours, friends and the community.
3. In what context is the activity performed? Community cultural context, family context and health care facility.
4. What is the energy source? Lack of awareness, denial and guilt feelings, lack of counselling, knowledge deficit, lack of empowerment and acceptance.
5. What is the guiding procedure or process? Need assessment, open communication, honesty, mutual trust, skilled health care professionals
6. What is the end point of the activity? Mothers of children with intellectual disability should be able to adapt and cope in caring for these children. Have knowledge and clear understanding about intellectual disability. They should have skills, be committed and competent in caring for their children.

5.5.2.1 Agents

An agent is an individual who specialises in facilitating the change process during which new values, attitudes and behaviour are fostered (Kamenye, lipinge & Van Dyk 2016:120). In the context of this study, agents comprised of the health care professionals from the health care institutions (doctors, nurses, occupational therapists, physiotherapists and psychologists). This is because they are involved in the diagnosis of intellectual disability, disclose to the mother, give counselling to the mother to enhance coping skills, provide information on what to expect, the do's and dont's and how to care for their children. They have knowledge and skills that enable them to interact as a team in order to provide quality care and information to both mother and child with an intellectual disability. They also follow the proper referral system from one professional to the other.

Nurses are the ones who are always in close contact with patients and clients. Mothers find it easy to share their challenges with nurses. Nurses' roles include patients'

advocacy and they are always there in all consultations with other health care professionals. The operational managers in paediatrics together with other managers of the multi-disciplinary team that are involved in caring for the intellectually disabled children, will be responsible in the facilitation and implementation of the developed model to support these mothers. The team or committee will also evaluate the developed model to support mothers of such children to ensure that the model indeed brought anticipated changes in the support of the mothers. The agent centred dynamics include: motivation, commitment, skills or knowledge and competence. It focuses on enhancing motivation, commitment, knowledge and competence of the agents to perform the activities in an effective manner.

- **Knowledge**

Health care professionals need knowledge regarding intellectual disabilities in order to give full and accurate information to the mother, family and the community at large. Lack of knowledge by health care professionals causes confusion and mistrust to the recipients. Knowledge given should be consistent all the time to ensure trust and build a good professional–patient relationship.

- **Motivation**

In this model, motivation is the energy source for all health care professionals. This is required because the context of disability is in itself extremely stressful. The mother and the family as a whole are expecting more from the health care professionals which requires knowledge and skills. Shortage of staff on the other hand is demotivating as sometimes when the counselling session is in progress, you are needed to assist in an emergency situation. This is very disturbing as counselling is also an important healing factor for the family of a child with an intellectual disability.

- **Commitment**

For the successful implementation of this model, there should be leadership commitment in the support of mothers. It must be from the highest level of management to ensure support for the agents. According to this model, motivation, commitment, knowledge and competence should form the basis of the support model in order to improve the programme implementation.

- **Competence**

Competency is defined by SANC (2004) as specific knowledge, skills, judgement and personal attributes required for a health care professional to practice safely and ethically in a designated role and setting. The health care professionals should maintain the highest standard and quality of health and professional services with the available resources. They should also be competent in line with the regulation requirements such as SANC (2005) to professional nurses. Any competent health care professional should have self-esteem, confidence, self-actualisation, self-reliance and be an independent practitioner. They should demonstrate good communication with patients and good interpersonal relationships with other health care providers. Clinical practice competencies include:

- **Competencies for care provision** which entails assessment, planning, implementation, evaluation, promotion of health, therapeutic environment, communication and advocacy.
- **Competencies for care management** entails safe environment, inter-professional and multidisciplinary teamwork, delegation, supervision, coordination, collaboration, information management and recording.



Fig 8: Represent the agent centre dynamics

5.5.2.2 Recipients

Recipient is a person who receives or persons who are receiving activities from an agent. Nursing care recipients include all those persons who receive action from an agent, including families, communities or societies. This means that a recipient is a person who benefits from the activities that are designed by the agent (Kamenye, Lipinge & Van Dyk, 2016:121).

In the context of this study, the recipients are mothers of children with an intellectual disability, their partners, relatives or family members, neighbours, friends and the community. They receive action from agents (doctors, nurses, occupational therapists, physiotherapists and psychologists) to achieve a certain goal. The goal to be achieved is that mothers of children with an intellectual disability should be able to adapt and cope in caring for these children and have knowledge and clear understanding about

the condition. Their partners, relatives or family members, neighbours, friends and the community should know how to support these mothers; these are the people who are in close contact with the mothers whom they meet with almost every day. Hence support is clearly expected from them. Mothers of children with intellectual disabilities are aware of their health care deficits and that they need guidance and support from health care professionals. Participative interaction between the agents and the recipients is of vital importance. This can be achieved by open communication with the health care professionals in order to achieve their goals.

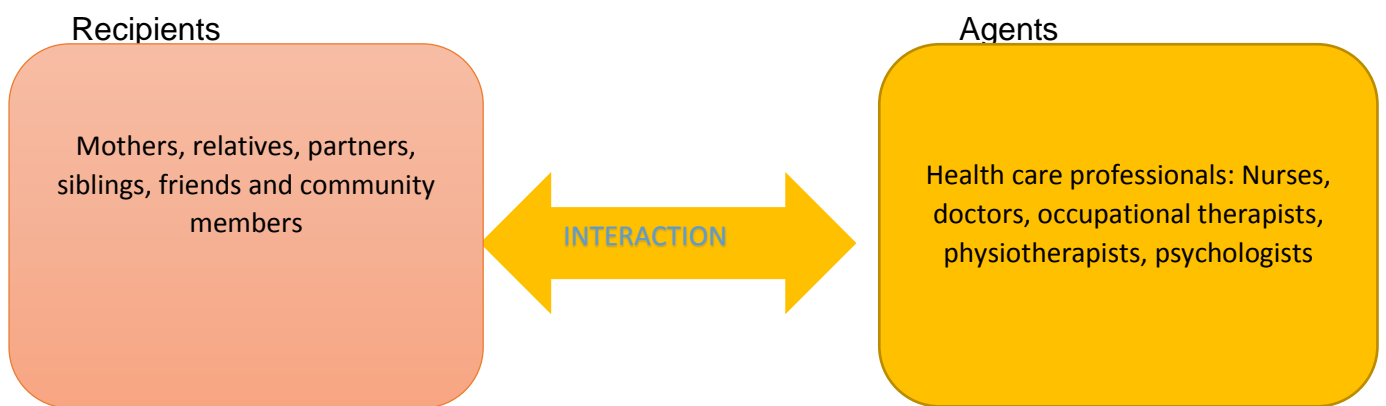


Figure 9: Structure of agents and recipients

5.5.2.3 Context

Context is the circumstances or a setting in which an event occurs, a situation in which the activities take place. It comprises human, environmental, professional and organisational institutions (Kamenye, Lipinge & Van Dyk, 2016:121). The context consists of community cultural context, family context and health care facility. This is where support, coping and adaptation of mothers of children with intellectual disability should take place. This includes the interrelation of other factors as constituting an organism, unity or total context of activity.

Factors involved in the whole context where coping is supposed to take place include:

- The norms, beliefs, values and attitudes of all people involved based on their cultural beliefs
- Clear description and acceptance of roles for each person involved
- Lack of knowledge and skills of the participants due to poor provision of information within communities
- Poor strategies to enhance coping with intellectual disabilities in children by mothers

Dickoff et al. (1968:203) emphasise that despite the fact that a clinical setting provides learning opportunities, it is influenced by internal and external context of the agent. The internal context of the agent that guides health care professionals' activities include skills of health care professionals, competency and knowledge of intellectual disabilities, counselling skills and policies involved. The model was developed within the context of patient's rights and Batho Pele principles. External context include those resources that are available for maintaining and supporting the agent's capacities and power. These include socio-cultural, economic and political factors.

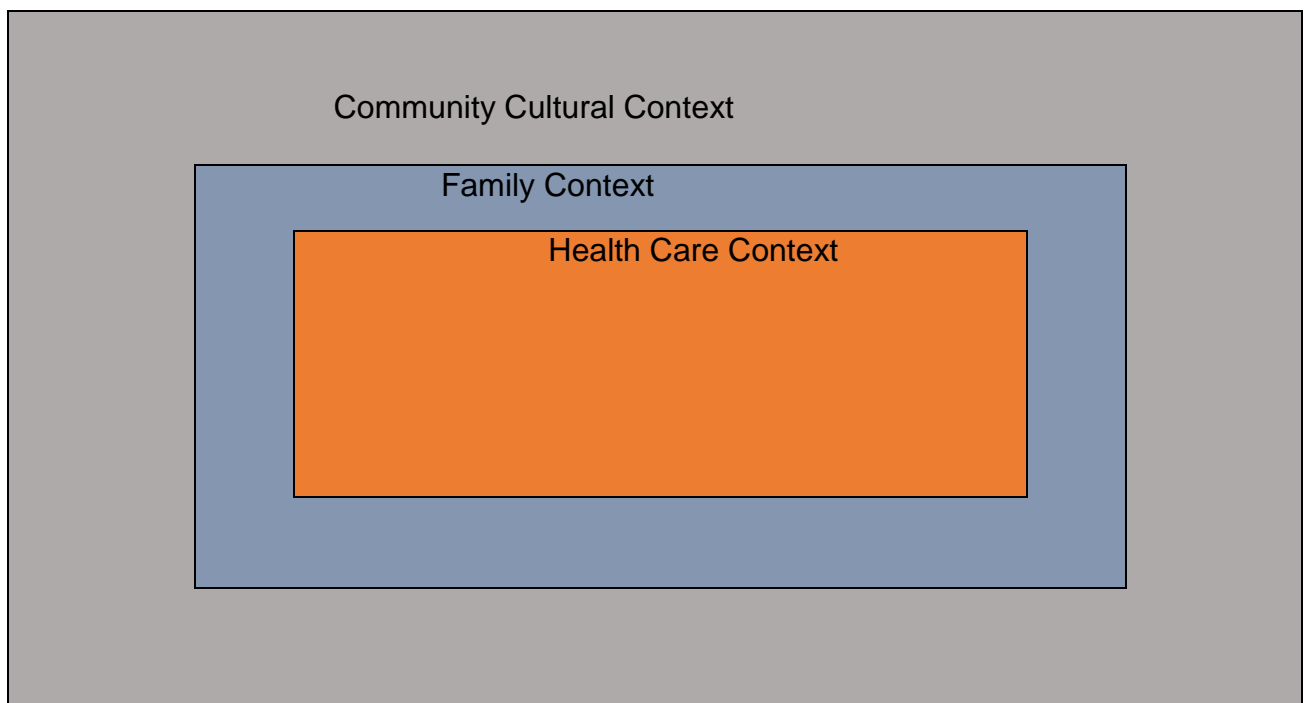


Figure 10: The context of support

Community cultural context

Socio-cultural beliefs that the community has an influence on how coping with intellectual disability should be conducted. The community socio-cultural beliefs where the participants were residing, impose certain rules on the people who live in such communities. Most African communities believe that disability is a punishment for wrongdoings, hence they laugh and mock the family or parents because of intellectual disabilities. Pregnant women are not allowed to touch or see those children with disabilities as they believe that they will also give birth to a child with a similar disability. This interferes with coping and support needed as it is enhanced by communication. Roy's Model of Adaptation indicated that a mother has physiological–physical need of group identification in order to interact well with the environment. A therapeutic environment should be created for the mother to feel more comfortable like any mother without a child with intellectual disability.

Family context

The family is one of the contexts within which adaptation and coping with intellectual disabled children should take place. The interrelated parts of the family are formed by members of the family such as husband, wife, children, and other extended family members. Each of the family members has a role to play for the survival of the whole family. Siblings can also be the source of both positive and negative influence on mothers of such children. Social support and care is characterised by the different roles that each person plays. All family members need to be involved in the support to make it more effective, hence family counselling. From the analysed data it was found that some family members were not supportive at all, thereby adding more stress to the mother. This was due to lack of knowledge and information about intellectual disabilities, norms, values, attitudes and their socio-cultural beliefs.

Health care context

The health context involves diagnosis, prescription of treatment, health education, quality patient care, home visits and professional development. Mothers of children with intellectual disabilities receive formal health education from the health care context. Quantitative data which were analysed revealed that certain health care professionals lacked adequate knowledge and skills as they were less experienced in working with children with intellectual disability. Materials needed were also not available, for example enough time to spend with the mothers due to shortage of staff. This did not promote an environment for effective coping with children with intellectual disability, hence there is inadequate support available.

5.5.2.4 Dynamics

Dynamics refers to energy sources of the activities inside an individual or the internal motivating factors for success (Kamenye, Lipinge & Van Dyk 2016:122). They can be chemical, physical, biological or psychological for any person or thing functioning as agent, patient or part of the framework in realizing the goal. The agent for the model to support mothers of children with intellectual disability acquired scientific knowledge and skills on the continuous support of mothers with intellectual disabled children. Some health care professionals only acquired basic knowledge concerning their profession. Therefore, the model had to be developed to address such challenges in order to support mothers of children with intellectual disabilities. The health care professionals through health talk will then make it a point that the mother and family members are aware of the child with an intellectual disability in the family and what is expected of them (their roles). The findings of this study indicated that adequate support was not given to mothers of such children as they were still unaware of their children's condition, delayed diagnosis, signs of denial and guilt feelings, lack of knowledge, limited access to health care services available, lack of family involvement and counselling, ineffective communication.

- **Lack of awareness about the child's condition**

According to Webster Dictionary 2017, awareness is knowing that something such as a problem, condition or situation exists. It implies knowledge gained by means of information. Mothers of children with intellectual disabilities need to be aware that the child they gave birth to is intellectually disabled despite their expectation of having a child without any disability. The agent plays a major role in this regard. This will help them to effectively get the support that they need and to adapt to the situation. They must also be aware of the changes that might occur in routine or activities at home so that they can adjust where necessary. This can be better facilitated when proper assessment and diagnosis is done at the earliest stage. This is an important stage as the way in which the information is disclosed, affects how the recipients will cope.

- **Denial and guilty feelings**

According to Beirne-Smith, Patton & Kim 2006: 89, denial is another early stage frequently observed in the grieving process and may be manifested in various ways. These may be reaction to the diagnosis itself, its performance or its impact. People who deny the diagnosis often tend to argue with health care professionals regarding the diagnosis as a result of guilt feelings. They may also deny the impact of a disability in their children and may express the view that special education has come a long way in recent years. The process of denial causes frustration to the health care professionals because mothers are unable to handle the impact of the intellectual disability on their children (Ross & Deverell 2004:93). The findings of this study revealed that some mothers were denying the fact that their children are intellectually disabled. This was supported by mothers who took their children deliberately to the normal school, despite the fact that they were told that their children were not coping in the mainstream schools. The recipients must be able to verbalise their fears and communicate openly with the agent for them to be able to accept their children regardless of their disabilities. When mothers interact with the health care professionals, they get accurate and exact plan and support that will help them to

respond well to the environment or the situation they are facing. This is also supported by Roy's theory as it addresses the physical and psychological dimensions in human life.

- **Lack of family involvement and counselling**

The agent is responsible for providing information to the recipients. Despite the information provided through media and newspapers, some families and communities are still in the dark as far as disability is concerned, especially intellectual disability. This is due to poverty as they cannot read newspapers, do not own a radio or television and their level of understanding is compromised. So, it is so important to develop a model to overcome this challenge.

- **Knowledge deficit about intellectual disability**

Knowledge is defined by Webster Dictionary 2017 as a fact or condition of knowing something with familiarity gained through experience or association. It implies the body of truth, information, and principles acquired by humankind. This can be through studying, investigating, observing or experienced. The findings of the study indicated that the recipients lacked knowledge about intellectual disability. The causes, care, treatments and prognosis were an issue of concern to mothers, hence self-blame. The recipients need to be empowered by the agent and this requires effective communication between the two factors. This can be enhanced through proper and continuous counselling.

- **Empowerment**

Empowerment is a process of becoming stronger and more confident especially in controlling one's life and claiming one's rights. It involves two or more people, the one

who empowers and the one who is being empowered. They both gain from the process. In this context empowerment should be to enable, equip and emancipate mothers of children with intellectual disability, family and the community. Respect on each other's knowledge should be seen during interaction rather than competing. Recipients should also show some readiness and willingness to learn and be empowered by the health care professionals. The health care professionals should also bear in mind that some recipients, especially the mothers are experiencing serious challenges of intellectually disabled children that may be bothersome, troublesome and uncomfortable and they might be very difficult to deal with. Hence the need for continuous support is very important.

- **Enabling environment**

Enabling environment in this study refers to the national guidelines, physical infrastructure and material and human resources that need to be in place for continuous support to be possible. However, RAM refers to the environment as a stimulus that requires a person to adapt. Intergration of human and environmental meanings results in adaptation. Mothers should be encouraged to be aware of self

- **Ineffective communication**

Some mothers and their family members of children with intellectual disability in this study showed some dissatisfaction as they were not getting information about their children's illnesses. The independence mode of adaptation according to Roy's theory focuses on attaining relational integrity through the giving and receiving of love, respect and value. This is achieved with effective communication and relations. The health care professionals should communicate and be transparent to the mothers concerning their children. There should be a mutual trust and mutual respect for the mothers to get the support they deserve.



Figure 11: Dynamics for continuous support

5.5.2.5 Procedure

Procedure is referred to as an orderly way of doing things. It is a general rule that guides activity and it comprises of the protocol and devices that enable an agent to attain a goal. It is the way in which activities take place (Kamenye, Lipinge & Van Dyk 2016:122). Procedure suggests the situation, steps and proper equipment to be used or taken towards some accomplishment.

According to Dickoff et al., it provides detail sufficient to enable an activity to be carried out. It is an outline of activity that may specify the typical agent, recipient and situation for the procedure. Dickoff et al. further explain that to view an activity is to see it in relation to other things, including persons and activities, the interrelation of these ideas as constituting an organism, unity or total concept of activity. The process of continuous support was derived from empirical findings which revealed that even though some

mothers of children with intellectual disabilities were getting support as expected from their relatives, some challenges were still encountered. Hence continuous support was viewed as being crucial for mothers of children with an intellectual disability.

As mothers were lacking adequate knowledge on intellectual disability, they experienced shock, denial and guilty feelings resulting from delayed diagnosis and poor disclosure of information to mothers, hence poor counselling skills. Therefore, for the mothers to receive adequate continual support, it must be from multiple levels of care (internal and external agents).

The procedure for continuous support in this model includes all activities needed towards effective and continuous support which can be possible through the following activities open communication, honesty, mutual trust, skilled health care professionals, commitment, social support and as seen in figure12 below:



Figure 12: The procedure for support model of mothers with intellectually disabled children

5.5.2.6 Terminus

Terminus is defined as the end point of the activities or the desired outcome an agent wishes to attain by implementing a certain procedure. Mothers with intellectually disabled children should be able to adapt and cope (through continuous support) in caring for their children with an intellectual disability. They are to be ready and willing to learn, have knowledge and clear understanding about intellectual disability. Their partners, relatives and siblings, neighbours, friends and the community should know how to provide continuous support to mothers of children with an intellectual disability. This is based on the findings of the study which revealed the need for continuous support to mothers of children with intellectual disability.

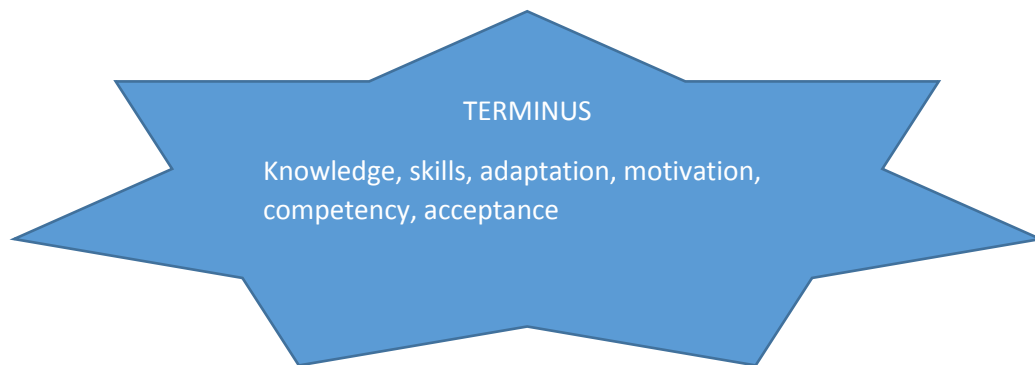


Figure 13: support outcome of mothers

5.5.2.7 Continuous Support Structure

Continuous support structure is characterised by the following effects:

- Mutual trust
- Mutual respect
- Mutual interaction
- Willingness and readiness to learn
- Knowledge and skills

5.6. MODEL DEVELOPMENT

A model is a schematic representation of how continuous support will be facilitated between mothers, partners, friends, siblings, neighbours and community. Model development for continuous support involves: phase 1 (awareness of diagnosis), phase 2 (acceptance of diagnosis), phase 3 (adaptation to diagnosis) and phase 4 (continuous support). These phases emanated from dynamics and procedure of support. Figure 14 below represents all phases respectively.

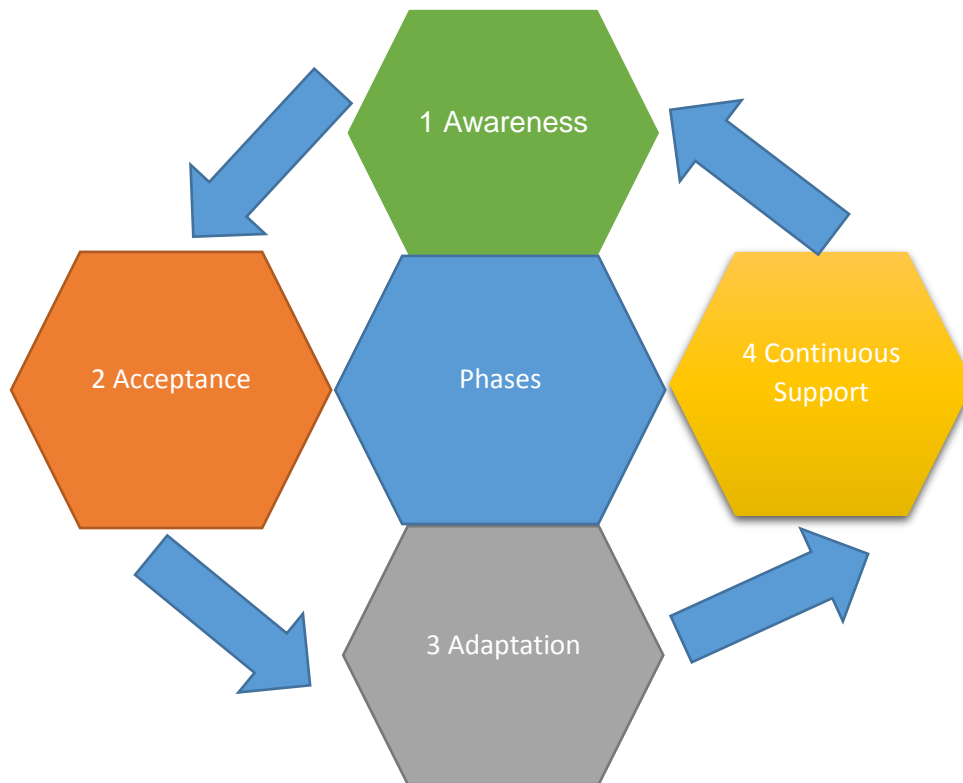


Figure 14: Represent the four phases for continuous support

5.6.1 Description of the model in phases

In phase 1, both the agent and the recipient are aware of the participant's self-care deficits. These are the support challenges that mothers of children with intellectual disabilities are facing. The dynamics involved are awareness, knowledge, family and community involvement, denial and guilty feelings, acceptance, empowerment and enabling environment. Mothers experience some feelings of shock, fear, guilt, shame, self-blame, frustration, disbelief and embarrassment after disclosure that their children are intellectually disabled. This was due to the fact that they were not expecting to have a child with a disability of some sort. Some were even hiding their children as a sign that they feel embarrassed. Some were very angry with themselves and even with some people they suspect to have caused that type of disability. Through information and support they got from health care professionals and some family members, they were able to understand and provide the necessary care that their children deserved. Some were no longer hiding their children. Hence, continuous support is necessary.

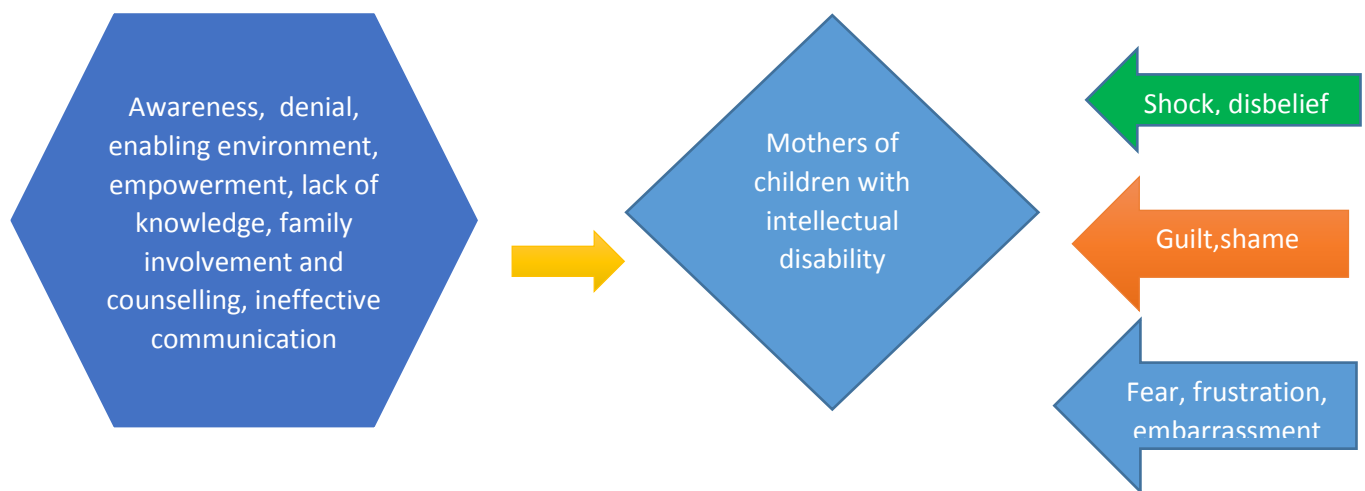


Figure 15: Awareness of mothers' self-care deficits

In phase 2, the dynamics include knowledge, open communication, availability of skilled health care professionals, mutual trust and honesty. Mothers as part of the community members are influenced by their community socio-cultural beliefs. As Africans, we believe that disability does not just occur without the involvement of our

ancestors or witchcraft, so mothers should have knowledge about this and be able to verbalise their beliefs during their discussions with the health care professionals who can then assist them, knowing what their beliefs are. They should be transparent enough. They should be honest and be committed in applying information from the health care professionals. Mutual trust must be seen between the agent and the recipient.

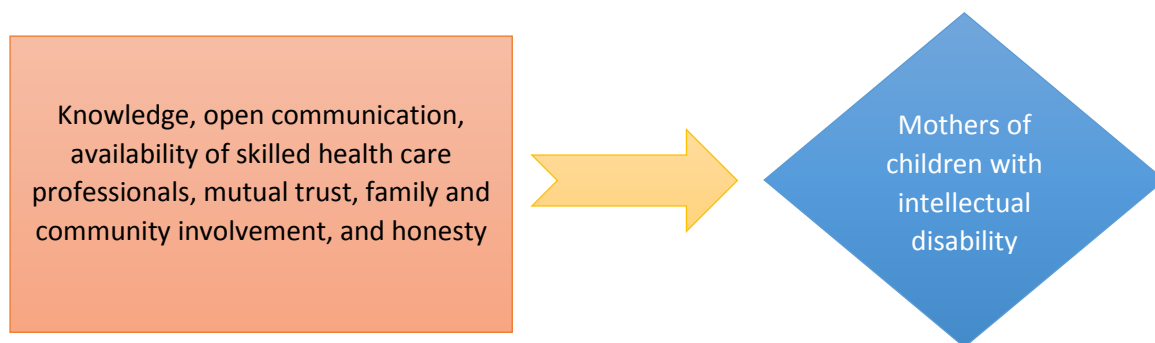


Figure 16: Action for continuous support

In phase 3, the dynamics involved includes adaptation, commitment, motivation and willingness to learn. Continuous support should assist mothers of children with intellectual disabilities to cope and adapt successfully with their disabled children. Health care professionals should encourage mothers to take responsibility for their own children. When mothers are committed and motivated effectively, they will be empowered to take responsibility for their own actions. Willingness to learn should be shown when mothers are no longer involved in taking risk actions or practices like taking their children to the traditional healers for help. They must also be willing to accept new information, knowledge and skill to effectively cope with their children.

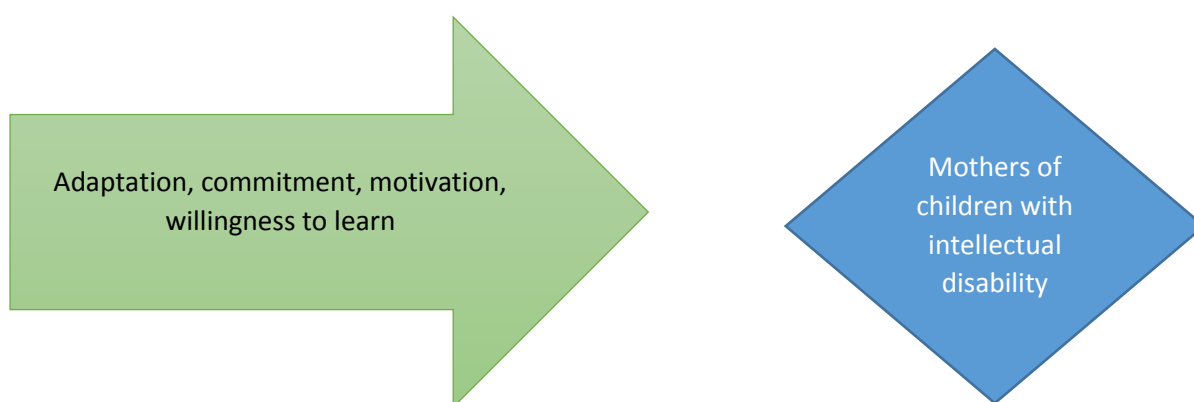


Figure 17: Adaptation with continuous support

In phase 4, the dynamics involved are self-efficacy, self-actualisation, support groups and social support. During adaptation, mothers should start to adjust to challenges they are facing due to their children with intellectual disability . They must be confident in managing the stress brought about by the child with an intellectual disability. When mothers have acquired adequate and reliable information, knowledge and skills, have received social support from the support groups and the other no-organisational structures to manage their children effectively, they develop self-esteem and self-actualisation. They will then be able to support emerging mothers of children with intellectual disability.

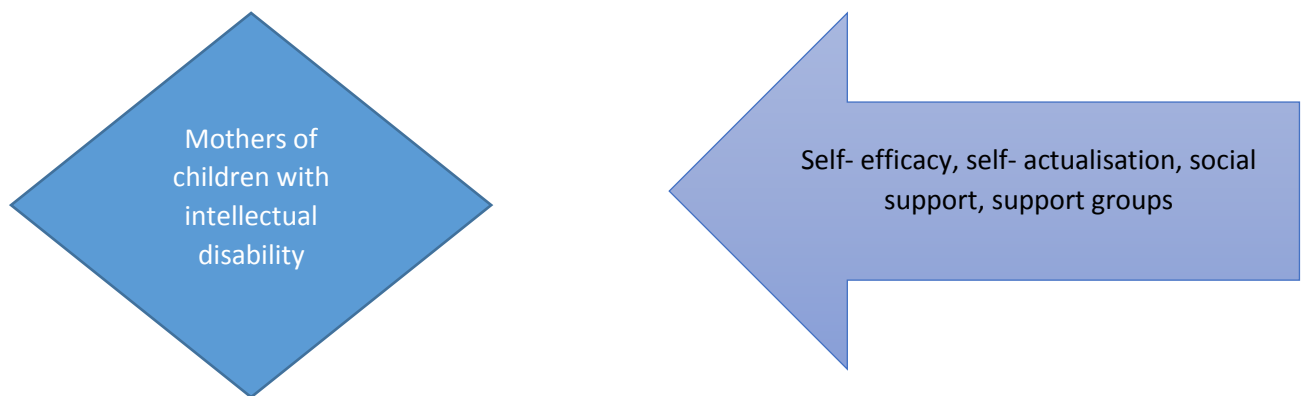


Figure 18; Continuous support for mothers

5.6.2 Purpose of the model

The purpose of the model was to facilitate continuous support for mothers of children with an intellectual disability. Continuous support can be achieved through four phases as indicated above in figure 14; phase 1 (awareness of diagnosis), phase 2 (acceptance of diagnosis), phase 3 (adaptation to diagnosis); and phase 4 (continuous support).

5.6.3 The nature of the structure

A model is a group of concepts and propositions that are brought together and explains the relationship between the concepts, thereby providing a deeper understanding about a phenomenon (Fawcett & Ellenbecker, 2015:290; McKenna, Pajnikihar & Murphy, 2014). According to Chinn and Kramer (2011:156), in order to identify and show the relationships that exist between concepts they should be illustrated in a structure. Figure 19 below, illustrated the structure of the model for continuous support for mothers of children with intellectual disability.

Community cultural context

Family context

Health Care Context

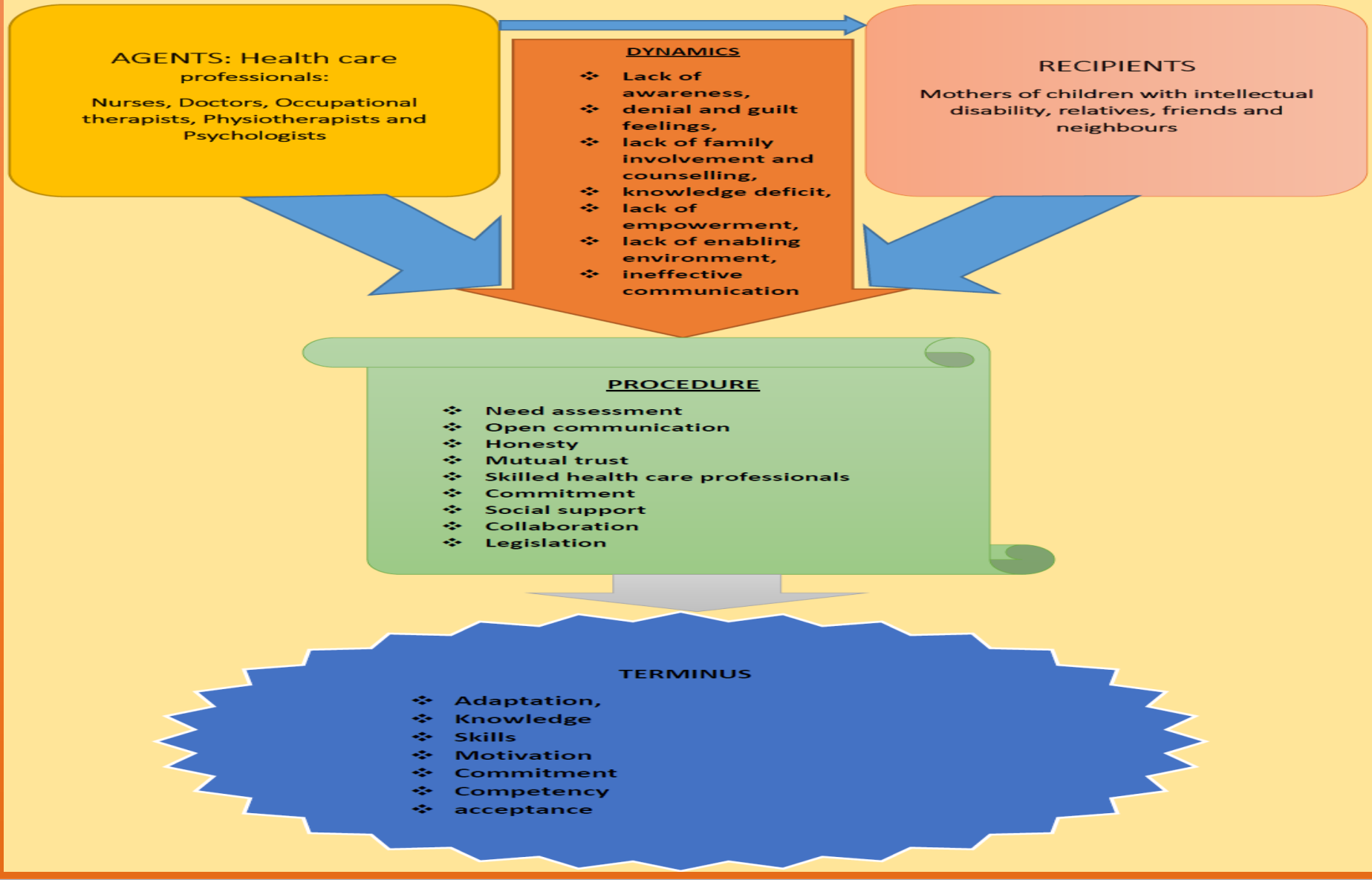


Figure 19: A model to facilitate support for mothers of children with intellectual disability

5.7. VALIDATION OF THE MODEL

According to Sousa 2014: 215, validation is a very important part of theory generation which enables the researcher to ascertain that the intended population understands the intended meaning of the theory/model or concepts involve in the model, and the diagram illustrating the model.

The developed model were reviewed by the promoter and the co-promoters of the study. The model was also presented to the operational managers of paediatric units, experts in maternal and child health and paediatricians. Validation of the model was done following the guidelines as outlined by Chinn and Kramer 1999:110). The participants were requested to check and evaluate the model for: clarity, simplicity, generalisation, accessibility and importance.

5.7.1 Clarity of the model

Participants gave evidence which makes the model clear. Concept analysis was discussed and made the model clearer. Major concepts and related concepts were consistent and assisted in forming a structure of the model for continuous support for mothers of children with an intellectual disability. Drawings were used throughout to illustrate the structures for continuous support.

5.7.2 Simplicity of the model

Simplicity seeks to establish whether the model is simple and straightforward to understand Participants involved in the review of the model acknowledged its simplicity and that it is easy to understand. The main aim of sending the model to the unit operational managers was to test or check for its applicability and its effectiveness. Major and related concepts were used to describe the four phases of the study. Hence, model simplicity was achieved by observing major and related concepts.

5.7.3 Generalisation of the model

Generalisation refers to the scope and the purpose of the model and was found to be relevant to other fields of nursing. The research was conducted in paediatric wards but the expert in midwifery understood the concepts and acknowledged its applicability in midwifery sections. The health care professionals provide information, knowledge and skills. In this study the agent, recipient and the context are involved. The recipient becomes competent after being empowered with knowledge, information and skills to cope with and accept their children. The context is the community, family and health care facility that assist in supporting mothers of children with an intellectual disability.

5.7.4 Accessibility of the model

The model would be accessible to the hospitals where data was collected through workshops that would be conducted by the researcher. This is where the model will be implemented and evaluated. Participants and paediatric managers would also be included. It could also be accessible in the research seminars including presentations at national and international conferences.

5.7.5 Importance of the model

The proposed model is important as it will serve as a standard that guides the health care professionals to support mothers of children with intellectual disabilities. Currently there is no model developed to support mothers of children with intellectual disabilities in Limpopo Province. Mothers of children with an intellectual disability lacked information on the situation. They were unable to cope and accept their children and could not take decisions to help their children as disabilities were culturally determined. The model will help community and the health care professionals to support mothers by empowering them with information necessary to cope.

5.8. GUIDELINES ON HOW TO IMPLEMENT THE MODEL

Application of the model is the last step in model development. It involves the description of guidelines on how to implement the model (Chinn & Kramer, 1999). The guidelines were presented in the table below according to the elements as presented in chapter five of this study.

Guidelines pertaining to context:

- The family
- Community
- Health care professionals

5.16.1 Guidelines pertaining to context

The following guidelines were derived from the data analysis and conceptualisation of the context where continuous support was to be facilitated. The community, family and health care facility were the context where continuous support for mothers of children with intellectual disabilities was to be facilitated as illustrated in table 22 below.

Guidelines for the mothers and their families	Guidelines for the community	Guidelines for health care professionals
<ul style="list-style-type: none"> • Mothers should be provided with support based on what they are lacking. The plan should be designed based on their need after thorough assessment • Family members are to play their role of supporting mothers of intellectually disabled children by showing love and acceptance of the child. • Mothers and family members must be encouraged to attend workshops and awareness campaigns regarding disability. • Mothers and family members must be encouraged by the researcher and the health care professionals to 	<ul style="list-style-type: none"> • Members of the community to continue supporting mothers of children with an intellectual disability. • Encourage interactive participation by all community members in the community regarding intellectual disability issues. • Social activities like recreation center activities and sports should be encouraged within the community as social support systems are recognised as a significant factor that enables families to cope and adjust better to a child's disability. • Provision of more resources and new indicators for the provision of intellectual disability services to 	<ul style="list-style-type: none"> • Collaboration to include local clinics as resource centres for the community, traditional healers, faith healers and church organisations to gain cooperation in the provision of health of children with an intellectual disability. • Attendance of workshops, seminars and conferences on intellectual disabilities to acquire adequate and current information in order to share it with mothers of such children in the communities. • The health care professionals should organise and facilitate workshops for the community to

<p>participate in community activities organised by the researcher at community level for them to share information and avoid isolating themselves.</p> <ul style="list-style-type: none"> • The researcher must also plan meetings with the family in order to involve the husband, siblings and relatives as source of both negative and positive influence on mothers and the need for continuous support. • Family members to seek information from various sources like knowledgeable family members, non-governmental organisations (NGO) regarding intellectual disability and family education programmes should be designed to equip families with the most up-to-date information about intellectual disability 	<p>communities are necessary, hence mental health communities should be monitored.</p> <ul style="list-style-type: none"> • Workshops to be conducted in the community with the help of the local clinics to empower them with knowledge about intellectual disabilities. • Workshops to involve people with expertise who will include relevant topics that will strengthen the community to be enlightened and accept people with intellectual disabilities and their families. • Collaboration to include local clinics as resource centres for the community, traditional healers, faith healers and church organisations to gain cooperation in the provision of health care of children with an intellectual disability. 	<p>enhance support and understanding to the community members.</p> <ul style="list-style-type: none"> • The health care professionals to adequately refer mothers of children with intellectual disabilities to other services for better management. • The health care professionals to demonstrate good communication and good interpersonal relationship with the community and the family. • The health care professionals to interact effectively with the community health committees in the planning and provision of continuous support to mothers of children with an intellectual disability.
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<ul style="list-style-type: none"> • Need for openness and transparency in the family and during interaction with the health care professionals about their feelings on caring for a child with intellectual disability. • Need for being honest with each other and in their relationships as honesty deals with the truth. • Families to trust each other as lack of trust will hamper information sharing among mothers of children with intellectual disability. • Mothers to be aware of their health care deficits, hence need guidance and continuous support. • The agents and the recipients must have a participative interaction in issues that involve their health to enhance coping. 	<ul style="list-style-type: none"> • Consideration of rights of other mothers when communicating disability issues to avoid infringing their rights. • Norms and values regarding disability to be considered by the agents and recipients as the community members. • Development of health education programmes by community members and strategies for strengthening the programme to ensure sustainability. • Some community members especially the community leaders must receive training on intellectual disability issues for them to empower other community members and be equipped to give them necessary continuous support. • Community leaders should collaborate with other social partners like pastors, 	<ul style="list-style-type: none"> • The health care professionals to provide continuous support to the communities and families of children with an intellectual disability. • The health care professionals to involve the prevention, promotion, diagnosis, prescription treatment care and referrals of both mothers and their children with intellectual disabilities. • The health care professionals to follow the mission, vision and philosophy of the community health care services in providing guidance and continuous support to the communities and families including mothers of children with an intellectual disability.
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<ul style="list-style-type: none"> • Family awareness on the formation of support groups with other families experiencing the same challenges • Mothers themselves need to belong to the support groups within the community's health care facilities in order to get continuous support and share information with other mothers to enhance coping skills. • Mothers need to clarify their values, norms and beliefs in order to plan activities based on their misdirected beliefs. • Mothers and the families should learn to have positive perceptions towards their children with intellectual or developmental disabilities and this can be achieved with more social support from friends and relatives 	<p>counsellors, principal of schools including parents within the jurisdiction or vicinity of that community in order to identify relevant transitional needs and plan appropriate services.</p> <ul style="list-style-type: none"> • School teachers should be trained as there is lack of trained personnel in special needs education. 	<ul style="list-style-type: none"> • They must recommend strengthening documentation and reporting on human rights violations against persons with disability rooted in stigma and customary beliefs. • The health care professionals must empower people with intellectual disability and supporting them as role models in the society. • The health care professionals must implement the school-based disability rights awareness programmes. • Health care professionals assist mothers to develop skills and strategy to interact with their children to increase the sense of
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<ul style="list-style-type: none">• Mothers should receive early and effective management of problems during Antenatal clinic (ANC) and intrapartum care and emphasizes on preventative measures should be done e.g maternal substance use of drugs, alcohol and tobacco.• Mothers should receive early interventions like family training, counselling and home visits at least once a month.		<p>self-efficacy in their role as parents</p> <ul style="list-style-type: none">• The health care professionals must work within the communities in order to transform negative attitudes and harmful practices into more positive perceptions.• Public education in communities and dissemination of information related to disability must be conducted in order to overcome false beliefs about the causes of disability by community-based sensitization and education campaigns including schools and in community gatherings.
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5.8 SUMMARY

This chapter discussed about the concept analysis which was done. The core concept which is continuous support emerged and sub-core concepts also came out and were discussed in detail. These concepts assisted the researcher in the development of a model for mothers of children with intellectual disabilities.

CHAPTER 6

CONCLUSION, LIMITATION AND RECOMMENDATION OF THE STUDY

6.1 INTRODUCTION

The previous chapters discussed the research design, methodology, findings and their discussions were presented. A model to support mothers of children with an intellectual disability was developed. The study was also established through the review of literature based on research orientation. This chapter presents the conclusions obtained from the results of the study and the recommendations to support mothers of children with intellectual disabilities in Vhembe and Mopani districts of Limpopo Province, South Africa. Limitations of the study and the concluding remarks were clearly stipulated in this chapter.

It was revealed from literature that continuous support to mothers of children with intellectual disability is essential to enhance the coping skills of mothers. This includes the need for being aware of the intellectual disability child, on-going counselling, acceptance, empowerment, family and community awareness and counselling, sufficiently trained health care professionals, competency, support groups and knowledge and skills.

The study emanated from the evidence that mothers were stigmatised, isolated and not receiving effective support from the family, community, friends, relatives and health care professionals.

6.2 THE OBJECTIVES OF THE STUDY

In phase 1a, objective 1 and 2 were met through exploration and description of experiences of mothers of children with an intellectual disability as set in chapter 1 and the objectives were:

- To explore and describe experiences of mothers of children with intellectual disabilities
- To determine the cultural practices and beliefs for mothers of children with intellectual disabilities

Participants' experiences and their challenges were explored during individual interviews. Discussions emanated from a central question of the in-depth individual interviews that were explored. Data were analysed and themes and sub-themes emerged. Dense descriptions of the findings were also done against relevant literature. The concept of continuous support was identified as the way of managing coping skills with intellectual disabilities in children by all participants. Culture was also found to have influenced the decisions taken by mothers of children with intellectual disabilities. Majority of mothers lacked adequate and relevant information on intellectual disability issues. Concept analysis and model development was done based on the data drawn from these participants.

In phase 1b, objective 3 and 4 were met and the objectives were to:

- Describe the views of health care professionals about supportive care to mothers of children with intellectual disabilities
- Determine the supportive care services available to mothers of children with intellectual disabilities in Limpopo Province South Africa

Health care professionals complained about the shortage of staff which limits them in providing quality care. They also saw a need to train more professionals who will assist in supporting mothers through continuous counselling. This will include mothers'

emotional, psychological and social challenges they met. Services available to support mothers were discussed and those not available were also highlighted.

6.3 RESEARCH APPROACH AND DESIGN

An exploratory sequential mixed methods design was used to investigate the necessary support services of mothers with intellectually disabled children. This means that the qualitative data were collected and analysed. The results for qualitative approach were used to build a subsequent quantitative phase. Phases were also linked by using the qualitative results to shape the quantitative phase. The researcher conducted a second phase based on the exploratory qualitative results to test or generalise the initial findings (Burns & Grove, 2010:219). The purpose was to see if they can be generalized to a sample and a population.

6.4 LIMITATIONS

The study was limited to Vhembe and Mopani Districts' public hospitals only. Mothers whose children were at the special schools and teachers from the special schools were not included due to time and financial constraints. Challenges were also met as some mothers were reluctant to give information despite a full explanation given to them. Doctors were not available for questionnaires, they stated the reason as being the shortage of staff.

6.5 RECOMMENDATIONS

Recommendations were made based on the findings of the study.

6.5.1 Fear, anger, blaming oneself, guilt, stigma, social rejection and embarrassment

The findings of this study revealed that mothers were overwhelmed with fear, anger, blaming oneself, guilt, stigma, social rejection and embarrassment. This was because

they did not accept their children with intellectual disabilities. The following recommendations were made:

- Health care professionals should work within the communities in order to transform negative attitudes and harmful practices into more positive perceptions
- Health care professionals should provide information on intellectual disabilities to all mothers during pregnancy
- Encourage mothers to attend ANC immediately they discover that they are pregnant in order to exclude abnormalities
- Providing parents with effective and timely health information to reduce the anxiety
- Proper screening during pregnancy should be done by a specialist personnel including relevant tests and referrals
- Mothers should disclose all the information related to their previous pregnancies, if any

6.5.2. Experiences regarding awareness of diagnosis of the child

This study revealed that mothers experienced shock after being told that their children had an intellectual disability. This was aggravated by the fact that there was no proper communication to the mothers. The following recommendations were made:

- Thorough preparation and assessment must be done before disclosing the diagnosis of a child with an intellectual disability to enhance acceptance
- Health care professionals should disclose to the mother immediately they discover the problem of the child
- Health care professionals should have more time to disclose the diagnosis to the mothers

6.5.3 Acceptance versus lack of acceptance of having a child with intellectual disability

The findings of this study revealed that most mothers who accepted the condition of their children easily, were those who were supported at home whereas those who lacked support were struggling. The following recommendations were made:

- Community involvement must be reinforced to empower them with knowledge on intellectual disabilities and what to expect from these children.
- Continuous family counselling should be initiated to enhance acceptance to the family as a whole.
- Family support by health care professionals should be emphasized to meet the needs of the family
- Scheduled sessions must be planned with the mothers to encourage them to participate in decision making
- School teachers must be taught on the important things to consider before declaring some children not to be fit in mainstream schools
- Mainstream school principals and teachers should be trained on how to handle children who seem to be intellectually challenged rather than discouraging and mocking them in front of other children

6.5.4. Challenges experienced by parents of children with intellectual disability

The findings revealed that appointment dates were problematic at the health services.

The following recommendations were made:

- Health care professionals should place the patient's file according to the scheduled appointments to avoid delays and missing files
- Health care professionals should combine their appointments to reduce the financial costs to the mother, for example OT and physiotherapy
- Paediatric team should be scheduled according to childrens' appointments to avoid disappointments for mothers when they bring their children for check-ups

- Available services should be centralized and have directions for better access of those services

6.5.5. Lack of special schools for children with intellectual disabilities

This study found that special schools for intellectual disability children are still lacking in our Province. The following recommendations were made:

- The government should initiate special schools for pre-school learners in Limpopo Province, especially in Vhembe and Mopani Districts as there are no preschools for these children.
- The government should initiate special schools for mentally retarded/intellectually disabled children and apply more effort at all levels of the education system to promote respect for disability rights
- Skillful and knowledgeable personnel should be trained so that they can empower mothers of children with intellectual disabilities

6.5.6. Lack of support groups for mothers of children with intellectual disability

This study revealed that support groups were not available in some of the institutions. The following recommendations were made:

- Support groups for mothers of children with intellectual disabilities should be initiated and full support from the health care professionals should be given
- Mothers should be encouraged to share their experiences and challenges in order to encourage each other
- Awareness should be made on the availability of support groups and its importance or benefits to the mothers
- Continuous support sessions to be programmed by the health care professionals according to the needs of mothers
- Mothers should be empowered on the skills and knowledge to help other mothers of children with intellectual disabilities

6.5.7. Inadequate assistance by health care professionals at health care facilities

This study revealed that the health care professionals were not helpful and supportive enough to mothers of children with intellectual disabilities when they need help. The following recommendation were made:

- Health care professionals, especially nurses should be trained on the care of children with an intellectual disability, including communication skills such as sign language for them to communicate with both mother and the child with speech problems.
- Staff training on the care of intellectual disabilities should be emphasised in order to impart sufficient knowledge to mothers
- Clinical decisions should be done with the mothers of children with intellectual disabilities to ensure active participation
- Public awareness training programmes in the society should be emphasised to promote recognition of skills
- Health care professionals to display positive attitudes towards disabled children to instil hope in mothers as some were seen to feel very hopeless and discouraged

6.5.8. Lack of knowledge about origin of disability by mothers and family members

The findings of this study revealed that mothers and family members of children with intellectual disabilities displayed lack of knowledge on the causes of intellectual disabilities. The following recommendations were made:

- Doctors should give themselves time to explain the possible causes of intellectual disabilities to relieve anxiety, self-blame and suspicions of witchcraft
- Midwives should counsel all mothers after delivery and emphasise the need to bring their children for assessment of their normal development

- Media awareness should be emphasised to ensure that persons with intellectual disabilities and their parents are portrayed respectfully to avoid stigma and embarrassment

6.5.9. Cultural beliefs and practices

The findings of this study revealed that mothers delayed seeking medical advice as they believed in cultural practices which contradicted the medical treatment. The following recommendations were made:

- The health care professionals should adopt effective and appropriate measures to combat harmful practices relating to persons with an intellectual disability

6.5.10. Future research

- Further research on continuous support to the siblings and fathers of children with intellectual disabilities should be done to enhance coping and empower them to overcome challenges they may face.
- More research should also be conducted to both the mainstream and special school teachers to determine their challenges and strategies to overcome the challenges of mother and the child with an intellectual disability.

6.6 CONCLUSIONS

The study focused on the development of model to support mothers of children with intellectual disabilities in selected health institutions of Limpopo Province , South Africa. A model was developed using the six elements of Dickoff and Wiedenbach. The findings of this study contributed to the body of knowledge as a model was developed since there was no model to support mothers of children with intellectual disabilities in place currently in Limpopo Province. The purpose and the objectives of

this study were discussed and evaluated if they were met, limitations and recommendations of the study that could be of benefit to the mothers of children with intellectual disabilities, health care professionals, the family, community, friends and neighbours. It is hoped that these recommendations will result in better coping of mothers of children with intellectual disabilities.

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ANNEXURE A: INFORMATION SHEET

Good Day

My name is Ndidzulafhi Selina Raliphaswa. I am a student at the University of Venda. As part of my degree, I am conducting a study titled “A supportive care model for mothers of children with intellectual disabilities in selected institutions of Limpopo Province, South Africa”.

The main aim of this study is to develop a model to support mothers of children with intellectual disabilities in selected health institutions Limpopo Province, South Africa. I am inviting you to participate in the study.

The interview will last for about 45 minutes to an hour. If you agree to take part, I will ask you a question in relation to the support given to mothers of children with an intellectual disability. We will have a conversation about the implementation of their support. My role as a researcher is to listen and understand your point of view, and not to pass judgement. If you feel uncomfortable with answering certain questions, feel free to express your discomfort; you will not be penalised.

Confidentiality

The information that you give will be kept confidential. No names will be used when transcribing the interviews. I undertake that all information provided by you will be used only for the purpose of the study. Everything that you say will be treated as private and confidential and no-one will know you have answered the question, apart from the researcher. The answers given by participants will be combined and analysed according to common themes and categories and the combined information will be in the form of a report.

Consent

Ethical clearance had been obtained from the University of Venda Ethical Committee. Permission to carry out the study was sought from the School of Health Sciences Higher Degrees Committee and from the Limpopo Provincial Department of Health, as well as the hospital management. I will request you to sign an informed consent form that indicates your consent to participate in the study and to record the interview.

If you are willing to consent, the researcher will appreciate your participation and the information you give.

Benefits and risks of participation

Please note that participation in this study is voluntary and there will be no direct benefits to anyone who participates. There will be no penalties if you want to withdraw from the study or if you do not want to answer some of the questions because you feel they are violating your rights. However, I would really appreciate it if you share your thoughts and feelings in relation to the questions asked.

Recording the interview

I would also like to ask for permission to audio record the interview because it is not possible to write down all your answers quickly enough to capture all the important information. In addition I might misrepresent your responses to some of the questions that you will be asked if a recording is not done. It is important for you to know that the digital voice data and notes will remain confidential and your identity will not be disclosed. I am only interested in your honest responses to the questions.

Recordings and digital data of the interview will be listened to only by the researcher and the co-coder and will bear no names of the interviewees. The information will be analysed and organised into a report according to themes. The recordings and digital data files will be kept in a locked safe. In accordance with the national requirements the voice recordings and digital data will be destroyed two years after the publication of the research findings.

Contact details

I will be happy to answer any questions or to offer clarity about any issues you may have during this study. This study had been approved by the Research Ethics Committee of the University of Venda. If you have any questions about your rights or any aspect of the study or further questions about the research or interview, please contact the researcher:

Mrs Raliphaswa NS.....

Cell: 073 248 7780 / 082 262 7809

ANNEXURE B: INFORMED CONSENT

I, on this day of of 2017

1. Being interviewed on the topic “A supportive care model formothers of children with intellectual disabilities in selected health institutions of Limpopo Province, South Africa”.
2. Follow-up interviews if necessary.
3. The use of data interviewer in a research report as she deems appropriate.

I also understand that:

1. I am free to end my enrolment, or to recall my consent to participate in this research at any time.
2. Information given up to this point of participation could, however, still be used by the researcher.
3. Anonymity is granted by the researcher in that the data will under no circumstances be reported in such a manner that my identity is revealed.
4. More than one interview might be necessary.
5. No payment will be made by the researcher for information given on my participation in this study.
6. I may refrain from answering questions, should I see an invasion of my privacy.
7. I will be given an original copy of this agreement on signing it.

I hereby acknowledge that the interviewer/researcher has:

1. Discussed the aims and objectives of this research project with me.
2. Informed me about the contents of this agreement.
3. Pointed out the implications of signing this agreement.

In co-signing this agreement, the researcher undertakes to:

1. Maintain confidentiality, anonymity and privacy regarding the interviewee’s identity.
2. Arrange in advance the time and place where interviews will take place.
3. Safeguard the duplicate of this agreement.

Researcher:

Participant:

Date:

ANNEXURE C:

LETTER REQUESTING PERMISSION TO CONDUCT THE STUDY - DEPARTMENT OF HEALTH LIMPOPO PROVINCE

To: LIMPOPO PROVINCE DEPARTMENT OF HEALTH (POLOKWANE)

RE: APPLICATION FOR PERMISSION TO CONDUCT THE RESEARCH

The above matter refers:

I, Ndidzulafhi Selina RALIPHASWA request permission to conduct research. The target group for the study will be mothers of children with intellectual disabilities, professional health care workers (nurses, doctors, psychologists, occupational therapists and physiotherapists). I am a student at the University of Venda and have registered for a Doctor of Philosophy in Health Sciences.

The title of the study is: "A SUPPORTIVE CARE MODEL FOR MOTHERS OF CHILDREN WITH INTELLECTUAL DISABILITIES IN SELECTED HEALTH INSTITUTIONS OF LIMPOPO PROVINCE".

The purpose of this study is to develop a model that will enhance supportive care given to mothers of children with intellectual disabilities in selected institutions of Limpopo Province. The study will assist mothers to adapt with the coping strategies of living with intellectually disabled children. It is also assumed that professional health care workers and special school teachers may modify the available services in order to meet the support needed by Mmothers of children with ID.

Should there be issues that you want clarified, I am prepared and willing to address them to your satisfaction.

Researcher: Mrs NS Raliphaswa (015 962 8682)/ 082 262 7809/ 073 248 7780)

Promoter: Dr NJ Ramakuela (015 962 8000)

Co-promoter: Dr A Tugli (015 962 8000)

Co-promoter: Prof LB Khoza (015 962 8000)

I look forward to your favourable response.

Yours sincerely -----

Mrs NS Raliphaswa

ANNEXURE D:

LETTER REQUESTING PERMISSION TO CONDUCT THE STUDY IN MOPANI DISTRICT HOSPITAL DEPARTMENT OF HEALTH, LIMPOPO PROVINCE

To: MOPANI DISTRICT MANAGER – LIMPOPO PROVINCE DEPARTMENT OF HEALTH

RE: APPLICATION FOR PERMISSION TO CONDUCT THE RESEARCH

The above matter refers:

I, Ndidzulafhi Selina RALIPHASWA request permission to conduct research. The target group for the study will be mothers of children with intellectual disabilities, professional health care workers (nurses, doctors, psychologists, occupational therapists and physiotherapists). I am a student at the University of Venda and have registered for a Doctor of Philosophy in Health Sciences.

The title of the study is: “A SUPPORTIVE CARE MODEL FOR MOTHERS OF CHILDREN WITH INTELLECTUAL DISABILITIES IN SELECTED HEALTH INSTITUTIONS OF LIMPOPO PROVINCE”.

The purpose of this study is to develop a model that will enhance supportive care given to mothers of children with intellectual disabilities in selected institutions of Limpopo Province. The study will assist mothers to adapt with the coping strategies of living with intellectually disabled children. It is also assumed that professional health care workers and special school teachers may modify the available services in order to meet the support needed by mothers of children with ID.

Should there be issues that you want clarified, I am prepared and willing to address them to your satisfaction.

Researcher: Mrs NS Raliphaswa (015 962 8682)/ 082 262 7809/ 073 248 7780)

Promoter: Dr NJ Ramakuela (015 962 8000)

Co-promoter: Dr A Tugli (015 962 8000)

Co-promoter: Prof LB Khoza (015 962 8000)

I look forward to your favourable response.

Yours sincerely -----

Mrs NS Raliphaswa

ANNEXURE E:

LETTER REQUESTING PERMISSION TO CONDUCT THE STUDY

IN VHEMBE DISTRICT HOSPITAL DEPARTMENT OF HEALTH, LIMPOPO PROVINCE

To: VHEMBE DISTRICT MANAGER – LIMPOPO PROVINCE DEPARTMENT OF HEALTH

RE: APPLICATION FOR PERMISSION TO CONDUCT THE RESEARCH

The above matter refers:

I, Ndidzulafhi Selina RALIPHASWA request permission to conduct research. The target group for the study will be mothers of children with intellectual disabilities, professional health care workers (nurses, doctors, psychologists, occupational therapists and physiotherapists). I am a student at the University of Venda and have registered for a Doctor of Philosophy in Health Sciences.

The title of the study is: “A SUPPORTIVE CARE MODEL FOR MOTHERS OF CHILDREN WITH INTELLECTUAL DISABILITIES IN SELECTED HEALTH INSTITUTIONS OF LIMPOPO PROVINCE”.

The purpose of this study is to develop a model that will enhance supportive care given to mothers of children with intellectual disabilities in selected institutions of Limpopo Province. The study will assist mothers to adapt with the coping strategies of living with intellectually disabled children. It is also assumed that professional health care workers and special school teachers may modify the available services in order to meet the support needed by mothers of children with ID.

Should there be issues that you want clarified, I am prepared and willing to address them to your satisfaction.

Researcher: Mrs NS Raliphaswa (015 962 8682)/ 082 262 7809/ 073 248 7780)

Promoter: Dr NJ Ramakuela (015 962 8000)

Co-promoter: Dr A Tugli (015 962 8000)

Co-promoter: Prof LB Khoza (015 962 8000)

I look forward to your favourable response.

Yours sincerely -----

Mrs NS Raliphaswa

ANNEXURE F:

TO: THE CEO – NKHENSANI HOSPITAL

RE: APPLICATION FOR PERMISSION TO CONDUCT THE RESEARCH

The above matter refers:

I, Ndidzulafhi Selina RALIPHASWA request permission to conduct research. The target group for the study will be mothers of children with intellectual disabilities, professional health care workers (nurses, doctors, psychologists, occupational therapists and physiotherapists). I am a student at the University of Venda and have registered for a Doctor of Philosophy in Health Sciences.

The title of the study is: **“A SUPPORTIVE CARE MODEL FOR MOTHERS OF CHILDREN WITH INTELLECTUAL DISABILITIES IN SELECTED HEALTH INSTITUTIONS OF LIMPOPO PROVINCE”.**

The purpose of this study is to develop a model that will enhance supportive care given to mothers of children with intellectual disabilities in selected institutions of Limpopo Province. The study will assist mothers to adapt with the coping strategies of living with intellectually disabled children. It is also assumed that professional health care workers and special school teachers may modify the available services in order to meet the support needed by mothers of children with ID.

Should there be issues that you want clarified, I am prepared to address them to your satisfaction.

Researcher: Mrs NS Raliphaswa (015 962 8682)/ 0822627809/ 0732487780)

Promoter: Dr NJ Ramakuela (015 962 8000)

Co-promoter: Dr A Tugli (015 962 8000)

Co-promoter: Prof LB Khoza (015 962 8000)

I look forward to your favourable response.

Yours sincerely

Mrs NS Raliphaswa.....

ANNEXURE G:

Questionnaire for health care professionals in the selected hospitals of Vhembe and Mopani District.

SECTION A - Socio-Demographic data for Health care professionals working in a Paediatric ward.

1. How old are you?	21—25 years	
	26—30 years	
	31– 35 years	
	>35years	

2. What is your occupation?	Nurse	
	Doctor	
	Physiotherapist	
	Occupational therapist	
	Psychologist	

3. For how many years have you been working with intellectually disabled children?	0-3	
	4-5	
	6-10	
	>10	

4. How many kilometres do clients travel from home to the Hospital?	<1km	
	2-4km	
	5-7km	
	8-10km	
	>10 km	

5. How old are most of the children that you see with intellectual disabilities?	6- 9 years	
	10-12 years	
	>12 years	

6. How many children with intellectual disabilities do you see per day?	1- 3	
	4- 6	
	7- 9	
	>10	

7.What are the children's main disability?	Down Syndrome	
	Attention Deficit Hyperactivity Disorders	

	Epilepsy
	Cerebral palsy
	Profound Intellectual and multiple disability

8. How old are most of the mothers of children with intellectual disabilities that that you see?	15-20yrs
	21-25yrs
	26-30yrs
	31-35yrs
	>35yrs

9. What is the educational attainment of mothers that you see bringing their children?	Primary	
	Secondary	
	Tertiary	

10. What is the occupation of most mothers that you see?	Employed	
	Not employed	
	Housewife	
	Self-employed	

11. How is your relationship with mothers during consultation?	Very poor	
	Poor	
	Good	
	Very good	

12. What is your religion?	Christianity	
	Islamic	
	Buddhist	
	Traditional	

SECTION B

Views of health care professionals on supportive care to mothers of children with intellectual disabilities.

Indicate if you agree or disagree with the statement by ticking 'strongly disagree' (SD), 'disagree' (D), 'agree' (A), 'strongly agree' (SA).

	SD	D	A	SA
1) Mothers of children with ID need support from the health care professionals				
2) Professional caregivers experience difficulties in keeping good relations or communication with the parents				
3) Professional caregivers experience distress from parents due to lack of support				
4) Training of more professionals who can properly deal with parents' mental health needs is important				
5) Specialists, especially psychologists are in demand to support the mental health needs of both children and the mothers				
6) Resources have been directed to the treatment of and services connected to the children and not the mother				
7) Children experience maltreatment when a mother suffered from signs of mental disturbances				
8) Mothers of children with intellectual disabilities are at an increased risk for parenting stress and psychological distress				
9) Health care professionals need to know and understand the cultural beliefs and practices of mothers				
10) More close teamwork with other facilities is available in the health institutions				
11) There is a practical use of social support networks for the mothers of children with intellectual disabilities				
12) Mothers are participating in family support groups				
13) Medical treatment for the parents' disturbance is offered				
14) Direct welfare support for the child with intellectual disability is available				

15)Mothers respect appointments with a physician or psychologist				
16)The ratio of nurses to patients is inadequate				
17)Health promotion services not sufficient to mothers of children with intellectual disabilities				
18)Children were likely to be emotionally disturbed and confined indoors				
19)Child shows signs of physical neglect				

Professional assessment on cultural practices and beliefs for mothers of children with ID	SD	D	A	SA
1. Believes in supernatural causes of disability such as witchcraft				
2. Believes that disability is punishment from God				
3. Believes that disability is a curse from ancestors				
4. Believes that a disabled child must be killed and offered to the ancestors				
5. Believes that disability is caused by disobedience of ancestors				

Emotional challenges	SD	D	A	SA
1) Experience stress due to behaviours of a child				
2) Worried about future life of the child due to inability to accomplish personal or social needs				
3) Do not understand the child, especially when he/she has problems or is sick				
4) Feel embarrassed that the child is intellectually disabled.				
5) Struggle with guilt feelings				
6) In-laws not accepting the disability of a child				
7) Child's behaviour very destructive				
8) Experience feelings of sadness, inner pain or bitterness				

	D	SD	A	SA
Physical exhaustion				
1) Child needs more time to feed, bath, and clothe				
2) Child needs close medical monitoring				
3) Child's weight more than 30kg and difficult to handle				
4) Other siblings, if any, need close observation				
5) Cannot meet other children's needs, if any				
6) Child lacks proper eating skills				
7) Child has many physician and other health care appointments				
Social challenges				
1) Getting support from neighbours and people in the community				
2) Feel socially isolated by the community				
3) Child at risk of being physically abused				
4) Child at risk of being sexually abused				
5) Lack of public awareness				
6) Social life is disrupted by the presence of intellectually disabled child				
7) Experience conflicts or accusation from the community when your child destroys somebody's property				
8) Stigma of giving birth to a child with an intellectual disability				
9) Siblings bullied by other children in the community because of having a sister or brother with an intellectual disability				
10) Avoiding going out to social gatherings with the child e.g. church				
11) Lack of peace with the neighbours				
Economic challenges	YES	NO		

1. Have enough funds to buy child's drugs when you do not receive them at the hospital		
2. Able to afford bus or taxi fare to attend clinic for appointment		
3. Funds needed for therapeutic interventions		
4. Funds needed for external services and institutionalisation		
5. Unable to meet some of the important needs due to poverty		
6. Depend on the partner for help		
7. Depend on the relatives for help		

SECTION C

Supportive care services available to mothers of children with intellectual disabilities

Professional/service support	YES	NO
1. Approaches to other family members for cooperation is needed		
2. There is effective collaboration with other organisations		
3. There are consultation centres for better community support		
4. Medical support for the parents provided by specialists such as physicians and psychologists		
5. There is direct advice for the mothers on the utilization of social support networks		
6. Home support		
7. Respite care/short-term break		
8. Speech and language therapy		
9. Music therapy		
10. Occupational therapist visit		
11. Social worker visits		
12. Clinical psychologist visits		

13.Community nurse visits		
14.Paediatrician		
15.Educational psychologist visits		
16.Career advice for a child		
17.Child minding		
18.Out of school activities		
19.Holiday provision		
20.Psychiatrist		
21.Befriending scheme		
22.Community support		
23.Family therapy and support groups		
24.Advocacy and legal support		
25.Support for siblings of intellectually disabled children		
26.Nutrition services		
27.Home-based nursing		

ADDITIONAL OPINIONS REGARDING SUPPORT TO BE GIVEN TO MOTHERS OF CHILDREN WITH INTELLECTUAL DISABILITIES

Please indicate your opinion regarding support services by responding to the following questions:

1.What are your professional needs regarding support services?

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2. Describe your opinion with regard to support of mothers

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3. Indicate your input with regard to challenges encountered by mothers

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THANK YOU FOR YOUR CONTRIBUTION

ANNEXURE H:

Interview guide for mothers of children with intellectual disabilities.

Topic: A supportive care model for mothers of children with intellectual disabilities in selected Health institutions of Limpopo Province, South Africa.

A central question was: Can you kindly tell me the experience of having a child with intellectual disability?

ANNEXURE: I

INTERVIEW TRANSCRIPT

Translated from Tshivenda into English to demonstrate how the support of mothers was analysed.

Key: Researcher =R, Participant =P

R: Good Morning

P: Good morning

R: Can you kindly explain to me some challenges with caring for your child.

P: My child is having CP and left side is not active, especially the hand which cannot hold anything and it is very weak. When I look at her also, she cannot see properly, but when we were busy preparing her for the special school, the doctor said that she can see.

R: What makes you to say that she cannot see?

P: It is because when I ask her to bring something to me, she will go to the direction where that thing is, but will not bring it or can even pass that thing but her memory is good because she can recall things that have happened.

R: What did you do about the eyes problem?

P: I told the special school teachers to observe her closely and report to me their findings but they did not tell me anything so far since she is still few weeks at school.

R: When did she start with the special school?

P: She started this year!

R: When you took your child to the special school, what was the reason or how did it happen?

P: I took my child from the normal school because other children were laughing at her saying that she is a disabled child (left leg is smaller than the right one and the hand

is not straight, she limps when she walks. The teachers were also complaining that she is very slow in writing but in other things she is fine. She writes few things and stops saying that she is tired. She was in grade 1 and she fails twice.

R: Which hand does she use to write?

P: She is right-handed and it is the hand that is active and working well.

R: When did you know that she is a slow learner and what are the doctors saying?

P: The doctors are saying nothing because even their assessment was not complete. I remember that because the assessment team from the special school was also complaining that the doctor who completed the form was very lazy. He did not do his job.

R: How is she doing at the special school?

P: I went to school to see her work on Monday. Teachers are saying she is doing well but is just that she is very stubborn.

R: Stubborn, how?

P: They explain to me that, for example they are writing from the beginning of the line till the end. She will only write from the beginning to the middle of the line and start the new line before she finishes writing on the first line.

R: Ok, are you saying that she does not follow instructions?

P: Yes, she does not follow.

R: Ok, except what you are saying, how is her general performance and her behaviour?

P: They said she is fine but sometimes she does not concentrate and she will always be up and down and does not settle down or sit down.

R: Ok, I heard all you said, can you just explain to me about the first time you heard about her problem. How did you feel? I mean when she was supposed to be moved from normal school to the special school.

P: Hmm, Ok. The first time they call me, it was when she was in grade R, and I was told to take my child to the special school. To be honest with you, it was a mountain to

me. I couldn't believe and understand what was happening. I was very stressed. The following morning I washed her and take her to school again (same school). At school they did not attend to her and teachers did not give her books and some work to do. At the end of the year she failed, and the following year I took her to the school again. This was because I went to the special school and they said I am late and did not complete the forms. Then late during the year is then that I started with the process of special school forms.

R: So now, how is she doing?

P: She is coping. Even in the normal school she was coping, is just that they wanted her to be competent like all other children without a challenge.

R: Whom do you stay with at home?

P: It is me and my 4 children only.

R: How is the support from other relatives? Are they able to accept the child?

P: Haa! It is very difficult. I stay next to my sister. Her children do not like my child. They do not accept her.

R: How do you see that they do not accept her?

P: When she has something or they want something from her, they do not ask from her, they just take it forcefully or they use insulting words. They even do not want to play with her.

R: How old are those children?

P: They are more or less of the same age. She can even see that they do not want her and sometimes she does not go where they are, she isolates herself or plays with children younger than her.

R: When she is playing with those children, how does she play with them?

P: She plays with them very well unless if behind doors, she is rough and I am not aware. She knows how to play with others as she attended crèche. But since she is growing, children are naughty sometimes, she might be naughty like any other child wherein they push each other and so on.

R: Ok, how are you supported by your neighbours?

P: Is not everybody who accepts her. Some do and some do not.

R: Those who show some rejection, how do they do it?

P: My neighbours have children but one of my neighbour's child is 4 years and my child likes to play with her, but her mother does not like my child. She only accepts her when she sees me but when she does not see me, she does not accept her. My other neighbour even told me what she witnessed. She told me not to allow my child to go and play with that child again. This was because when my child go there, that mother does not want my child to touch anything there. She will take a mat that she puts on the floor for her dog and allow my child to sit there as if she is a dog too.

R: How did you feel about that?

P: It was very painful to me that to be a disabled person is like being a dog and not human being. Then I said maybe it is a punishment from God, and that is what God gave me, I cannot kill her. That is one thing that makes me to be always stressful. I was taken to the psychologist but as this problem is continuous it affects me more. I cannot go to that woman and approach her because she will say "may you please fasten/tie your child and not come to my house. My child has a right to play with other children. I cannot keep her under lock and key in the room. Now it is better as she is in a special school, though I cannot spend a month without seeing her. I go to the special school and take her home fortnightly on weekends. So when she is back home like last weekend, I did not allow her to go out, she was at home. I want to train her to stay at home. This will limit the problem that is affecting me as her mother.

R: But except that mother who is funny, how are her children?

P: No problem with my neighbour's children. They love her. Even with myself where she needs to be rebuked, I do.

R: Ok, what about in social gathering. Do you take your child along e.g. to church?

P: Yes, I am always with her. All the events that occur in the community, I go with her. I may rather leave my youngest child at home and go with this one because I

know she needs more attention from me and nobody can handle her better than I do because I know her.

R: Ok, but when you are walking with her, how do people react?

P: Others are funny and others accept her. Is just that my child will go to them or when they talk to me or her, she will grab them and pull their clothes and some people do not like it when pulled off their clothes and they start to be very aggressive to her.

R: How aggressive?

P: Others will react harshly to say “*Do not touch me. Your dirty hands are spoiling my clothes.*” I will tell her not to pull people’s clothes but she will continue to do that even when rebuked.

R: Who brings the child for check-ups?

P: Her grandmother also accompanies her for physiotherapy check-ups and I also accompany her myself.

R: Are you working?

P: No, I am no longer working!

R: Why, no longer working?

P: I have been retrenched!

R: When you were still working, who was taking care of her?

P: She was at crèche!

R: Since you are no longer working, who is supporting you financially?

P: She is getting her grant. I am doing everything using this money even if it is not enough. I am trying to prioritize things that she needs the most like paying for special school as she is staying there. The time she was still at the normal school she was using a public transport and I was paying.

R: Who takes her from the taxi?

P: We stay next to the road and we are able to see her when the taxi drops her off.

R: I heard you saying that you stay with your children only. Where is your husband or her father?

P: He is staying with another wife.

R: Is he supportive to your children?

P: Yes, he is supportive and also loves my child.

R: Why is he not staying with your family?

P: We never stayed together.

R: Is he the father to all your children?

P: Yes he is.

R: Can you tell me about the professional support here at the hospital? How are you and your child supported?

P: Things did not go well at all because she was discharged prematurely from physiotherapy department. It is true she crawl and sit on time but her left hand was still in need of a great support from the specialists. Maybe it was going to help her and be able to use this hand because now she is using one hand and it worsens her condition. The worst painful thing is when I was told that the physiotherapist team will visit her at home every month from that time of discharge. But unfortunately until today I have not seen anyone visiting us at home. It was just a false promise. She was discharged when she was 4 years old and now she is 8 years nobody came to visit her and is very traumatize to me because this hand is now affecting the whole side and when I try to stretch it she cries of pain and who knows, maybe I am exercising it wrongly and now I no longer touch it and the bone on the wrist is protruding.

R: Were you told or shown how to exercise it?

P: Yes, I was but that was when she was still very young and she is growing. In the special school they bath themselves and to her it is very difficult because she is still learning to use the active hand because at home I was bathing her. That is why time and again they are reporting her to be fitting because it is very hot and she sleeps without taking a bath.

R: Anything that you think is important to be done for her?

P: I want people to help me by letting my child to be controllable, able to take instruction and to be trained to do something for herself.

R: Ok, thank so much. Do you have any other information that you would like to share with me?

P: No, that is all, thank you.

R: Thank you so much for your time and sharing your experiences with me. Should I need more information I might contact you. I hope it is fine with you.

ANNEXURE J

UNIVERSITY OF VENDA

OFFICE OF THE DEPUTY VICE-CHANCELLOR: ACADEMIC

TO : MR/MS N.S RALIPHASWA
SCHOOL OF HEALTH SCIENCES

FROM: PROF J.E. CRAFFORD
DEPUTY VICE-CHANCELLOR: ACADEMIC

DATE : 24 MARCH 2016

DECISIONS TAKEN BY UHDC OF 24TH MARCH 2016

Application for approval of Thesis research proposal in Health Sciences:

N.S Raliphaswa (11595813)

Topic: "A model to support mothers of children with intellectual disabilities in selected health institutions of Limpopo province, South Africa."

Promoter:	UNIVEN	Dr. N.J Ramakuela
Co-promoters:	UNIVEN	Dr. A Tugli Prof. L.B Khoza

UHDC provisionally approved the proposal with the following recommendations:

Revise the time frame

ANNEXURE K

**RESEARCH AND INNOVATION
OFFICE OF THE DIRECTOR**

**NAME OF RESEARCHER/INVESTIGATOR:
Ms NS Raliphaswa**

**Student No:
11595813**

**PROJECT TITLE: A Model to Support Mothers of
Children with Intellectual Disabilities in selected
Health Institutions of Limpopo Province, South
Africa.**

PROJECT NO: SHS/16/PDC/07/2804

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

NAME	INSTITUTION & DEPARTMENT	ROLE
Dr NJ Ramakuela	University of Venda	Promoter
Dr A Tugli	University of Venda	Co- Promoter
Prof LB Khoza	University of Venda	Co- Promoter
Ms NS Raliphaswa	University of Venda	Investigator - Student

**ISSUED BY:
UNIVERSITY OF VENDA, RESEARCH ETHICS COMMITTEE**

Date Considered: April 2016

Decision by Ethical Clearance Committee Granted

Signature of Chairperson of the Committee: 

Name of the Chairperson of the Committee: Prof. G.E. Ekosse



University of Venda

PRIVATE BAG X5050, THOHOYANDOU, 0950, LIMPOPO PROVINCE, SOUTH AFRICA
TELEPHONE (015) 962 8504/8313 FAX (015) 962 9060

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ANNEXURE L



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

Enquiries: Latif Shamila (015 293 6650)

Ref:4/2/2

Raliphaswa NS
University of Venda
Private Bag X5050
Thohoyandou
0950

Greetings,

RE: A model to support mothers of children with intellectual disabilities in selected Health Institutions of Limpopo Province, South Africa

The above matter refers.

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:-
 - Research must be loaded on the NHRD site (<http://nhrd.hst.org.za>) by the researcher.
 - Further arrangement should be made with the targeted institutions, after consultation with the District Executive Manager.
 - In the course of your study there should be no action that disrupts the services.
 - After completion of the study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
 - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
 - The above approval is valid for a 3 year period.
 - If the proposal has been amended, a new approval should be sought from the Department of Health.
 - Kindly note, that the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated.


Head of Department

15/06/2016
Date

18 College Street, Polokwane, 0700, Private Bag x9302, POLOLKWANE, 0700
Tel: (015) 293 6000, Fax: (015) 293 621 1/20 Website: <http://www.limpopo.gov.za>

ANNEXURE M



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

**DEPARTMENT OF HEALTH
MOPANI DISTRICT**

Ref : S5/4/1

Enq: Mohatl I.E

Tel: 015 811 6500

TO: Raliphaswa NS
University of Venda
Private Bag X5050
Thohoyandou
0950

Re: Permission to conduct research titled a model to support mothers of children with intellectual disabilities in selected Health Institutions of Limpopo Province, South Africa

The above matter refers:

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:
 - Research must be loaded on the NHRD site (<http://nhrd.hst.org.za>) by the researcher.
 - In the course of your study there should be no action that disrupts the services.
 - After completion of the study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
 - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
 - The above approval is valid for a 3 year period.
 - If the proposal has been amended, new approval should be sought from the Department of Health
 - Kindly note, that the Department can withdraw the approval at any time.

Regards


DIRECTOR: CORPORATE SERVICES

DATE

27/6/11

ANNEXURE N



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

**DEPARTMENT OF HEALTH
VHEMBE DISTRICT**

REF: S8/4/9

TO: ACTING DIRECTOR HOSPITAL SERVICES: MR MAKHWANYA TE

FROM: CHIEF DIRECTOR

DATE: 2016/06/22

SUBJECT: ACTING CHIEF DIRECTOR HEALTH SERVICES

-
1. The above matter has reference
 2. Kindly note that you are appointed to act Chief Director on the 22 June 2016.
 3. During the acting process you are entitled to run the district affairs and you are shouldered with full responsibilities in managing all programs and Hospital Services in the district
 4. Hoping you will get the assistance you need for the sake of delivery of health services.

CHIEF DIRECTOR: HEALTH SERVICES VHEMBE

DATE: 2016/06/22

Private Bag X5009 TSOHOVANDOU 0950
Old Parliamentary Building Tel: (015) 962 1000(Health) (015) 962 4958(Social Dev)
Fax (015) 962 2274/4623.

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ANNEXURE O



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH
SILOAM HOSPITAL
Confidential

Ref: S5/3/2
Eng: Netshikweta N.D
Date: 2016/08/02

To: Ms Raliphaswa N.S.



RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH AT SILOAM HOSPITAL .

1. The above matter refers:
2. Receipt of your letter regarding application for permission to collect data for the fulfilment of your Doctor of Philosophy degree in Health with the University of Venda (UNIVEN) is hereby acknowledged.
3. Kindly note that your application to conduct research has been approved.
4. Wishing you success in your study.


Chief Executive Officer

2016/08/02
Date

ANNEXURE P

CONFIDENTIAL



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

**DEPARTMENT OF HEALTH
MOPANI DISTRICT
LETABA HOSPITAL**

Ref: 8/1/1
Enq: Machimana G.G
Date: 19 August 2016

Raliphaswa N.S
University of Venda

RE: Supportive care model to mothers of children with intellectual disability in selected institutions of Limpopo Province

4. The above subject matter refers.
5. You are granted permission to conduct the above research at Letaba Hospital as per permission granted by the Head of Department, Limpopo Department of Health.
6. Hoping that you will find this to be in order.



CHIEF EXECUTIVE OFFICER

2016/08/19

DATE

Private Bag X 1430, LETABA, 0870
Cnr. Tarentaal and Lydenburg Road, Tel: (015) 303 8200, Fax no: 015 303 8421

CONFIDENTIAL
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ANNEXURE Q

CONFIDENTIAL



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA


DEPARTMENT OF HEALTH
MAPHUTHA L. MALATJI HOSPITAL

Ref: S5/2/3
Enq: Selkgobela G.L
Tel: 015 769 1520

To: Raliphaswa NS
University of Venda

RE: PERMISSION TO CONDUCT RESEARCH TITLED A MODEL TO SUPPORT MOTHERS OF CHILDREN WITH INTELLECTUAL DISABILITIES IN SELECTED HEALTH INSTITUTIONS OF LIMPOPO.

1. The above matter refers:
2. Kindly be informed that permission to conduct research at the above mentioned institution is hereby granted.
3. The approval is valid for a period of four Months effective from September to December 2016.
4. You are requested to ensure that service delivery is not affected during your research.
5. Further you are requested to ensure that all conditions laid in your approval from the Department are adhered to.
6. Your cooperation will be highly appreciated.


Chief Executive Officer


Date

Stand 3519, Zone 2, Maphutha Drive, Namakgale, 1391,
Private Bag x11020, Namakgale, 1391
Tel: (015) 769 1520; Fax: (015) 769 3531 /
Fax to email: 086 425 7530/ E-mail address: Registry.M@dhsd.limpopo.gov.za

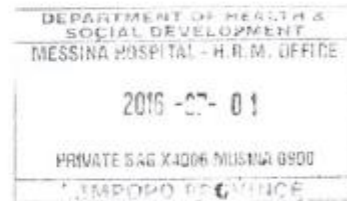
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ANNEXURE R



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

REF: S5/4/1/2
ENQ: Radzilani A.C
DATE: 01 July 2016
FROM: HUMAN RESOURCE DEVELOPMENT
TO: Mrs. Raliphaswa N.S



RE: APPROVAL TO CONDUCT RESEARCH ON A MODEL TO SUPPORT MOTHERS OF CHILDREN WITH INTELLECTUAL DISABILITIES IN SELECTED HEALTH INSTITUTIONS OF LIMPOPO PROVINCE

1. The above matter has reference.
2. This office wish to inform you that your application has been approved. You are requested to liaise-with office of the Chief Executive Officer on the commencement date.
3. Your co-operation will be highly appreciated.


.....
CHIEF EXECUTIVE OFFICER

2016.07.01
DATE

P.o. Box 60 Musina 0900
Tel: 015 534 0446 Fax 015 534 0819

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ANNEXURE S



LIMPOPO

PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH
NKHENSANI DISTRICT HOSPITAL

Private Bag X9581

Giyani, 0826

Tel: (015) 811 7300

Fax: (015) 812 2461

Ref: S5/1/6/2

Eng: Masangu NI

Date: 30 August 2016

TO: Ms Raliphaswa N.S

RE: APPLICATION FOR PERMISSION TO CONDUCT THE RESEARCH STUDY

1. It is with pleasure to inform you that your application for the aforementioned study has been approved at Nkhensani District Hospital.
2. The approval of your research study is subject to the following conditions:
 - 2.1 During the course of your research study, hospital services should not be disrupted.
 - 2.2 Upon completion of the study, you should be prepared to assist in the interpretation of the study findings/recommendations where possible.
 - 2.3 After completion of the study, it is mandatory that the findings should be submitted to the Department of Health to serve as a resource.
3. You should liaise with the Office of the Chief Executive Officer (CEO) as and when you intend to start research study.
4. Your cooperation is always appreciated


CHIEF EXECUTIVE OFFICER

30/08/2016
DATE:

ANNEXURE T



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

**DEPARTMENT OF HEALTH
ELIM HOSPITAL**

Ref: SS/3/1/2
Enq: Chauke N.E
Date: 2016.07.22

University of Venda
Private Bag X5050
Thohoyandou
0950

To: Mrs Raliphaswa N.S:
Contact Number: 0822627809/0732487780

From: Human Resources Organizational Strategy and Planning.

SUBJECT: MODEL TO SUPPORT MOTHERS OF CHILDREN WITH INTELLECTUAL
DISABILITIES IN SELECTED HEALTH INSTITUTIONS OF LIMPOPO PROVINCE”.

1. The above matter refers.
2. Receipt of your request dated 22 July 2016 on conduct the above indicated research is hereby acknowledged with thanks.
3. Kindly be advised that there is no objection as the Head of the Department has granted you the opportunity to conduct your study at the institution.
4. Kindly take note that the institution is granting you permission; therefore you are expected to adhere to the conditions as set out in the approval from the Head of the Department .
5. Your understanding will be appreciated.



CHIEF EXECUTIVE OFFICER

04 / 08 / 2016

DATE

P/Bag X312, Elim Hospital, 0960
Tel (015)556 3201/2/3/4/5, Fax (015)556 3160, Email: elimhospital@dhw.norprov.gov.za
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ANNEXURE U

STEVENS EDITING AND PROOFREADING

~ EDITING ~ PROOFREADING ~ WRITING ~

BA: English; Industrial psychology (UNISA)

Sole Proprietor

Membership:

PEG (SA)

IPEd (WA)

7 May 201

THIS IS TO CERTIFY THAT:

I have language edited a Doctor of Philosophy thesis for Mrs Ndidzulafhi Selina Raliphaswa titled '*A supportive care model for mothers of children with intellectual disabilities in selected health institutions of Limpopo Province, South Africa*'. Ms Raliphaswa is a student at the University of Venda, South Africa. Email: ndidzulafhi.raliphaswa@univen.ac.za; student number : 11595813.

The scope of my editing comprised:

- Spelling
- Tense
- Vocabulary
- Punctuation
- Word usage
- Language and sentence structure
- Checking of referencing style

It was a pleasure reading and editing a very well-prepared paper on a very relevant matter. My best wishes accompany this student and I wish her great success in her studies and future career.

Yours faithfully,

Charlotte Stevens (Ms)

Stevens Editing and Proofreading

e: ajc.stevens@gmail.com

[Note: Signature withheld for security purposes.]

ANNEXUTE V

Qualitative data analysis

Doctor of Philosophy in Health Sciences

Ms NS Raliphaswa

THIS IS TO CERTIFY THAT:

Prof. Tebogo Maria Mothiba has co-coded the following qualitative data:

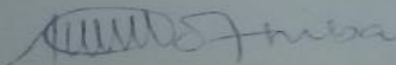
Unstructured one-to-one interviews

For the study:

Development of a supportive care model for mothers of children with intellectual disability in selected health institutions of Limpopo Province, South Africa

I declare that the candidate and I have reached consensus on the major themes reflected by the data during a consensus discussion meeting. I further declare that adequate data saturation was achieved as evidenced by repeating themes.

Prof TM Mothiba



TM Mothiba (PhD)