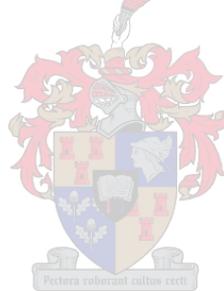


**THE PSYCHOSOCIAL NEEDS OF MOTHERS WITH
PRIMARY SCHOOL PHYSICALLY DISABLED CHILDREN:
THE ROLE OF SOCIAL WORK IN COMMUNITY BASED
REHABILITATION**

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MARCH 2011

DECLARATION

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DEDICATION

This thesis is dedicated to my loving and supportive husband Masego Office and my son Refentse Simba Office who continued to pray for me throughout my studies. I will always remember his little voice saying “thank you God for my mum, bless her food and make her pass.”

“May the favour of the Lord our God rest upon us; establish the work of our hands for us.”
(Psalms 90:17).

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ABSTRACT

Disability can be physical or mental and have different causes, which determine how it is classified. This study will concentrate on physical disability. In the past, the causes of disability were associated with many beliefs of which most perceived disability as something bad. In Botswana, even though people now understand the causes of disability, they still associate it with something bad or have not fully accepted disabled people. The beliefs surrounding physical disability are worse due to the fact that the disability is visible.

The way people perceive physical disability does not only affect the disabled person, but also their families. As the causes of disability vary and can develop prior to birth or be acquired later in life, they affect the different age groups in different ways. This study will focus on physical disability in school children and will explore the impact it has on their mother's psychosocial needs.

The physical disability of school children has different challenges depending on the type of disability. The challenges can be physical, social, economic and psychological. Due to these challenges these children are considered to have special needs and require special care. The special care involves providing for their special basic needs and their medical, social and psychological needs at home and at school. The physically disabled school children also use special equipment which helps them with their daily activities. This equipment needs special care and these children therefore need to go for regular checkups. They also need to be assisted with how to use this equipment at home and school.

The challenges of physically disabled school going children are administered by social workers under the Community Based Rehabilitation (CBR) Programme. The CBR must assist with improving the lives of disabled children and their families. When the social workers attend to the disabled school going child, they concentrate on the medical part of the child's disability, often forgetting other needs. They also do not attend to the mother and her needs, as she is the primary carer.

This study was conducted in Letlhakeng village in Botswana. Twenty (20) biological mothers of physically disabled school going children were interviewed using a semi structured questionnaire. The sampling was a non probability purposive sample and the study used both quantitative and qualitative methods of research.

The quantitative study has shown that the mothers in the area have limited education and are non-skilled. They are still active and most of them are single parents engaged in low income economic activities or not doing anything and they have a reasonable number of children. Their housing structures are poor and not accessible for the disabled children.

The results indicated that mothers know about disability, but the causes have not been fully communicated to them. Even though they consider physical disability to have a natural cause, they still associate it with other beliefs according to which the disability could have happened at birth or after birth. This indicates that cultural beliefs still have an impact.

The mothers send their children to school but their schooling is not taken seriously as the mothers do not know about programmes like special education that can help their children. They still have negative feelings when the child is at school. In addition the mothers are not comfortable with the school environment and still believe a disabled child does not have the capacity to learn.

The qualitative study showed that mothers have psychosocial needs which are not provided for, as they feel that CBR does not involve them and assist them accordingly. This therefore deprives them of the information and confidence to provide for their disabled children.

The mothers do not interact well with their relatives and the community due to the negative attitudes they have towards the disabled. They also lack support from them and from the social workers, because at the time of this study there was no social worker in the area.

The mothers showed that they have the burden of caring for their disabled children and this is affecting them physically, economically, socially and psychologically.

The role of social work in rehabilitation is still not taken seriously as indicated by the fact that the post at the rehabilitation office has remained vacant for so long.

Overall, mothers have psychosocial needs and experience difficulties in coping with the burden of providing for their physically disabled school going children and the social workers are not playing their role in this regard to assist them.

The recommendation is made for advocacy to assist the physically disabled children and their families especially the mothers as the primary caregivers and to improve the role of the social worker.

OPSOMMING

Gestremdheid kan liggaamlik of geestelik wees en het verskillende oorsake waarvolgens dit geklassifiseer kan word. Hierdie studie fokus op liggaamlike gestremdheid. In die verlede is die oorsake van gestremdheid met allerlei gelowe verbind, wat meestal as negatief beskou is. Selfs al is die oorsake van gestremdheid vandag bekend, is daar steeds mense in Botswana wat gestremdheid as iets boos beskou of diegene met gestremdhede nie ten volle aanvaar nie. Die gelowe rondom liggaamlike gestremdheid is selfs eger omdat die gestremdheid sigbaar is.

Die manier waarop mense liggaamlike gestremdheid beskou, beïnvloed nie net die gestremde persone nie, maar ook hulle gesinne. Aangesien die oorsake van gestremdheid verskil en dit by geboorte of later opgedoen kan word, beïnvloed dit verskillende ouderdomsgroepe op verskillende maniere. Hierdie studie fokus op liggaamlike gestremdheid by skoolkinders en ondersoek die impak daarvan op hulle moeders se psigososiale behoeftes.

Die liggaamlike gestremdheid van skoolkinders bied verskillende uitdagings na gelang van die soort gestremdheid. Die uitdagings kan liggaamlik, maatskaplik, ekonomies en sielkundig wees. Hierdie uitdagings beteken dat die kinders beskou word as kinders met spesiale behoeftes wat spesiale sorg nodig het. Die spesiale sorg behels dat voorsiening gemaak moet word vir hulle spesiale basiese behoeftes, asook hulle mediese, maatskaplike en sielkundige behoeftes tuis en by die skool. Liggaamlik gestremde skoolkinders gebruik ook spesiale toerusting wat hulle in staat stel om hulle daaglikse aktiwiteite te kan uitvoer. Aangesien hierdie toerusting deel uitmaak van spesiale sorg, word die kinders gereeld medies ondersoek. Hulle moet ook hulp kry om die toerusting tuis en by die skool te gebruik.

Die uitdagings wat die skoling van liggaamlik gestremde kinders bied word ooreenkomstig die Gemeenskapsgebaseerde Rehabilitasieprogram (GBRP) deur maatskaplike werkers aangebied. Die GBRP is gemik daarop om kinders met gestremdhede én hulle ouers se omstandighede te verbeter. Wanneer die maatskaplike werkers met skoolgestremde kinders werk, fokus hulle op die mediese sy van die kind se gestremdheid en vergeet dikwels van die ander behoeftes. Hulle sien ook nie om na die moeder – wat die hoofversorger is – en hár behoeftes nie.

Die studie is uitgevoer in die dorpie Letlhakeng in Botswana. Onderhoude is gevoer met twintig biologiese moeders van skoolgaande liggaamlik gestremde kinders deur gebruik te

maak van 'n halfgestruktureerde vraelys. Die steekproefneming behels 'n doelgerigte niewaarskynlikheidsteekproef en die studie gebruik kwantitatiewe sowel as kwalitatiewe navorsingsme.

Die kwantitatiewe studie dui daarop dat die moeders in die gebied oor 'n lae opvoedingsvlak beskik en weinig vaardighede het. Ofskoon hulle nog aktief is en die meeste van hulle die hoof van die huishouding is, is hulle betrokke by ekonomiese aktiwiteite wat lae inkomste bied. Ander beskik oor geen inkomste nie, terwyl die getal kinders binne die nasionale gemiddeld is. Die huisstruktuur is swak en ontoeganklik vir kinders met gestremdhede.

Die resultate dui daarop dat die moeders vertrou is met gestremdheid, maar dat die oorsake daarvan nie volledig aan hulle oorgedra is nie. Selfs al besef hulle dat liggaamlike gestremdheid wel 'n natuurlike oorsaak het, assosieer hulle dit steeds met ander gelowe wat by geboorte of na geboorte 'n rol kon speel. Dit dui daarop dat kulturele gelowe wel 'n impak op hulle het.

Alhoewel die moeders hulle kinders laat skoolgaan, word die skoling nie in 'n ernstige lig beskou nie, aangesien die moeders onbewus is van spesiale onderrigprogramme wat hulle kan help. Hulle bly dus negatief oor hulle kinders se skoolbywoning. Verder het die moeders nie vertrou in die skoolomgewing nie en meen gestremde kinders se leervermoë is ontoereikend.

Die kwalitatiewe studie wys dat moeders psigososiale behoeftes het waarin daar nie voorsien word nie. Hulle meen die GBRP betrek hulle nie en staan hulle nie dienooreenkomstig by nie. Dit ontnem hulle dus die inligting en selfvertroue om vir hulle gestremde kinders te kan voorsien.

Die moeders kommunikeer nie juis met familieledede en die gemeenskap nie weens die familieledede en gemeenskap se ingesteldheid. Die moeders kry nie bystand van hulle óf van maatskaplike werkers nie. Met die studie is daar vasgestel dat daar geen maatskaplike werkers in die omgewing is nie.

Dit was duidelik dat die moeders gebuk gaan onder die las om hulle gestremde kinders te versorg en dat dit hulle liggaamlik, ekonomies, sosiaal en sielkundig beïnvloed.

Die rol van maatskaplike werk in rehabilitasie word steeds nie ernstig opgeneem nie en daarom staan die rehabilitasiekantoor dikwels vir lang tye leeg.

Oor die algemeen het moeders psigososiale behoeftes en hulle vind dit moeilik om die las te hanteer wat die skoling van hulle liggaamlik gestremde kinders op hulle plaas, terwyl daar onvoldoende maatskaplike werkers is om bystand hiermee te verleen.

Daar word vervolgens aanbevelings gedoen en voorspraak gelewer om die gesinne en families van liggaamlik gestremde kinders te help, veral betreffende die rol van die moeders as versorgers en om maatskaplike werkers se betrokkenheid te verbeter.

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CHAPTER ONE

INTRODUCTION

1.1 INTRODUCTION

This chapter presents an overview of disability, the psychosocial needs of mothers of school-going physically disabled children and the role of social work in community-based rehabilitation. A brief description of Botswana, its population, history, geographical information and socioeconomic status is also presented. The chapter also describes the mother-child attachment, different types of physical disabilities found in children and the methodology used in the study.

1.2 RATIONALE OF THE STUDY

The World Health Organisation (WHO) (2001:13) defines disability as the restriction or lack of ability to perform activity in the manner or range considered normal for human beings. However, different people in different countries have varying views about disability, The United Nations Report, The World Programme of Action (1983) reflects that causes of disability vary throughout the world as does the prevalence and consequences thereof. Each society has its own method of helping and providing for the welfare of the disabled. Despite these variations, there is some consensus that a person with disability can either have permanent physical or mental impairment, chronic disability or be challenged in respect of their mental health. (Encyclopaedia of Social Work, 1995).

According to the World Health Organisation's (WHO) (2001) national estimation, 10% of a country's population is disabled. Even though disability is viewed differently in each society, it is a significant challenge for each society. Disability is different in developed countries to what it is in developing countries, with most African countries falling into the category of developing country. Mark Priestly (2001) highlighted that the United Nations estimates show that 80% of disabled people live in the so-called developing countries, and mostly in isolated and rural areas. Two hundred million of these people have sensory, intellectual or mental health impairments. This gives a benchmark of 2.5% of children aged 0-14 years with self evident or moderate to severe levels of sensory, physical and intellectual impairment, while an additional 8% have learning or behavioural difficulties or both.

Dealing with disability has always been a challenge to society, affecting it in numerous ways such as socially, medically, economically, physically and psychologically. According to Nichols (1977), the greatest effect is on the families of the disabled persons and the mothers in particular. In accordance with Sheafor, Horesji and Horejsi's (2000) explanation of systems theory, a family is a system comprised of subsystems and if one subsystem does not work it affects all other systems.

This study will concentrate on physical disability in children. Gulliford and Upton (1992) state that disabilities can be congenital or acquired. Philpott (2006:273) indicates that the incidence of congenital conditions and birth defects is prevalent throughout the world, but that some developing countries have a higher incidence of these disorders. This author continues by saying that these disorders affect up to 60% of children and come in the form of a variety of conditions, seen either at birth or after birth. Gulliford and Upton (1992), and Bowe (2000) explain that physical disabilities are conditions that primarily affect mobility (gross or fine motor control), including some conditions like muscular dystrophy, spina bifida and spinal cord injury as well as arthritis, multiple sclerosis and traumatic brain damage. These authors also state that physical disabilities are generally either neurological or musculoskeletal in nature. Neurological conditions involve the central nervous system, according to Philpott (2006). The WHO indicates that 10% of neurological disability, for example multiple sclerosis, is part of all disabilities. Musculoskeletal conditions involve the muscles or the skeleton, for example, muscular dystrophy.

Research by UNICEF-Innocenti No 13 (2001) emphasizes that it is a daily reality that children with a disability often have a poor start in life and are denied opportunities to develop their full potential and to participate in society. This may therefore lead to them not having access to good education, health, welfare, protection and an enabling environment. In other words they are in places where it is not easy to find solutions to challenges associated with their disability. Due to societal stigma and discrimination of the physically disabled, mothers of disabled children may find it difficult to freely access and utilise services intended for them.

In Botswana, the Census Report of 2001 showed that 2.99% of Botswana's population is disabled, which is below the WHO's national estimation. Disability nevertheless remains a serious challenge to the country. The same report states that

2.68% of the school going population are disabled and 58.99% of them live in rural areas. The major physical disabilities are hearing, visual and speech impairment. However, according to Tsheko, Odirile, Segwabe and Bainame (2006), statistics reveal that provision of services to vulnerable children is limited to orphans. In other words orphans are always considered vulnerable and given more attention than the disabled children and their families. What this therefore implies is that disabled children are not included in the care and support services provided by social welfare programmes.

The Botswana government has no grant for mothers of disabled children or for the disabled children themselves. Much attention is given to orphans and destitute persons. According to the Botswana Social Security Programmes (2005) there are no statutory benefits for the disabled child except for those registered for the orphans or destitution programmes. The special needs of disabled children require additional income on the part of their mothers hence the need for financial assistance. This is supported by Lonsdale (1978:116) who reflects that “No one will deny that in rearing a handicapped child there is extra expenses that will not occur with a normal child.” A further indication that a child needs a mother who is committed to fulfilling her mothering role effectively. Having a disabled child demands greater commitment to ensure that the child develops to the best of his/her potential and can be integrated into mainstream society. Mothers have their own cultural, physical and emotional needs that must be met in order for them to effectively mother their disabled children. Consequently, this study will concentrate on the psychosocial needs of mothers of disabled primary school going children. There are social service programmes designed to assist disabled children and their families to cope with the disability and its challenges, but this study will focus specifically on the role of the social worker in community based rehabilitation.

Most experts on child development agree that mothers provide the first best relationship to an infant (Nichols, 1977). The mother has inbuilt and acquired characteristics that help her to affectionately nurture the helpless child. The attachment theory by John Bowlby (1969), Erikson (1959) and family systems theory by Sheafor *et al.* (2000) re-affirm the importance of a mother’s role in child development. However, Nichols (1977) further explains that there are certain factors like religious commitment, cultural elements, socio-economic motives and personal

experiences, which can make mothering a challenging experience. In these cases mothers need support to overcome these challenges, which is why in this study the focus will be on the psychosocial needs of mothers of disabled children.

Felix Silwimba (1992) notes that in Africa, disability was culturally perceived as punishment from God. In Botswana, some families still hide their disabled family members for fear of discrimination or stigmatisation. In some cases families blame each other or witchcraft. The high prevalence of HIV/AIDS and the stigma attached to it has compounded this problem as some families affected by the disease may then also be blamed by society for any disabilities that occur within their families. Regrettably, the Constitution of Botswana does not include disability in its anti-discrimination policy. Regardless of the fact that since the nineteenth century people have started accept disability, Breakwell and Rowett (1982), Marks (1990), Davis (1995), Dale (1996), Barnes and Mercer (2005) purport that disabled persons are still affected due to their identity, relationships, group membership and physical environment.

The Botswana government has adopted initiatives like the United Nations Agreement on Human Rights and the African Charter on the Rights and Welfare of the Child (1999) to demonstrate that the rights and welfare of all its citizens are protected. In addition the government launched the African Decades of People with Disabilities in 2002 and adopted the United Nations Standard Rules on Equalisation of Opportunities for People with Disabilities. Botswana adopted the national policy on care for people with disabilities which came into effect in 1996. The National Education Policy was revised to include services for special education for people with disabilities and special education courses were introduced at the University of Botswana. In its vision for the future the Botswana government has aligned its mission with the provision of services for people with disabilities. The main problem has been lack of legislation concerning disabled people to ensure that these programmes are effectively implemented and monitored. However, draft legislation that is currently being formulated will hopefully address this shortcoming.

The situation in Botswana is very different to that of South Africa where legislation is already in place that stipulates what must be implemented. In South Africa there is for example the Social Assistance Act No 59 of 1992, the Employment Equity Act No 62 of 1998, the Skills development Act No 58 of ,2001 which all relate to disabled

persons and their special needs. All these acts are implemented for provision of quality services to disabled persons. Lack of legislation regarding assistance for disabled persons will then automatically result in delayed provision of programmes for assisting the mothers of disabled children.

The Botswana government does not have programmes designed to offer psychosocial support to mothers with disabled children. However, according to UNICEF-ARK for children (2007), progress has been made in that material assistance is being offered to orphans, which is essential because of the escalating number of orphans due to HIV/AIDS. With the result more orphans received better assistance than disabled children. In this situation the psychosocial needs of mothers with disabled children remain unattended to, hence the need for empirical research in this regard.

The Botswana Government has adopted the Community Based Rehabilitation (CBR) approach to address the needs of disabled and affected families. The Ministry of Health in collaboration with the Ministry of Local Government use this strategy to provide rehabilitation services. The government also provides financial assistance to Non Governmental Organisations (NGOs) through the Botswana Council for the Disabled. Although these organisations are given grants, in most instances they do not meet the needs of the disabled. The CBR renders services to disabled people in community centres and schools through different professionals such as social workers and physiotherapists. Psychosocial support is one of the core duties of social workers. The results however are still unimpressive because the programme is administered through two ministries which complicates the monitoring and evaluation of the programme.

For example, in Botswana there is one (1) rehabilitation social worker per district who addresses all CBR services including psychosocial support for physically disabled children and their mothers. Although CBR programme objectives and National Policy on Care and Care for People with Disabilities (1996) emphasize community education that includes parental involvement, there are no outlined programmes to offer psychosocial support to parents of disabled children. According to the Report of the Survey of HIV/AIDS Awareness, Education and Needs of People with Disabilities in Botswana (2005), most disabled people live in rural areas. Considering the vast distances between villages and the large number of disabled people in the districts, it

becomes very difficult for the social worker to effectively accomplish his/her duties. It is clear then why the psychosocial needs of physically disabled children and their mothers are not adequately addressed. The rehabilitation officer only sees the mother when the child is due for an important appointment with other professionals. The likelihood of meeting the psychosocial needs of the mothers when there is one rehabilitation social worker per district is low. The rehabilitation officer shares resources and facilities with health officials and priority is always given to health officials, making it difficult to offer psychosocial support in privacy. The limited budget reduces distribution of services to disabled children and their mothers leaving them even more disadvantaged. In their studies Pirila, Van der Merwe, Seppanen, Korpela and Nieminen (2005) concluded that the families cope and adapt well in a crisis situation if they have previously received assistance particularly if psychosocial support has been given.

Other literature reveals that mothers of disabled children suffer from emotional, social and psychological disturbances. Studies have shown that mothers of children who need intensive care are more emotionally disturbed than the fathers as they worry about the health and future of their disabled children. Branch and Brinson (2007) reaffirm the attachment theory by stating that attachment is a strong continuous bond between primary care givers and infants, which in most cases are mothers. When a mother thinks of all the issues concerning disability and societal attitudes, she is overwhelmed by the fact of having a disabled child. Their reaction can be negative or positive depending on their coping mechanisms, but mostly it is negative due to the permanency of disability. Also, the Children's Act No 59 of 1981 does not make provision for emotional and rehabilitative support for children and their families (NGO complimentary report on the status of CRC implementation in Botswana, 2004).

McMichael (1971), Burden (1978:173), Lonsdale (1978), Munro (1985), Yim, Moon and Rah (1996), Brearley (1997), Quinn (1998), Heinman (2002), Green (2003), Mckeever and Miller (2004) believe that disabled children have an impact on the emotional and social life of their parents, which was reinforced by Wishart, Bidder and Gray (1981:269), Lemes and Barbosa (2007). They go on to say that disabled children cause most mothers to respond negatively and experience feelings of depression, shock, anger, denial, self blame, guilt, sorrow, grief, confusion, despair, hostility and emotional breakdown. They are forced to make changes to their lives as

these children have special needs which are financially demanding. It may be necessary for these mothers to change their careers and social activities in order to accommodate the needs of the disabled children.

Although Young and Harper (1981) and Turner (1983) believe that with counselling mothers can overcome negative feelings and reach a level of maturity and tolerance regarding their physically disabled child, they will however still experience anxiety about the child's future and integration in society. An example could be anxiety about enrolment in school and social integration into society, as shown by Young and Harper (1981) in their studies of children with Hunter's syndrome.

Yim *et al.* (1996), Brealey (1997), Ferland and Piper (1981) and Brandon and Hogan (2001) indicate in their studies that childbirth automatically changes the mother's life due to the developmental and physical needs of the child. At the same time the family also needs the mother to care for them, which is why mothers need psychological and emotional support. McMichael (1971), Quinn (1998), Wishart *et al.* (1981) and Landsman (2006) further state that even parents of normal children are concerned about parenthood as it brings change and adaptation to their lives, whereas mothers of disabled children are faced with even more overwhelming challenges in caring for and loving the physically disabled child. Wishart *et al.* (1981:269) and Lemes and Barbosa (2007) add to this by saying that mothers of disabled children lack psychosocial support that can provide a conducive, welcoming and accepting environment; without stigmatisation and discrimination. They also lack emotional and financial support. According to Erikson's (1959) psychosocial theory, attention should be paid to the person's ego and personality development. This will assist mothers to cope with the challenges of living with disabled children.

Due to the negative effects, various authors suggest that, mothers of disabled children need psychosocial support. The National Monitoring and Evaluation Framework for Orphans and Vulnerable Children (2008:16) stated that "Appropriate psychosocial support interventions ensure that quality of life and motivation to live are optimised." Although mothers may try to be positive about their children's physical disability, the pressure experienced due to stigmatisation and discrimination from families and society makes it difficult for them to cope psychologically and socially, leading to depression, anxiety and hopelessness, hence the need for a study such as this.

1.3 STATEMENT OF THE PROBLEM

Social workers in Botswana do not play an active role in programmes that assist in addressing psychosocial needs of mothers of disabled children. They concentrate on disability programmes only, which tend to show little progression. While most mothers care for their children relying on the lay knowledge they have, it is not an easy task. They need professional guidance, assistance and support from social workers. Social workers could address issues of disability more holistically by helping the whole family instead of just the disabled child. This would promote social development; because the goal of development is to improve the living conditions of all people and empower them to fully participate in economic, political, maternal, cultural and social arenas.

1.4 THE AIM AND OBJECTIVES OF THE STUDY

1.4.1 The aim of the study

The aim of this study is to contribute to an understanding of how social workers could be more attentive when attending to the psychosocial needs of mothers with disabled children. It also aims to present guidelines for social workers on how to address the psychosocial needs of mothers with disabled children.

1.4.2 The objectives of the study

Based on the aim of the study the objectives are as follows:

To describe different physical disabilities of disabled primary school children and the care they require.

To discuss the psychosocial needs of mothers who are responsible for the care of their physically disabled primary school children.

To identify and explain the role of the social worker in community based rehabilitation, in addressing the needs of families with disabled primary school children.

To explore the perceptions of social workers on how to address the psychosocial needs of mothers with physically disabled primary school children, from a community based rehabilitation approach.

To develop guidelines for the social workers to use in addressing the psychosocial needs of mothers with physically disabled primary school children.

1.5 DEFINITIONS OF CONCEPTS

1.5.1 Disability

Disability is described by the World Health Organisation (WHO), (2001:213) as restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being. It describes a functional limitation or activity restriction caused by impairment, for example, difficulty seeing, hearing or speaking, difficulty moving or climbing and difficulty with eating, bathing, toileting, reaching and grasping.

1.5.2 Child

According to the African Charter on the Rights and Welfare of the Child, a child refers to every human being under the age of 18 years (1999:3).

1.5.3 Primary school child

The age for enrolment of primary school children varies from one country to the next. Hence the use of the UNESCO (2005:94) definition here, which states that a primary school child is a child enrolled at primary school, which is generally the first six to eight years of formal structured education usually beginning at the age of five, six or seven years.

1.5.4 Psychosocial

Garske and Turpin (1998:29) describe psychosocial as the internal and external factors. These internal and external factors are those psychological, social and disability related factors that play a primary role in adjustment to disability.

1.5.5 Biological mother

According to the Oxford Dictionary a biological mother is a female parent of a child.

1.5.6 Carer

The Oxford Dictionary describes a carer as a person who takes care of a sick or old person at home.

1.5.7 Community Based Rehabilitation (CBR)

Although there are different definitions, the World Health Organisation's definition cited by Lightfoot (2004:457) will be used. Community based rehabilitation is all measures aimed at reducing the impact of disability and handicapping conditions, and at enabling the disabled and the handicapped to achieve social integration. It promotes the use of community resources and personnel to promote basic rehabilitation services in a low cost, yet accessible manner.

1.6 AREA OF THE STUDY

The study took place at Letlhakeng village in the Letlhakeng sub district. The respondents involved were chosen by the district physiotherapist at the rehabilitation office with the assistance of a family welfare educator. They used a register of the names of disabled persons in the district. The district serves 20 villages, but the respondents were only taken from Letlhakeng village as it is the largest in the district and, their register was easy to follow and respondents were easy to reach.

1.7 DESCRIPTION OF BOTSWANA

Figure 1.1 represents a map of Botswana showing its main areas and the neighbouring countries. Letlhakeng is in the Kweneneg area and that is where the study took place.

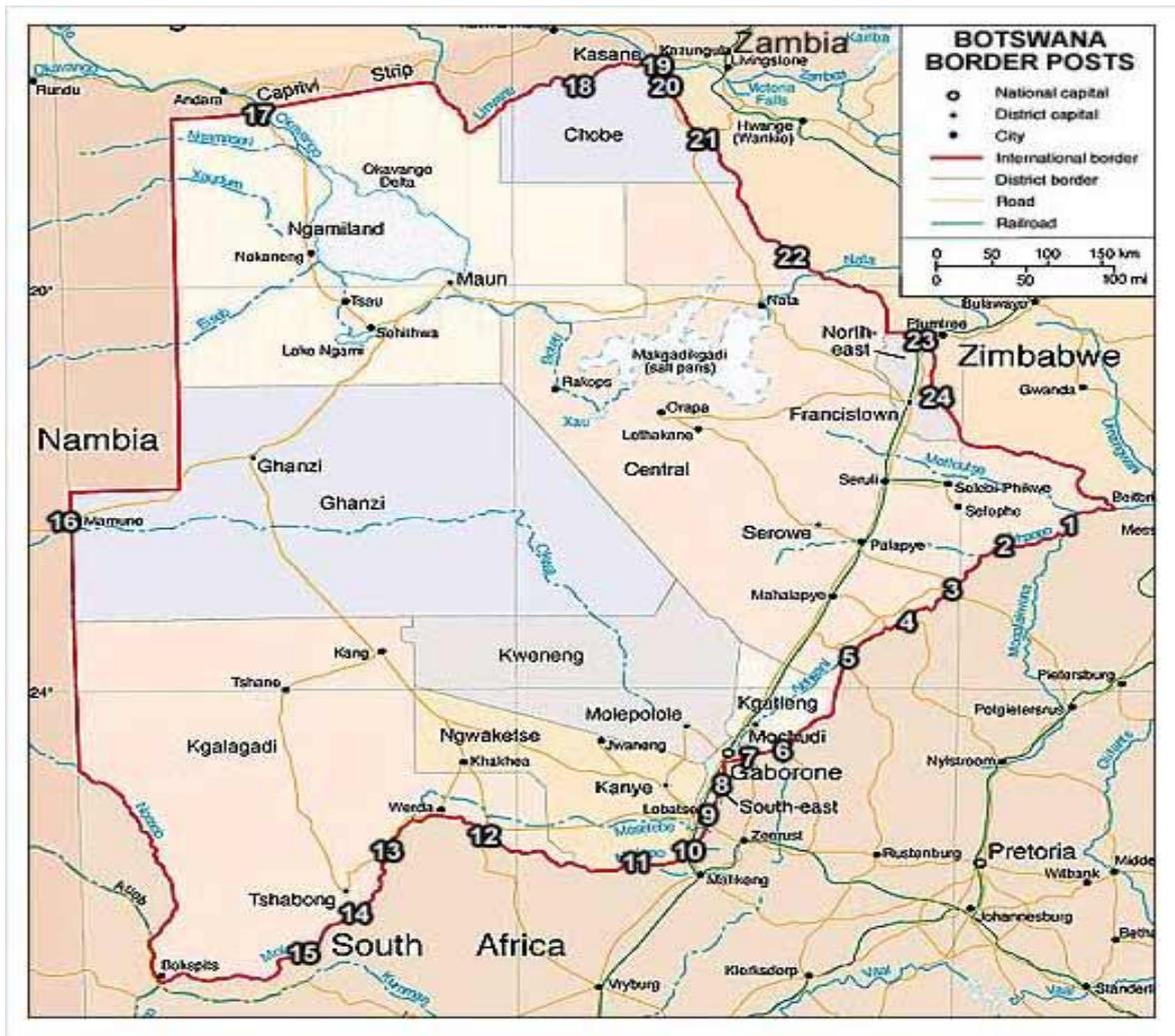


Figure 1.1: Map of Botswana

1.7.1 Geography

As shown in figure 1.1, Botswana is a landlocked country about the size of Texas that covers an area of 582,000 sq. km (224,710 sq. miles) and its neighbours are South Africa in the south, Zimbabwe in the east and Namibia in the west and north. There is a river crossing into Zambia in the north east. Most of the country is covered by the Kalahari Desert which has a low rainfall, sandy soil and sparse savannah woodland vegetation. It has a population of about two million according to the 2001 Census Report of Botswana. Most of the population live in the eastern part of the country where there is a higher rainfall and more fertile soil, while the remainder of the population are scattered over the southern and western parts. The country is divided into administrative divisions comprised of nine districts and four town councils: Francistown, Gaborone, Lobatse, Selebi-Phikwe.

1.7.2 History

Since gaining independence from Britain in 1966, the Republic of Botswana has been a parliamentary democracy with an elected president. The country has a long and unbroken democratic tradition and has held eight national elections since independence. Unlike its neighbours, the country did not struggle for independence as the process was a political one. Its legal system is based on Roman-Dutch law and local customary law; judicial review is limited to matters of interpretation and has not accepted compulsory International Court of Justice jurisdiction.

1.7.3 Socio-economic background

Traditionally Botswana relied on cattle farming for income generation. After independence diamonds were discovered, this increased the country's wealth. Since the 1970's, the economy has been largely reliant on diamonds, but cattle production and tourism also play an important role particularly in terms of employment. The government has been trying to diversify the economy, but this has been difficult. A large amount of the country's resources have been used to develop education, health and general infrastructure. Even though the diamond industry generates a lot of wealth, there is disparity with the division of wealth and most people are poor (Central Statistics Office, 2001).

According to the Central Statistics Office (2001), the rapid spread of HIV/AIDS in Botswana has become a major challenge and threat to its economic and social development plans. The country is one of the most affected in the world, with levels of infection exceeding 30% in the 15-49 year age group. In order to combat the situation most of its financial and manpower resources have been diverted towards HIV/AIDS programmes, for example the provision of free anti retroviral drugs.

1.7.4 Letlhakeng Village

Brief background information on Letlhakeng will be provided as this is where the study took place. Letlhakeng is situated in Kweneng West District. It shares borders with the Khutse Game Reserve in the west, Lentsweletau Sub District in the north, Kweneng District in the east and the Southern and Kgalagadi District in the south west. Letlhakeng village is the capital of the Letlhakeng Sub District. It's about 120

km west of Gaborone. The population of Letlhakeng is 6 032 with 3339 women and 2 693 men (Central Statistics Office, 2001). Women comprise 55.3% of the population.

Letlhakeng is primarily a rural district and communities depend on farming for survival. In some cases, families depend on handouts from Government provided in terms of its Destitute Policy. The dominant language in Botswana is Setswana, although the community also speaks other minority languages such as Sekgalagadi and Seshaga. It is a typical settlement with traditional housing where most of the households do not have running water, proper sewage and electricity. The Department of Water Affairs provides standpipes for use by the villagers who do not have running water in their homes. Most families use firewood to cook rather than gas or electricity.

Letlhakeng is made up of traditional settlements, which still embrace the extended family culture of caring, although there are signs that the extended family bonds have begun to disintegrate. The extended family has always provided a safety net, but is now undergoing tremendous social and economic change that has a direct impact on their ability to provide care. The socio-economic developments taking place in the country have had both a positive and negative impact on society. One such negative impact has been the break-up of the extended family, as more and more family members move into the towns to seek employment. As a result of these movements and the rise in the cost of living, families are no longer able to remain intact and the nuclear family is replacing the extended family (Tsheko *et al.*, 2006:5-6).

1.8 RESEARCH METHODOLOGY

1.8.1 THE LITERATURE REVIEW

In this study, reference is made to related literature on the psychosocial needs of mothers with disabled children. The library, internet and personal communications were used as sources of related literature. A mixed methods approach was used to meet the aims of the study.

Literature on the types of physical disabilities found in primary school children was consulted as well as the effect of physical disability on disabled children at school. In addition, the impact of physical disability on the functioning of disabled primary school children and the psychosocial needs of their biological mothers, were studied. The biological mothers are the primary caregivers within the family. Literature on the

family systems model was also reviewed as the physically disabled child and the mother live within the context of the family. To understand the family system an investigation of their environment and needs is important. The literature was also studied in order to determine how these psychosocial needs of mothers can be attended to by the social worker in community based rehabilitation services. The study examined how childhood physical disability impacts on the psychosocial needs of mothers within the community.

Social work literature and literature from other related disciplines was consulted using both local and international information obtained from the library, internet and personal communications. Sources included scientific books, journals, newspapers, government policies and television news programmes.

1.8.2 RESEARCH APPROACH

Both quantitative and qualitative approaches were used in the study.

1.8.2.1 A quantitative approach

A quantitative approach was used and Creswell (1994:1-2) cited by De Vos, Strydom, Fouche and Delport (2005:74) described quantitative research as an inquiry into a social or human problem, based on testing a theory composed of variables, measured with numbers and analyzed with statistical procedures in order to determine whether the predictive generalization of the theory hold true.

In this study a quantitative approach was applied to look at the psychosocial needs of the biological mothers of disabled primary school children in the village. This was done by administering a semi-structured questionnaire to collect data on their views, background and the services provided. The data collected was analyzed to prove if the problem exists and to assist in formulating guidelines which will help social workers to provide support to these mothers.

1.8.2.2 A qualitative approach

De Vos *et al.* (2005:74) said a qualitative approach is a method that elicits participant's account of meaning, experience or perceptions and it also produces descriptive data in a participant's own written or spoken words and involves identifying the participant's beliefs and values that underlie the phenomena. It is concerned with understanding, natural observation and exploration of reality.

The semi-structured questionnaire was used during interviews. The open-ended questions and answers were organised or grouped to assist the researcher with the background knowledge she had obtained (Rubin & Babbie, 1993:342-343). The researcher interviewed the biological mothers of the physically disabled primary school children for a period of 50-60 minutes. These interviews were recorded so that some of the physical and emotional reactions expressed by these mothers could be captured. Their perceptions of the level of assistance from the social worker was also captured.

1.8.3 Research design

The empirical study was based on and supported by information from the literature sources. It was done to gain an understanding of the psychosocial needs of mothers with physically disabled primary school children and also to find out what assistance they get from the social work programme in the form of community based rehabilitation.

The community based rehabilitation programme is a programme used by rehabilitation social workers to address the needs of the physically disabled children, their families and the community. From literature gathered for this study, it is evident that disability is an area surrounded by a lot of sensitive issues and that this is the case throughout the world. This indicates that the disabled person should be regarded as a person with special needs. Although these special needs are addressed, the system from which the physically disabled child comes is often ignored. The mothers of the physically disabled who are the primary carers have psychosocial needs and some of these needs are made worse by the fact that they are caring for a person with special needs. The rehabilitation social workers focus on the correction of the disability of the child, so the psychosocial needs of both the child and the mother are not always attended to. The study therefore explored the psychosocial needs of these mothers and the role of the rehabilitation social workers by examining the physical environment, emotional reactions and by asking questions relating to the topic during the pilot study. The researcher talked to Dr Mompoti of Botswana University who recommended books on disability that should be read prior to starting with the study. The researcher also went to the Rehabilitation Division but they had little to contribute except to encourage the researcher to investigate the

topic as no research of this nature has been done in Botswana. Barbie (1993:107) encourages exploratory study as it helps the researcher to examine a phenomenon and get a better understanding of it. For the purposes of this study, an exploratory and descriptive design was utilised, as it helped to gain insight into the psychosocial needs of mothers of physically disabled children (De Vos *et al.*, 2005:109).

The goal of the study is to observe the psychosocial needs of the mothers of the physically disabled children and how, by adopting a holistic approach, the rehabilitation social worker in the community based rehabilitation programme attends to the whole family's needs, not just the disabled child.

This study then tries to explain the situations which could be preventing the rehabilitation social workers from attending to the psychosocial needs of these mothers. This explanation is supported by the views provided by Rubin & Babbie (1993:108).

1.9 SAMPLING METHOD

According to Arkava and Lane (1982:27) quoted by De Vos *et al.* (2005:194) a sample comprises elements of the population considered for actual inclusion in the study, or it can be viewed as a subset of measurements drawn from the population in which one is interested.

A non-probability sampling selection was used and, according to De Vos *et al.* (2005:201), in non-probability sampling the odds of selecting a particular individual are not known because the researcher does not know the population size or members of the population. The sample used in this study is the purposive sample as the sample was selected at the rehabilitation office. This is defined by De Vos *et al.* (2005:196) as the method of drawing a sample of a population so that all possible samples of a fixed size have the same probability of being selected.

1.9.1 Criteria for inclusion

In order to draw the above sample, a letter requesting permission to conduct the research was sent to the ministry of Local Government who in turn requested permission from the Chief Executive of Letlhakeng Sub District in Botswana, the necessary permission was granted. The sample consists of twenty mothers of primary school children with physical disabilities from Letlhakeng village in Botswana who met the following two criteria for inclusion. Their children's ages ranged between

five and 12 years. Their children were registered with the Rehabilitation Department. The physiotherapist and the family welfare educator helped to select the mothers as the office has registers containing the particulars of the parents of physically disabled children. The physiotherapist assisted with choosing the sample as there was no rehabilitation social worker, because she had been transferred to another district and was never replaced.

1.9.2 Instruments for data collection

A semi-structured questionnaire was used to solicit information from mothers with children with different physical disabilities. The questionnaire was formulated using information from the literature review. Therefore deductive and as such deductive reasoning was used. This is described by Rubin and Babbie (1993:39-40) and De Vos *et al.* (2005:47), as moving from the general to the particular (applying a theory to a particular case). It moves from a pattern that might be logically or theoretically expected to observations that test whether the expected pattern actually occurs. The research follows a quantitative as well as a qualitative approach to capture perceptions and emotions of these mothers. The mothers were interviewed using a semi-structured questionnaire with open-ended questions to explore their psychosocial needs and social work services that are provided to assist them. The mothers were interviewed at their homes in order to observe their home environment and their interaction with the child when they are at home. The researcher was shown the homes by the family welfare educator and the physiotherapist. The interviews took place over a period of six days and on each day three to four mothers were interviewed. Each interview lasted 50-60 minutes, sometimes longer depending on the emotional reactions of the mothers.

Mothers were the correct group to be interviewed for the purposes of this study, because according to Cook, Cook, Tran and Tu (1997:216) they are the primary caregivers of children with disabilities. Cook *et al.* (1997) and Heinman (2002) also state that as caregivers mothers are the ones that must bear the challenges like social and environmental barriers, psychological issues, health problems, feeling restricted, financial problems and inadequate resources. They are also faced with the lack of coordination between different social services, agencies and authorised

workers. During the interviews they expressed the psychosocial needs they have in caring for their physically disabled primary school children.

1.9.3 Piloting of the Study

The questionnaire that was used in the research was piloted before being used. According to De Vos *et al.* (2005:2006) a pilot study is a small study conducted prior to a larger piece of research to determine whether the methodology, sampling, instruments and analysis are adequate and appropriate. The pilot study was not done with the research sample, but rather with three social workers, one home economics officer and one friend of the researcher who has a physically disabled husband. The aim was to obtain the opinions of experts about the topic, which according to De Vos *et al.* (2005:207) provides one with insights into the experiences of others who are involved on a daily basis in one's field of study and can therefore offer informed opinions. The second pilot study was conducted with mothers of disabled children whom the researcher knows. One mother has three physically disabled children and the other two mothers each have two mentally disabled children. The pilot study assisted the researcher to identify some areas that had been overlooked, such as a question on support groups, a column for comments and the need to reduce the length of the questionnaire from 25 pages to 14 pages as the researcher was interviewing people who are already stressed and the topic was an emotional one for them.

1.10 DATA PROCESSING

The findings were analysed in tables, figures and narratives which led to the formulation of guidelines needed by social workers to address the psychosocial needs of mothers with disabled children. Data collected from the empirical study was used to confirm the information gained from literature sources and quotes from the parents showing their true feelings and their psychosocial needs. The data was collected in the following four areas: physical and material services provided for the physically disabled child that can assist the mother; school services for the child, the psychological needs of the mother and services offered through community based rehabilitation.

1.11 ETHICAL CONSIDERATIONS

A written letter from the researcher's supervisor at Stellenbosch University confirming the intention of the study was given to the Ministry of Local Government as a request for permission to undertake the study (Annexure A). Written permission was issued by the Ministry of Local Government, as Letlhakeng Sub District falls under the said ministry (Annexure B). Permission was requested to ensure that the government was aware of the research being conducted as it dealt with a sensitive issue involving people with special needs. Each mother signed a consent form before participating in the research (Annexure C). The researcher explained the research and its aim to each mother prior to her signing the form so that she could exercise her right to abstain from participating in the research if she so desired.

1.12 LIMITATIONS OF THE STUDY

Most people living in the village that was selected were peasant farmers who spend most of their time in the fields ploughing or herding cattle. Some mothers were not found at home. A message was left at their homes requesting that they return home. Even though the purpose of the interview was clearly explained to the mothers, some of them were uncomfortable with disclosing information to a stranger. They did not allow the researcher to record the interviews as they believed she wanted to use these recordings to cause trouble for them with the government. Some parents stated that they have never been visited by the rehabilitation social worker and hoped that this interview would change that.

1.13 PRESENTATION OF CHAPTERS

Chapter 1

This chapter presents an overview of disability and a description of Botswana. In addition it discusses the methodology of the study.

Chapter 2

This chapter presents a review of the literature that was studied, which encompasses the psychosocial needs of mothers of disabled primary school going children and describes the different physical disabilities found among primary school children. It also focuses on the perceptions of social workers in addressing the needs of mothers of disabled primary school going children.

Chapter 3

This chapter looks at the psychosocial needs of mothers who are responsible for the care of their physically disabled primary school children.

Chapter 4

Chapter 4 discusses the role of a social worker in community based rehabilitation in addressing the needs of the families with physically disabled primary school children.

Chapter 5

This chapter presents the findings and discussion of the study together with a literature control of the findings of the study.

Chapter 6

The final chapter provides conclusions and recommendations of the study. These commendations will assist in developing guidelines for social workers on how to meet the psychosocial needs of mothers.

CHAPTER TWO

AN OVERVIEW OF PHYSICAL DISABILITIES OF PHYSICALLY DISABLED PRIMARY SCHOOL CHILDREN

2.1 INTRODUCTION

This chapter focuses on the literature review of the different physical disabilities of disabled primary school children. This literature was obtained from different sources, both national and international. The following topics will be discussed: an overview of disability, definition of physical disability, prevalence of physical disability, causes of physical disability, disability and education, physical disability and its impact on children, the psychosocial needs of mothers with physically disabled children and disability and community based rehabilitation. Specific reference will be made to the Botswana situation in terms of the needs of mothers of primary school children with physical disabilities.

2.2 AN OVERVIEW OF DISABILITY

As disability is viewed differently in different areas, the definition of disability is broad. The fact being that disability can be based on legal, sociological, psychological, economic, social, medical, cultural and even on subjective matters (Edmonds, 2005:2; Robson & Evans, 2002:2-3). Disability is more than a health issue, because it also depends on peoples' culture, social institutions and physical environment. However, there are world standardised definitions which are used by many researchers in different countries worldwide and the following frameworks and descriptions will be used in this study.

2.2.1 Definition of disability

According to Borzutzky (2000:11), the 1980 Preliminary International Classification of Functional, Disability and Health Report described the conceptual framework for disability in three parts: impairment, disability and handicap which were defined as follows:

Impairment: In the context of a health experience ... the loss or abnormality of psychological, physiological or anatomical structure or function.

Disability: In the health context ... any restriction or lack of ability to perform an activity in the manner within the range considered normal for a human being.

Handicap: In the health context ... a disadvantage for a given individual, resulting from impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual.

The above explanation provided by Robson and Evans (2002:3) shows that disability has different levels, namely impairment which is the individual limitation, disability which is restriction forced by the contemporary organisation of society, and handicap which results from both disability and impairment.

This means that the worldwide concept of disability varies depending on how society views it, and in the WHO manual entitled “International Classification of Functioning, Disability and Health” (2001) (ICF), the view is that an individual’s ability to function in society depends not only upon one’s body and functioning, but also upon environmental and personal factors. It is the way in which societies are organized, in terms of prevailing attitudes, environment and institutions, that either increase opportunities or create barriers for disabled people to participate.

Even in Africa, society holds a similar view of disability, as the Disability Act of Zimbabwe (revised edition: 1996:51) defines a disabled person as “...a person with a physical, mental or sensory disability, including a visual, hearing or speech functional disability, which gives rise to physical, cultural or social barriers inhibiting him from participating at an equal level with other members of society in activities, undertakings or fields of employment that are open to other members of society.” This implies that disability can be understood as malfunctioning, which does not depend only on one’s body, but is also influenced by environmental and personal factors.

Ingstad (1990:18) stated that Botswana does not have a Setswana word that is equivalent to the English words “disability” or “handicap”, which covers all types of impairment. The word “segole” is used for people with physical disability. However some also use it to describe mental disability, but it is then used together with the

part of the body they are describing. Generally Botswana, like other countries, uses world standardized definitions.

The above definitions can be used to define disability in children. Most researchers who have written about disabled children agree that children with disabilities have difficulties in seeing, in hearing, in communicating, in moving and in learning. The report on the Overview of the Situations and Rights of Children with Disabilities in Africa (2000:1) indicates that children with disabilities also have behavioural problems and emotional problems that present challenges to themselves, their peers, their parents, to institutions, and to service providers, that are different from non-disabled children. Compared to adults, children with disabilities have special needs and the main difference is that children are still growing and vulnerable. Field, Jette and Martin (2002:144-145) indicate that disability in child populations is pertinent for the following reasons:

Those with disability health conditions have the prospect of long term survival and reach adulthood.

Disability in children has exceedingly high costs to society, their family and its members.

Children's health is important because they are society's natural resources and so they determine the future of nations and societies.

It has been realized that most causes of adult disability have their origins in childhood.

What this shows is that disability not only involves disabled persons, but also their families and society as a whole. That is why it is important when intervening to consider the whole environment from which the disabled person comes.

2.2.2 Definition of physical disability

Gulliford and Upton (1992:150) stated that physically disabled children cannot be described as a homogeneous group, because they are expected to show the same diverse characteristics and abilities as the normal population that they are part of. According to these authors, physical disability can be described as disability of different organs of the body affected by heredity, traumatic, congenital and medical conditions. The Australian Bureau of Statistics (1996:14) stated that physical conditions cover all

conditions other than mental disorders, including disorders of eyes and ears, head injury, stroke and other brain damage. "Mental disorder" covers mental psychoses and all other mental disorders including intellectual impairment. Physical impairments are identified by limitation on physical activity or work, difficulty gripping or holding things, lack of full use of arms or fingers, and lack of full use of feet or legs. These views indicate that it is difficult to have a separate definition of physical disabilities in children, because the disability is accompanied by other conditions, as stated above.

2.2.3 Classification of disabilities in Botswana

The classification of disabilities in Botswana is outlined below. Even though other kinds of disabilities are not included here it does not mean that they do not exist in the country.

The population census report of 2001 categorized disability as shown in the table below.

Table 2.1 Classification of disability in Botswana

| NAME | EXPLANATION |
|------------------------|---|
| Blind | Complete loss of sight |
| Deaf | Complete loss of hearing |
| Dumb | Complete loss of speech |
| Defects in seeing | Defect impairment in seeing resulting in the person having difficulty in seeing |
| Defects in hearing | Defect impairment in hearing resulting in the person having difficulty in hearing |
| Defects in speech | Defect impairment in speech resulting in the person having difficulty in speaking |
| Inability to use limbs | Loss of power to use one or both arms and legs or combination of both |
| Epilepsy | - |
| Mental retardation | - |
| Mental illness | - |

According to the Botswana Population and Housing Census Report of 2001, because there are difficulties in defining disability, it is normally only those disabilities which are visible or obvious that is included in the census. In this study even though this classification will be used, it will be supported by the definitions of different authors.

For the purposes of this study blindness, deafness and inability to use limbs will be referred to as physical disabilities, because according to Floyd and Gallagher (1977:360) any physical disability can significantly reduce mobility or sensory functions, disrupts independent functioning, or restrict the disabled child's activities and requires special prosthetics or training.

2.3 CAUSES OF PHYSICAL DISABILITIES

There are different causes of disabilities that can be explained according to various models. These different models each have their own view or explanation of different issues. In this section, the causes of physical disabilities will be discussed according to the medical, social and cultural models.

2.3.1 Medical model

According to the medical model Seligman and Darling (2007:5-6) view disability as illness. The model tends to dominate and regards disability as a negative condition that needs treatment, rehabilitation or cure. Despite this situation, mothers of the physically disabled children usually seek ways that will improve their children's ability to be included in society. In Botswana the medical model used for understanding the cause of physical disability is still dominant even though society and environment are trying to change this (Ingstad, 1990). However the changes are still only in theory.

According to Edmonds (2005:51), Ransom (2000:2) and Borzutzky (2000:18-31) the main causes of disabilities are malnutrition and unsanitary living conditions accompanied by poor parental care. Also communicable and non communicable diseases, old age, injuries due to violence, conflicts and accidents, disasters all contribute to the causes of disabilities. These causes can be prevented with preventive medical interventions, awareness raising campaigns and rehabilitation services through primary health care through the health ministries. Edmonds (2005:8) added that at least 50 percent of these causes are preventable in Africa and Asia through primary health care. People with complex disabilities mostly do not survive and so a high number of disabled persons have mild to moderate disability, with children being a large percentage of these. Edmonds (2005:51) elaborates that one third of the population who have disabilities are children and two thirds of them are born or have acquired preventable disabilities due to preventable diseases, congenital causes, malnutrition, micronutrient deficiencies, accidents and injuries, armed conflicts and landmines. In the 20th century two million children were killed at war and five million were disabled.

Under the medical model Borzutzky (2000) describes the list of disabilities as lengthy and varied ranging from physical disabilities, mental health disorders to cognitive, vision and hearing disabilities. This study concentrates broadly on physical disabilities that range in severity from general limitations on stamina to complete paralysis. Some mobility disabilities are caused by conditions present at birth while others are the result of illness or physical injury. Injuries cause different types of mobility impairments, depending on what area of the spine is affected. Furthermore, Power (2001:85) indicated that the root cause of physical disabilities in most parts of Southern Africa is related to landmine accidents, malnutrition, iodine and vitamin A deficiencies, poliomyelitis, Hanson's disease and child birth complications. Ingstad (1990) believes that in Botswana, physical disability is largely due to accidents, tuberculosis of the spine, cerebral palsy, club foot and various types of congenital malformation of limbs. This then shows that disability can be caused by various problems in the body and the environment.

2.3.2 Cultural model

Abosi and Koay (2008:4) stated that there are cultural views which perceive physical disability as a curse or punishment from God because of misconduct on the part of the disabled person's family. Despite the fact that people's attitudes are changing to accommodate and accept physically disabled persons, this cultural view from the past has caused disabled persons to be stigmatised as minorities and regarded as incapable, because people still associate disability with something bad. The Botswana Population Census Report (2001) shows that disabled persons are often not registered because families are hiding them for fear of discrimination and stigmatization. In some communities, families accuse each other of performing witchcraft and casting evil spells. Dart (2007:58) emphasized that in Botswana, despite exposing the disabled to societal activities, they are still the victims of superstition and revenge forces. It is therefore not easy for them and their families to find assistance. Ingstad (1990) continues by explaining that disability can also be viewed as the result of the mother not taking care of herself during pregnancy by not eating good food. For example in Botswana it is believed that there are certain foods a pregnant woman should not eat like eggs or animal hooves, because they cause certain body changes in the child. Another belief is that if a pregnant woman is frightened by something such as an animal or a disabled person, she will have a

child who looks like that animal or person. They also believe that magic or witchcraft can cause the child to be disabled.

Van Dyck, Kogan, McPherson and Weissman (2004) showed that Africans' perception of disease or disability is that it is a form of punishment from God or the ancestors, which is why it is always difficult to deal with these issues. This indicates that effective community based education is needed to change the attitude of mothers, families and the community in general towards diseases and disabilities.

A study on physically disabled persons in Barbados reveals that culturally, physically disabled people are not expected to fulfil normal adult roles and even if they did, their adult status is not guaranteed. This shows how culture can limit the disabled person's participation in society, affects the way the mother relates to the disabled child and influences the way families would care for their disabled members.

2.3.3 Social model

Mout (2007:5-6) and Edmonds (2005:12) state that according to the social model of disability, the causes of disability are different to when viewed according to the medical model. The social model describes disability as arising from the interaction between a person's functional status with the physical, cultural, and policy environments. If the environment is designed to accommodate and support the disabled person's functioning, then they will not be excluded from participation in society's activities. Attention is not focused on correcting the individual's disability, but rather in involving society. For example, making accessible infrastructure, inclusive education systems and campaigning against stigma. Even though in Botswana recent attempts have been made to accommodate the disabled by building disability friendly structures; no hotel, road or recreation facility is truly user-friendly. Taleporos and McCabe (2002:1971) believe that the social model views physically disabled people as likely to be different in respect of their feelings and attitudes about their self image due to factors such as education, social support and perceived social attitudes. In their lives, particularly during childhood and adolescence, their body image is affected by environmental factors and social attitudes. When the environment accepts physically disabled persons, then others will accept them and they in turn will accept themselves, which then ultimately leads to destigmatisation.

Trevillion (2007:938) stated that the model is related to social work as it is committed to human rights, anti-discriminatory practice and empowerment.

Understanding the causes of physical disabilities from different perspectives is important for this study as this lays the foundation for understanding and interpreting the psychosocial needs of mothers with physically disabled children.

2.4 PREVALENCE OF PHYSICAL DISABILITY: A BROAD PERSPECTIVE

As already stated, it is difficult to define disability and therefore it becomes difficult to obtain reliable statistics on physical disabilities in most countries. Most countries follow the international standard of estimation which, according to the World Health Organisation, is that ten percent of a country's population is disabled. Most research done by different authors such as Michael and Sapey (2006) and big organizations like the World Bank, United Nations (UN) and the World Health Organization (WHO), have indicated that it is difficult to obtain reliable statistics on the prevalence of physical disabilities in most countries. This was confirmed by the World Bank, UN and the WHO in 2005. However a few countries have collected statistics on the prevalence of physical disability in their countries over the last decade.

The Australian Bureau of Statistics (1996:14) quoted by Chamie (1995) who states that international data appears to show that physical disabilities are the most commonly reported disabilities. For example, the 1987 national disability survey of Spain estimated that 60.2 percent of people with a disability reported physical impairments as their underlying condition. Data from the 1989 Survey of the National Registry of Germany show that underlying physical conditions were reported by about 70 percent of all people with a severe disability receiving rehabilitation services.

According to the UN and the WHO it is estimated that between 500 and 600 million people in the world today are affected by some type of disability. About two thirds of these people live in developing nations. The prevalence of disability can be as much as 20 percent of the total population in some countries. The impact of disability on development and social advancement can be crippling, affecting some 50 percent of families in high risk countries. The more the population grows around the world, the higher the impact of the burden of disability. Disabled people are stigmatized, excluded from schools or the workplace and often end up depending on others in the

family and community for physical, social and economic support. They are also poor (Edmonds, 2005; Ransom, 2000). Given that many governments are still battling to deal with the issues relating to disability, it will take even longer for them to start dealing with the issues concerning the psychosocial needs of the mothers and caregivers responsible for caring for them.

In 17 of the 27 Eastern European and Central Asian (ECA) countries, the total number of people with disabilities is estimated at about 29 million, or about eight percent out of a total population of 385 million. Changing economies, new social and political strategies along with post conflict situations, de-institutionalization, HIV/AIDS and mental health issues are among the many challenges facing the region. According to Haider (2008), in Pakistan the 1998 census shows that 32,86,630, people are disabled and 0.82 million (24.8%) are of school going age (5-14 years), but only 2.4 percent are enrolled in special schools. In a study done in the USA by Van Dyck *et al.* (2004) the highest prevalence of disability was among boys, school age children and children in lower income families.

In Africa, an estimated 60 to 80 million people are living with disabilities. These numbers are rising due to conflict, malnutrition, natural disasters and HIV/AIDS. The Disability Statistics (DISTAT) of 2005 includes disability statistics from over 75 countries, including 28 African countries. According to DISTAT data, the prevalence of persons with disabilities in African countries ranges from 0.5 percent to 4.0 percent. The numbers of children with disabilities, aged 0-14 years, ranges from 0.1 percent to 1.0 percent. There are serious concerns about the apparent underreporting of the prevalence of disability as reflected in the DISTAT figures. The South African Census of 2001 has produced more accurate and indicative data of its disabled population, which indicates overall disability prevalence at 5 percent. In 2007 UNICEF published for the first time statistical data on levels of disability among children in selected African countries, ranging from 16 percent (Ghana) to 35 percent (Djibouti).

Mpofu, Jelsma, Maart, Levers, Montsi, Tlhabiwe, Mupawose, Mwamwenda, Ngoma and Chombe (2008) stated that due to underdeveloped health care systems, lower health literacy, high levels of poverty and diseases in developing countries, Africa is supposed to have a high prevalence of disability but that statistics have proved otherwise, they are in fact low. For example, in Sub-Saharan countries like South

Africa, it is 5 percent, Zimbabwe 5.6 percent, Zambia 10 percent, Botswana less than 3 percent and Tanzania 3 percent. These figures are far less than the world estimation of 10 percent, which shows that disability is underreported leading to difficulty in planning for services for the disabled and their families, thus denying them of their right to access and enjoyment of these special services.

The South African Census Report of 2001 indicated that about 5 percent of the population (about 2.2 million South Africans) had various forms of disability. The prevalence of physical disability was high, constituting about 30 percent of the population surveyed and second to sight disability. Females were more likely to be disabled than their male counterparts. Age also factored in heavily as a risk factor for the likelihood of being disabled. Demographic and socio-economic indicators reflected that on average the older the population the greater the prevalence of disability. Other factors such as education and race were highly correlated to disability. About 30 percent of disabled people were not educated as compared to 13 percent of educated people.

The Botswana Population Census Report of 2001 recorded that 2.99 percent of the population is disabled. The most common disability being sight defects with 24.19 percent being affected, hearing 12.01 percent and difficulty in using legs is 16.01 percent. The report further illustrated that the number of school going age children (5-17 years) is 308595 of which 8281(2.68 percent) are disabled. Out of 8281 children, 26.87 percent have never attended school while 9.72 percent were reported to have left school. Most children who have never attended school live in the rural areas; they comprise 29.51 percent of the children in comparison to 23.03 percent in the urban areas.

Most statistics on disabilities refer to the fact that there are a lot of problems associated with disability. Despite services being available in these countries, they are not always easily accessible to disabled people. Each geographical area has its own issues and ways of dealing with them (Seligman & Darling, 2007).

The above statistics revealed that there are a significant number of children with disabilities and they are not well integrated in the education system, even where services are available. The above statistics also indicate that children in less developed countries are in more stressful situations than those in developed

countries, with greater dependency on the mothers as caregivers. Hence the need for a study of this nature to determine the psychosocial needs of mothers with physically disabled children.

2.5 PHYSICAL DISABILITY AND EDUCATION: THE CHALLENGES IN PRIMARY SCHOOLS

The global statistics above indicated that most disabled persons are not educated and a high percentage of disabled children are not enrolled at school thus denying them the opportunity to have a future and increasing the burden on their mothers. Even those who attend school are not well integrated into society, the prevailing attitude being that they should attend special schools even if suited to mainstream schooling (Ransom, 2000:1). The United Nations Enable-World Programme of Action of 2005 states that many countries have taken action to eradicate barriers denying disabled people full participation in education. Legislation like The National Policy on Care for People with Disabilities of 1996 has been drafted to give disabled persons equal opportunities for schooling, employment, access to community facilities and to remove cultural and physical barriers and discrimination. The disabled children constitute 10 percent of the global population and should have a right to education like other children. United Nations Enable World Programme of Action (2005) proposes that there needs to be active intervention and specialized services. In addition, the disabled children in developing countries are denied these services as there is no legislation attending to the needs and shortage of teaching staff and facilities. In denying the disabled children access to these services, they and their mothers suffer because they always try to find some means of providing for their children, but most do not have the financial means to do so.

Johnson and Winman (2001:5) pointed out that globally between 1997 and 2000, about 150 million children with disabilities were not enrolled in school and only three percent actually attended school. For example, in the Philippines out of 3.5 million disabled children only 40710 (1.16 percent) were enrolled in schools and in Mozambique out of the 170 000 attending regular schools 1167 (0.7%) were children with special education needs.

Robson and Evans (2002) indicated that 85 percent of disabled children are under 15 years of age in developing countries and they are either not receiving education or absent from schools and invisible in national policy agendas. They further explained

that lack of relevant data on disabled children makes it difficult to achieve major goals in education. Johnson and Winman (2001) showed that the number of children with disabilities enrolled at schools is far less than those without disabilities, which is estimated at one to three percent. They stated that according to UNESCO, 10 to 15 percent of children are identified as disabled and need active intervention and specialised services.

According to UNESCO, only one to two percent of disabled children in developing countries receive an education, thereby confirming the World Bank Report that about one-third of all children not enrolled in school are disabled children. There are 115 million children who are not attending primary school in the developing world; about 40 million of them are estimated to be disabled children. The global literacy rate for all individuals with disability may be as low as three percent and as low as one percent for disabled women.

Edmonds (2005) highlights UNESCO's emphasis on inclusive education for all children regardless of their physical, intellectual, emotional, social, linguistic or other abilities. Robson and Evans (2002:32) however discovered that many countries are failing to achieve the goal of universal primary education which is "UNESCO global efforts to achieve Education for All by 2015". The United Nations Convention on the Rights of the Child (CRC of 1989) Article 23 declares that children have the right to education. Article 11 of the African Charter on the Rights and Welfare of the Child, adopted in 1990, provides comprehensively for the educational rights of the child and Article 11 (3) expresses that every member state of the Charter should conform to the Article and offer free and compulsory education. An abiding outcome of the United Nations Declaration, is that most developing countries have adopted inclusive education policies. For example, South Africa's Schools Act (1996), has non-discrimination policies, Botswana has the Revised National Policy on Education (1994) that is reinforced by the country's vision for 2016 to have an "informed and educated nation." None of these developing or developed countries have however implemented a fully inclusive education system.

Yssel, Engelbrecht, Oswald, Eloff and Swart (2007) explained that inclusive education allows disabled children to be placed in mainstream schools where there is accessibility and support. The South African Schools Act (1996) gives parents the right to place their disabled children in neighbourhood schools. Yssel *et al.* (2007)

found that since the emergence of the new democratic South Africa in 1994, things have changed and parents are considered partners in inclusive education of their children with disabilities. In the United States of America inclusive education allows disabled children in general education schools with provision of special education support services.

The intention with inclusive education is to offer quality education for students who have been excluded from education. Hakim and Jaganjac (2005:18) explain that there is a combination of Community Based Rehabilitation and Special Needs Education with the aim of providing education for all. They further stated that education systems in the Middle and East Africa (MENA) region still exclude more than 95 percent of the disabled school-aged population at primary school level and totally exclude them at university level. With the assistance of inclusive education policies and programmes though, the situation is improving. For example, “Tunisia has declared its commitment to inclusive education for the disabled and is providing the needed resources under its Tenth Development Plan (2002-2006) and Jordan has adopted partial inclusion of disabled students enrolled in resource classrooms. In Egypt, however, disabled students are excluded from public schools due to misperceptions.” Jaramillo and Mingat’s (2008) presentation of early childhood care and education in Sub-Sahara Africa found that school children can do well if they are supported in their early years and if their parents are healthy, educated and supported in providing care. This is reinforced by the following statement: “While there is provision for the disabled learners in the mainstream sector, there is no obligation for the mainstream sector to accommodate such learners”.

This shows that globally, efforts have been made to make improvements to accommodate people with disabilities in education systems, but that countries react differently in respect of the action they take and efforts they make.

2.6 THE DESCRIPTION OF DIFFRENT PHYSICAL DISABILITIES OF PRIMARY SCHOOL CHILDREN AND THE CARE THEY REQUIRE

2.6.1 Physical disabilities in children

This section will describe the different physical disabilities found in children and, where possible, the causes thereof. These descriptions will show how severe

disability can have implications for the families of the disabled and for the mothers in particular as the primary caregivers. This will provide insight into what the physically disabled children and their mothers go through in order to address their needs. Lundgren-Lindquist and Nordholm (1993:85) report that a door-to-door survey was carried out in a village in Botswana to determine the prevalence of childhood disabilities. The findings revealed that 10.4 percent of the population has disabilities, of which 22 percent were children under 15 years of age.

2.6.2 Different types of physical disabilities commonly found in children

Philpott (2006:273) states that “Children suffer from a wide range of complex conditions that require care from many health professionals, often at different levels of the health care services.” The following are some of the familiar physical disabilities found in children.

1. Cerebral palsy

McCarthy (1992:95) states that cerebral palsy is not a single condition and describes it as a disorder of posture and movement caused by a non progressive brain lesion, arising before or around birth, or during the time of rapid brain development. Gulliford and Upton (1992:151) regard it as a non progressive disorder caused by damage to the brain either before or during birth, or in early childhood. Cerebral palsy has three main types, which include spasticity, athetosis and ataxia, determined by the site damage in the brain, each type characterised by a particular state of general muscle tone and associated patterns of movement, and sometimes also described by including the limbs involved.

- a) Spasticity** is the result of damage to the motor cortex of the brain and increase in muscle tone leads to lack of movement. The limbs involved may be stiff, weak and difficult to move, and be subject to strong spasm or muscle contraction. Deep tendon reflexes and imbalance in major muscles lead to deformity of limbs or the trunk. Children with this type of cerebral palsy may show these characteristics as stated, but all children with cerebral palsy show some degree of spasticity.

- b) **Athetosis** is caused by damage to the basal ganglia, the part of the brain which organises the body motor activities and is characterised by involuntary movements and lack of body control. The result is face grimacing, dribbling and difficulty speaking. This type affects few children.
- c) **Ataxia** is caused by damage to the cerebellum and the body loses control of its equilibrium resulting in lack of balance and muscle coordination. The children will have difficulty in walking and negotiating their environment, appear clumsy and fall frequently. This type affects five percent of children with cerebral palsy.

2. According to McCarthy (1992:279) and Gulliford and Upton (1992:153) **Muscular Dystrophy** is gradual and progressive weakening of the body muscle cells replaced by fat and fibrous tissue. The child is characterised by clumsy or unstable movement and develops an awkward gait. The common type is Duchene which boys get through a gene carried by their mothers.

3. **Arthrogryposis** (curved joints) described by McCarthy (1992:293) as a clinical condition with stiff contractures of the joints arising from prolonged foetal immobility. All four limbs can be affected or only the legs.

4. McCarthy (1992:331) defines **Osteogenesis** (brittle bone disease) as a condition caused by an abnormality of the protein collagen, which is essential for building strong ligaments and bones, resulting in the child being prone to fractures that can lead to skeletal deformity or the need to use mobility aids.

5. McCarthy (1992:189), Gulliford and Upton (1992:155) define **Spina Bifida** (related group of congenital conditions) as a developmental defect caused by a failure of fusion of the neural tube during the early stages of pregnancy. The neural tube develops into the brain and the spinal cord and the failure to fuse results in physical disability depending on the type of condition.

Spina Bifida occulta is when the spinal vertebrae have failed to cover the spinal cord. It is the mildest form, and with minor surgery it can result in only minor physical disability.

Myelomeningocele is the protrusion from the spine with the spinal cord on the surface of the back. Early closure of the defect will reduce the infection but causes paralysis and loss of bodily function. Most children suffering from this condition have

hydrocephalus as a result of the blockage of circulation of cerebrospinal fluid in the brain. If the condition is not corrected, more pressure on the brain leads to intellectual impairment, spastic paralysis in lower limbs or epilepsy.

6. **Limb Deficiency** which according to McCarthy (1992:305) is when the child is born with one or more limbs either partially or completely absent. This could be a result of medical problems or injury during pregnancy. The deficiency can involve upper limb anomalies or lower limb anomalies

7. Gulliford and Upton (1992:159) define **epilepsy** as the convulsive disorders of the central nervous system. It can occur as a result of infection such as meningitis or head injury. During a convulsion the child will experience a seizure of muscles and may lose consciousness. Epilepsy can occur with other conditions like hydrocephalus and cerebral palsy. There are three common types:

Grand mal which can last one to two minutes. The child will lose consciousness after crying or falling down. Then the limbs will become stiff, extended and go into jerky spasm. Afterwards the child will feel confused and tired.

Focal fit is the same as grand mal, but affects only one part of the body such as a hand or leg, it then extends to the rest of that side of the body on which the attack occurred. The child does not lose consciousness.

Petit mal is the mild epileptic attack in which the child will, for example, experience a staring spell or momentary loss of attention, causing a particular limb to jerk. The child may even fall, although he/she will be able to stand up straight away.

The abovementioned physical disabilities reveal that the severity of the disability depends on the type of disability. Gulliford and Upton (1992:163) state that physically disabled children do not "...form a homogeneous group." They have different educational needs depending on whether their disability condition is mild, moderate or severe.

Children with mild physical disabilities are expected to have normal bodily function and be able to communicate effectively, but will experience difficulty with their motor control and will be clumsy and slower than other children.

Children with moderate physical disabilities can function by themselves, but with the assistance of equipment such as walking aids and artificial limbs. They will also need

special facilities like ramps, adapted toilets, wider doors and will have difficulty communicating.

Children with severe physical disabilities cannot move around alone, have no control of their body functions, cannot communicate effectively and they have severe learning difficulties.

The mild and moderately disabled children are found in mainstream schools and can be integrated easily with the aid of an accessible environment like the right facilities, support, appropriate equipment and an inclusive curriculum. The severely disabled children will need the same assistance, but will require more attention and are mostly placed in special schools.

Gulliford and Upton (1992) purported that for the physically disabled children to be able to fit in well into the mainstream primary school education system, there should be the following:

Adequate support through the provision of resources, trained staff and educational policies on special needs. As well as support plans and coping plans for the teachers and the disabled children.

There should be access to physical, social and educational programmes in the school, thereby enabling the physically disabled children to easily integrate with their peers.

Wallander and Noojin (1995:255) note that mothers require information on these conditions and should get this from the different professionals who are dealing with the disabled child and that it is the social worker who needs to facilitate these efforts to provide such information. It is important for these mothers to have knowledge of the different physical disabilities in children because physical disability as suggested by Tansella (1995:297) can bring family and social change and it can also affect their psychological wellbeing. Furthermore, Cook *et al.* (1997) indicate that by having an integrative education programme and using existing services as a support for implementation of information exchange, children's disability education can be used for greater social change in the family and community. Woolfson (2004:2) pointed out that understanding physical disability will help the mothers to work with professionals to dispel unhelpful cultural beliefs, which in turn can contribute to the wellbeing of the child and the family.

Knowledge about different common physical disabilities, their causes and the common experiences associated with them can help non medical professionals like the teacher and the social worker who are most often involved with these children. It can also assist them to work well with the physically disabled children and their families.

Many researchers in the field of physical disability, already referred to in this study, emphasize that children with these disabilities need multidisciplinary care and community based rehabilitation so that their needs and those of their caregivers can be identified for effective and efficient intervention. This is stressed by Philpott (2006:277) who says that children with the above conditions "...require multidisciplinary care at all levels, including a full range of surgical services. In addition these children require rehabilitation services and management of inter current problems. This care needs to be available at the client's home."

2.7 THE SPECIAL NEEDS OF THE PHYSICALLY DISABLED CHILDREN OF PRIMARY SCHOOL AGE

This section will discuss special education in the primary school education system and the needs of the physically disabled children in primary school.

2.7.1 Special education for the disabled children in Botswana

As noted above, most international organisations recognise the right to education for every child and Article 23 of the CRC emphasizes the special needs of disabled children to guarantee that they have access to and receive education, training, and health services in a way that is conducive to their social integration, individual development, as well as their cultural and spiritual development. Despite the Jomtien Declaration (UNESCO, 1990) stipulating the right to education for all, statistics show that disabled children have been discriminated against and have not fully enjoyed this right.

In Botswana, traditionally education can be traced back to informal institutions like initiation schools for adolescents such as "*bogwera*" (for males) and "*bojale*" (for females) which have no information or record of how they included disabled adolescents. "There are no records to show how traditional society in initiation schools catered for children with special needs" (Dart, 2007:57). This was worse for the physically disabled children because this indicates that physical disability in

young children was viewed as a sign of past and ongoing misfortune brought on by ancestral displeasure, human machinations or the mysterious actions of a distant God. This discrimination was neutralized by the fact that the country was part of the above international organisations giving every child the right to education including the disabled ones. Also in 1994 the Botswana National Assembly approved the Revised National Policy on Education (RNPE) (1994) which stated that the Government is committed to the education of all children, including those with disabilities. Furthermore, this was reinforced by the formulation of the National Policy on the Care of People with Disabilities which ensures that the welfare of disabled people is catered for in development programmes in the education, health, social, physical, economic and employment sectors.

Historically, before the approval of RNPE, the education of disabled persons was managed by Non Governmental Organisations (NGOs). Botswana formally commenced with special education in 1969 when the Dutch Reformed Church opened a centre for the Blind in Mochudi. Since then various missionaries have established different institutions for different disabilities in the country. Even though the government was indirectly involved, they have since then, like other African countries, taken an active role in the provision of special education. There was the establishment of a unit for special education in 1994 within the Ministry of Education and in 1994 the unit was upgraded to a division. Currently there are about 22 government primary schools with special education resource units coordinated by special education teachers for children with mental, sensory and physical disabilities. Also seven resource centres for children with visual impairment , four schools for children with hearing impairment, three centres catering for various disabilities, nine stimulation centres and 11 vocational rehabilitation schools. They all receive financial assistance from government (http://www.moe.gov.bw/dspe/schools_units/entry.html).

According to Abosi (2000a:51), there is a Central Resource Centre which deals with identification, assessment and placement of physically disabled children. It also provides other services like low vision services, occupational therapy, referrals, research and material production, for example, Braille for the blind. The centre could be doing a good job, but the fact that it is the only one in the whole country, means that its services are not well coordinated and the complex procedures that must be followed make it impossible to accomplish its mission.

Despite all commitments made by the government to provide special education to cater for the special needs of disabled children, progress is slow. This is due to various factors such as a shortage of manpower, lack of interest by teachers, stigma associated with disability and low budgets for improvement of infrastructure to make facilities more accessible for children with special needs. In Botswana “the policy of special education shows commitment to social inclusion but operational practice offers exclusion” (Hopkins, 2004:99).

According to RNPE (1994), primary education is the most important level of education within the formal system of education, because it is the foundation of other levels of education. In Botswana primary education is managed between two ministries, namely the Ministry of Local Government, Land and Housing (MLGLH) and the Ministry of Education (MOE). MLGLH is responsible for construction of primary schools and ancillary facilities, provision of stationery, equipment, transportation and housing needs, while MOE is responsible for employment, training and management of teachers, maintenance of the school curriculum and overall development of education. Primary education assists the disabled children through the provision of special education. Here consideration is given to strategies which can help disabled children to achieve universal primary education. The present policy is to integrate them into the formal education system with other children. However the severely disabled children attend special schools run by NGOs. Llewellyn (2000:112) however believes that in most instances the school is unable to meet the psychological, social and clinical needs of physically disabled children.

The clash of obligations between the various systems in the environment (teacher-parent-physically disabled) places a burden on the physically disabled child at school. The parents are concerned with the welfare and wellbeing of the child at school, the teacher is concerned with discipline and school routines while the child is concerned about his/her welfare and survival in the school. The teacher may not have a good understanding of the child’s condition or of the difficulties experienced by the parents in raising a physically disabled child. The physically disabled child’s needs cannot be normalised just because he/she is in a normal classroom. Lack of training can result in teachers ignoring some of the needs, for example toileting needs. In addition these children are isolated and bullied by the other non-disabled children. Children with physical disabilities and their parents “... experience their

presence within mainstream education as a burden both to teaching staff and other pupils” (Llewellyn, 2000:113). This can then have a negative effect on their personal comfort and security.

All these issues lead to the physically disabled children experiencing difficulties in pursuing their education, which is one of the rights of every child both nationally and globally.

2.7.2 Physical needs: schooling physically disabled children

Physically disabled children are usually limited in their mobility and need assistance to move around the house or school. For example, the wheelchair users need someone to train them and to push them around. They therefore depend on the family and the mother in particular to help them move around. At school there need to be installations which are user friendly for the disabled child. These would include wide doors, lifts and elevators, ramps to allow for wheelchairs, guiding canes and/or dogs. The physically disabled children need access to the physical environment of the school. The RNPE (1994) recommended that the government develop standards for the construction of all educational buildings to ensure that they are accessible to all disabled children, because it was realised in 1993 that this is not the case in all government schools. Inadequate facilities and resources make it difficult to meet the needs of the physically disabled children in Botswana. In addition Abosi and Koay (2008:3) state that physically disabled children need to be assessed before admission to schools because it is not uncommon for these children to have other physical conditions in addition to their physical disability like epilepsy, tuberculosis, respiratory problems and heart diseases.

This is illustrated by Applequist (2009:11) who explained that the physically disabled children’s needs are not met in the classroom. Even if they have aids to assist them, the teacher sometimes just ignores them. This may be due to the stigma associated with disability or a teacher’s lack of interest or training on special education. For example, a child in the classroom using his foot to write, will need more time to write and to copy things from the board, but the child would be scolded for his/her slowness and for delaying other children. This could then lead to other children teasing him/her about the issue and his/her disability which in turn will affect the child emotionally. This typically occurs in Botswana too as supported by Dart, Didimalang

and Pilime (2002:48) who stated that children who are physically disabled are usually not accepted by teachers and they end up not being supported in the classroom, not well integrated in school activities or there is lack of planning on how they can be included in activities. These authors gave an example of a student in a wheelchair that they observed during physical education activities. The child was left to watch the others doing the activities and no attempt was made to include him. This is frustrating for the child because it is isolating him and making him feel useless and incapable of doing anything. Floyd and Gallagher (1997:369) mention that the disabled children attending school need more community support systems than other ordinary families.

Physically disabled school children depend heavily on other people to assist them and this may be frustrating and emotionally disturbing. The child may need someone to take him/her to school, in most instances this would be the mother as she is usually the primary caregiver (Llewellyn, 2000). Moreover, Shewchuk, Elliott and Richards (1999) stated that mothers of physically disabled children may become the primary sources of assistance with such activities as feeding, dressing, transfers and toileting. This type of assistance is usually required in varying degrees for an indefinite period. Shewchuk *et al.* (1999) further explained that if mothers are unable to fulfil their role as caregivers, the risk of complications for the life of the disabled child and greater health care expenses may increase. Therefore, it is important to identify the mother's characteristics that may help the disabled child to adjust to his/her disability. The differences among caregivers may be related to the emotional and physical adjustment of the physically disabled child.

Due to the fact that they need assistance with their daily activities, the physically disabled children usually require transport when they travel. The government is providing transport to take the children to school, but like Applequist (2009:14) noted it is available to children in urban areas only.

The physically disabled school going children face challenges in meeting their physical needs and they need support from school, home and their mothers. The mother of the disabled child therefore carries a heavy burden and needs intensive assistance herself.

2.7.3 Social needs

Cultural beliefs also influence the way the physically disabled children are treated. Llewellyn (2000:106) and Abosi and Koay (2008:4) report that the average person has a negative association with physical disability. In Africa, including Botswana, Abosi and Koay (2008: 5) noted that because people associate disability with bad luck, they hide these children and do not want them to attend special schools where they are taught together with others who they consider normal. For example in some cultures like in Vietnam, these children are hidden at home, treated as unteachable and not fit for school.

The physically disabled children are usually isolated by family members, relatives and peers at school. According to Antle (2004:173), they lack social skills and the ability to form friendships. This makes them feel alone, frustrated and depressed. School is the place where the disabled child can experience the most isolation. Abosi and Koay (2008) reinforce this by stating that at school only a few children without disabilities will prefer to have a physically disabled child as a friend rather than a child that is not disabled. This is due to the negative attitudes and beliefs associated with disability. In Africa there is the belief that disability is associated with something evil and a disabled person is regarded as hopeless and helpless. This has not made it easy for physically disabled children to make friends or playmates. They further explained that people should understand that the causes of disability are physiological rather than cultural, as it is these misconceptions that result in physically disabled children having poorly developed social skills, being isolated,, becoming unfriendly and being excluded from their peers' social gatherings such as birthday parties and teen camps.

According to Applequist (2009:10), disabled children have many appointments with different professionals and states that managing them is challenging, as it is an additional task left to the mothers and other family members which requires energy and time. The researcher continues by stating that the school does not meet the needs of the disabled children, as they are placed in regular schools that do not make provision for their specialised equipment such as wheelchairs. They are also teased by the other children. Their transportation is another problem as most have difficulty with mobility and therefore need to be transported. In addition their mothers have inadequate information about special education. All these issues have a social,

physical and emotional impact on the child who then takes his frustrations home. This in turn can impact negatively on the family leaving them feeling isolated, inadequate and in need of more information and guidance. The situation is worse in rural areas than in urban areas.

Llewellyn (2000:112) noted that many physically disabled children use equipment to aid their mobility and to enable them to perform their daily activities. These devices include wheelchairs, artificial limbs, urine bags and special boots. Many also have atrophied limbs, spasticity and need physical assistance, which can contribute towards emotional disturbance on the part of the disabled child and lead to the development of low self-esteem. The situation is worse when the child is in a classroom. In Botswana, according to Brandon (2006:46), a study done on attitudes of teachers to physically disabled children revealed that even though teachers were neither positive or negative regarding the inclusion of physically disabled children in the mainstream classes, “their attitude towards the teaching of students with physical disabilities was negative.” Brandon (2006:47) also indicated that Botswana does not have experts and trained teachers to teach physically disabled children.

Despite the changes that have been made in the education system, the physically disabled are still facing challenges of stigma and isolation at school, so their mothers need support to encourage them.

2.7.4 Psychological and emotional needs

Turner and Noh (1988:34) stressed that physical disability in children is linked to depression regardless of their age or sex, because it constitutes chronic strain which often has mental health implications. Then they need support. Depression is a significant problem among the physically disabled and the severity of this problem is conditioned significantly by the extent of functional limitation and pain.

Llewellyn (2000:106) expressed that the general public lack knowledge about disability, this ignorance is even worse in children making it difficult for them to relate well with their physically disabled peers at school. In turn this impacts psychologically on the physically disabled children. He stated that “Psychological problems are common in young people with physical disabilities during their school years” (Llewellyn, 2000:106).

Antle (2004) explained that physically disabled children are less emotionally adjusted compared to their non-disabled counterparts. They may find it difficult to adjust to their disability and this can lead to distress, anxiety and frustration. In this instance the child will need the mother to emotionally support him/her, but the mother may have other responsibilities and may therefore not adequately meet the emotional needs of the child. Taleporos and McCabe (2002:978) stated that “living with a physical disability had clearly impacted upon their psychological experiences, feelings and attitudes towards their own bodies.” According to Abosi and Koay (2008?) the child may not receive adequate assistance from other children and the teacher. Llewellyn (2000) explained that this can lead to poor academic performance and impact psychologically on the child who may develop a negative attitude towards school. Lack of skills on the part of the mother to nurture the child in order to develop positive self-esteem may also cause more stress in the child, the mother and the family.

All the above psychological, physical and social needs of physically disabled children must be met for them to be comfortable with their education at primary school level. According to most researchers these needs are either not met or are inadequately met. According to Abosi (2000b), Brandon (2006) and Dart (2007), the Botswana government emphasizes inclusive education in schools, but no concrete plans are in place. This is reinforced by Abosi and Koay (2008:8) who say that factors like poor planning, traditional practices and beliefs, attitudes of teachers, administrators and students affect the implementation of special education. Then the burden is felt by the children themselves and their families especially the mothers who are the primary carers. Hence the need to assess the psychosocial needs of mothers with physically disabled school going children.

2.8 SUMMARY

The various physical disabilities are complex as they have different causes and affect the disabled child physically, psychologically, economically and socially. All these aspects also affect their families because they have to understand disability, the causes thereof and how to care for the disabled, in order to cope. They also need resources so that they can cope. The parents also need to know about more systems within their countries that work with people with disabilities. More education is needed in the public, government and non-governmental organisations for better planning and provision of services for physically disabled school children.

CHAPTER THREE

THE PSYCHOSOCIAL NEEDS OF MOTHERS WHO ARE RESPONSIBLE FOR THE CARE OF THEIR PHYSICALLY DISABLED PRIMARY SCHOOL CHILDREN

3.1 INTRODUCTION

This chapter focuses on the impact of physical disability on the family, the role of the mother as primary carer will be outlined as well as their psychosocial needs. This is necessary as a person belongs to a family which constitutes his/her immediate environment. Erdman and Caffery (2003:4) stated that “working jointly with all family members was a procedure that held considerable hopes for successful intervention”. This chapter will outline the family as a system, the impact of physical disability on the family, followed by the effects of the psychosocial needs of mothers of the physically disabled school children.

3.2 PHYSICAL DISABILITY AND ITS IMPACT ON THE FAMILY

3.2.1 The family as a system

According to Sheafor *et al.* (2000) systems theory involves a pattern of living among the people who make up a system. Systems have boundaries that separate the individual system from the rest of the environment and control the flow of information, energy and matter between the system and the surrounding environment. The boundaries reflect the family’s psychic energy and internal processes.

The family system as a component of the contingency model of long-term care, the boundaries inside that are broken to show the openness of the family system with its individual subsystems and its supra systems, are presented in figure 3.1 below.

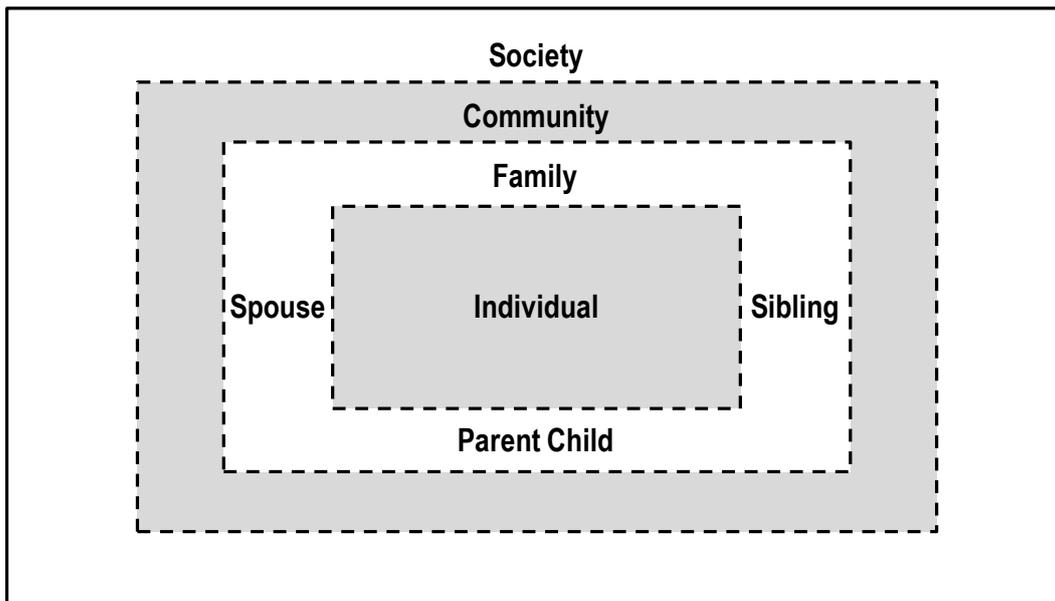


Figure 3.1 family systems

The figure shows the family system in relation to other systems in the model. It contains individual members in relationships (parent-child, spouse, siblings) with one another and interacting with its supra systems (community and society). As the figure depicts, the disabled child belongs to the family and the child will interact with them through the care and assistance that they will be providing to him/her. Then the disabled child will be interacting with society and community through meetings, hospital appointments, going to school and playing.

While Bowlby (1969) support the importance of the mother-child relationship, the family system theory also considers the efforts of other members of the family. This is the case when the family is functioning well. According to Sheafor *et al.* (2000), Collins, Jordan and Coleman (2007), general systems theory assumes that each subsystem in any system interacts with other subsystems so thoroughly that cause and effect cannot be separated. According to Seligman and Darling (2007), the family is the primary and most powerful system which a person belongs to. This shows that the mother and the physically disabled child belong to a system that influences how they live. Collins *et al.* (2007) view a family as a complex and interactive, interdependent and reactive social system in which all members' needs and experiences affect each other. The family as a system has subsystems within it which are family members Erdman and Caffery (2003:4) state that when one subsystem is dealt with, all the subsystems (parents, siblings, spouse and extended family) should

know and understand the situation at home, their roles and responsibilities. This will help to exercise their roles and responsibilities within their boundaries so that there is no confusion. Also, the family can be an open system which can allow all members to be open to their situation and allow for outside assistance, while the closed system can be the opposite. Most literature on disabled persons shows that the physically disabled child affects the family subsystems positively or negatively, but mostly negatively. According to Ferrari and Sussman (1987) and Seligman and Darling (2007), this can be explained as follows:

The parental subsystem – The relationship that parents in family systems have with their children and extended family, their attitude towards discipline at home, guidance and roles that will impact on each member of the household. They should be able to offer the same treatment to the physically disabled child because the child will be dependent on them to meet their daily needs such as bathing, dressing and doing school work. If the family is functional the support they give can bring some relief to the mother of the disabled child. The family can stand by each other in dealing with the challenges that are associated with caring for a disabled child, like dependency, social isolation, stigma and continual care.

Spousal subsystem – The relationship that the couple have with each other is important as they will support each other in raising the disabled child. They will experience challenges like the financial burden due to additional expenses both at home and school as well as medical and social services. They will also have to cope with the long term grief and depression the child may suffer from not being able to participate in all activities. Furthermore, they should be able to face community and societal reactions (Ferrari & Sussman, 1987; Seligman & Darling, 2007).

Sibling subsystem – This relationship can be different in each society and it will depend on how other subsystems function in the family. This will assist the siblings to learn to show mutual support to the physically disabled child. Their relationship can be positive or negative depending on the level of care they can give to the disabled child (Ferrari & Sussman, 1987; Seligman & Darling, 2007).

All the above relationships will work if the family is functional, has cohesion and also functions as an open system in order to work within the system as well as to be open to systems outside the family. This will assist the mother who is usually the primary

caregiver to cope with the situation. Pirila *et al.* (2005), established that while the mothers of children with physical disabilities can try to provide all the care, it is not always easy to fulfil the caring role alone. They emphasize that household appraisal, support from concerned others, psychological and social action can help mothers to cope. Hopkins (2004:91) reports that in Botswana, the transition to urbanisation and wage earning inhabitants has strained traditional relationships, especially within the extended family and that this is worsened by other issues like HIV/AIDS, which makes it difficult for people to assist one another. Hence further evidence of the need to consider the psychosocial needs of mothers with physically disabled children.

3.2.2 Economic impact

The impact of the physical disability of a child on the family can have financial implications. The parents may have to pay for medication and specialised equipment like wheelchairs, hearing aids and special boots. The family may also have to make necessary adjustments to their home in order to make it more accessible to the disabled child. Van Dyck *et al.* (2004) also mentions that the presence of children with special health care needs has an impact on the family. Meyers, Brady and Seto (2000) in their study in California found that families spend extra money trying to buy special food, special clothes, to pay for specialised child care, transportation and medicine. Furthermore some family members may forgo their work to care for the child especially if there is more than one child with severe disabilities. Unless the families are supported by the government through provision of material aid, they can experience hardships which can even result in poverty. Hungerford and Cox (2006) point out that financial stress can negatively impact on parents' wellbeing and affect their attentiveness and sensitivity to their children. In Botswana before the introduction of Social Safety Nets (SSNs), families were relying on subsistence economy. In addition, the extended families were obliged to assist family members, followed by informal social security mechanisms such as *mafias*, *metshelo* and burial societies. These are no longer supportive due to the diminishing spirit of communalism and self-help. Furthermore, the disabled persons in Botswana are not comprehensively covered by SSNs. They fall under the destitution policy and yet disabled persons have their own special needs as stated above. This indicates that the families of disabled persons are faced with financial constraints especially in rural areas where, according to statistics, the largest number of disabled children live.

Seleka *et al.* (2007:42) stated that “although the Revised Policy for Destitute Persons covers material needs of people with disabilities, the disabled people have special needs that must be met. For example, they may need wheelchairs, guide dogs, care, shelter and money.”

The presence of physical disability does not affect the disabled persons alone, but also affects their families and communities either directly or indirectly. Furthermore, physical disability has ongoing repercussions for an entire household, especially in terms of time and money that is required to provide special care for an individual with disabilities.

3.2.3 Social impact

The physically disabled children need assistance with most of their daily activities. Depending on the severity of the disability, the disabled child needs someone around to take care of their physical needs. For example the child needs to be assisted with feeding, bathing, toileting and dressing. This view is supported by Ishizaki, Ishizaki, Ozawa, Fukai, Hattori, Taniuchi and Kobayayashi (2005:128) who state that families are responsible for the medical care of their physically disabled child, which may include stoma hygiene for a physically disabled child, nursing care for a child with cognitive deficits and arranging for them to attend a rehabilitation programme or class for people with disabilities.

According to Laurvick, Msall, Silburn, Bower, De Klerk and Lenord (2006:1162), systems theory finds that “family needs and aspirations, family strengths and capabilities, social supports and resources are separate but interdependent components that influence family functioning.” Inadequate personal and family resources impact negatively on the wellbeing and health of the child. Van Dyck *et al.* (2004) and Laurvick *et al.* (2006) explain that most families with a disabled child would experience the professionals who help them as being child-centred who focus on correcting the disability of the child. The systems theory encourages interactions between family members and the impact they have on each other, which as Laurvick *et al.* (2006) reports, can influence the child. Therefore the combined efforts of the parents, family and professional help can result in a better outcome for both the child and the family. This support in addition to medical assistance, rehabilitation and educational input, will assist their caregivers to sustain their roles.

Scheiner (1998:9) explained that until 1900 disability was perceived as an individual problem and this view was associated with the medical model. Currently disability is viewed as part of the environment, in accordance with the bio psychosocial model that states that the support of the family should be part of the environment. The environment includes the person's whole external world – the physical world, the attitudinal world and social world and how services are organised, societal norms, policies and systems for implementing and monitoring. Often impairment at the physical level is a manifestation of underlying health conditions or problems. Ishizaki *et al.* (2005) state that if the physically disabled child's daily participation in community events is limited, it could be difficult for the family to be integrated in the local community. He explains further that in communities that discriminate against the physically disabled, like Japan, the family can become isolated from the community leading to closeness among the family members. If the parents are overly concerned about their physically disabled child this may lead to rejection or neglect and denial of the severity of the disability (Mattsson, 1972).

3.2.4 The psychological impact

Nicholas (1997:880-881) highlighted the fact that the parent-child relationship is affected by many issues relating to the family like marital conflict that affects children, role conflicts, self awareness, personal development as well as other social issues such as child abuse, abortion, day care and population control. It is not only the joy of having a child, but also the continuous stress of trying to balance it with dealing with these issues. Parents share the emotional and physical experiences of bearing and rearing a child. It is important to note that the outcome of adequate parenting is a child who develops in such a way that he/she can be socially integrated into society. Hungerford and Cox (2006:632) confirmed that the attachment theory by Bowlby (1969/1982) and developmental theory emphasize that the parent-child relationship in early childhood plays an important role in determining the type of person the child will grow up to be. According to Llewellyn (2000:107), "Parents are the most important influence in their child's development and they will be most aware of changes in their child's behaviour patterns that occur as a consequence of changes within the life of the young person with a physical disability." They further stated that factors like education and income have an influence on effective parenting; other influences would include psychosocial factors such as parents' mental health,

spousal support and quality of social support. Financial and emotional stresses negatively affect the wellbeing of parents and this has a negative impact on attentiveness and sensitivity towards their children. Social support networks beyond the family are helpful for facilitating responsive parenting and positive child development.

Mattsson (1972) has shown that children with long term physical disorders are prone to emotionally stressful situations. It does not matter how children interpret their physical condition, it is traumatic for the child-parent relationship. This can be overcome by continuous personalised support and counselling and through the mother's acceptance of the disability with its uncertain course and impact on the family. This shows that mothers need psychosocial support from social workers in order to achieve this. Feldman, Champagne, Korner-Bitensky and Meshefedjian (2002) in their study of physically disabled Canadian children under the age of 18, found that when there are no resources parents are more susceptible to stress and the negative outcomes of disabilities. In addition, having to wait a long time to receive services can detract from the potential benefits as early intervention promotes cognitive and motor development in children. It can also have a negative impact on the family as a whole, as the more severe the disability the more care that will be required.

Dew, Balandin and Llewellyn (2008:486,496) stated that parents of children with more severe physical disabilities, who require high levels of intensive support, experience a greater negative impact on their psychological and physical health than other caregivers. Mothers have more negative views than the siblings because they may be reflecting the stresses and strains of mothering a child with disability and the guilt associated with lack of sufficient time or energy to give to children who do not have disabilities.

The Botswana Vision Council of 2016 has recommended the revision of the Destitute Policy of 1980, to provide minimal standards of living, assist the disabled and protect the growing number of orphans. It was revised in 2002, but 90 percent of the policy still only caters for the poorest of the poor. The destitute and their families are catered for while the disabled persons are included under the Destitute Persons Policy (2002), yet they have their own vulnerabilities and their own special needs which are not catered for by the destitute policy. If these needs are not catered for, the disabled persons and their families will continue to suffer and the burden will be

felt more by the mothers. Hence the need to study the psychosocial needs of mothers so as to help them cope with the burden of caring for their physically disabled children. For example, the elderly have been receiving pensions for the past 13 years without there being any policy in place. The same strategy can be used for disabled people and their families as an interim measure until something can be done to help them.

3.3 PSYCHOSOCIAL NEEDS OF MOTHERS WITH PHYSICALLY DISABLED CHILDREN

In this section, the psychosocial needs of mothers with physically disabled children will be discussed without separating the psychological needs from the social needs as they influence each other in one way or another. This is supported by Maslow's (1954) hierarchy of needs, which suggests that if basic needs are satisfied, like level 1 physiological needs – food, shelter, and clothing, level 2 needs – safety and security and level 3 needs – belonging, love and social interaction; the person will be motivated to satisfy higher needs like level 4 needs – esteem and status and then level 5 needs – self actualisation.

If there is a disturbance in a person's social life, then the repercussions will be the emotional reactions, and if the emotional disturbance continues for a certain period, then the physical body will be affected. This is reinforced by Wright and Florida (2003:30) who state that "the maps of emotional high and low zones tell us a great deal about the nature and quality of life in different social positions."

De Blecourt, Preuper, Van der Schans, Groothoff and Reneman (2008:13) found in their study that psychosocial support is important for their patients. It is the primary goal to achieve functional improvement as the person's functioning is influenced by biological, psychological and social factors. The fulfilment of psychosocial needs is very important as these form part of the hierarchy of needs. Pupavac (2001:364) believed that psychosocial programmes help to affirm the selfhood of the person. Furthermore, Pupavac (2001) confirmed that psychosocial support is recognised by international bodies dealing with human rights such as Article 39 of the Convention on the Rights of Children of 1989.

Bowlby (1969/1982) confirmed that the difficulties that a mother experiences in life can disturb the mother-child relationship with the result that when the child grows up to be an adult he/she may be unable to deal with life issues. Hence the need to

address the psychosocial needs of mothers so as to ensure that they can easily care for their physically disabled children.

In a report from a conference held in 1998 on the implications of being orphaned in Botswana, it was clearly stated that mothers are primary caregivers in most places. It further highlights that in Botswana, contemporary culture indicates that women are the custodians of the majority of minors and teenage children and in 49 percent of households they are the guardians of such children. Most legislation like the Deserted Wives Act of 1999, the Children's Act of 1981 and the Affiliation Proceedings Act of 1998 is based on the premise that the care of a child is done by a mother. This is supported by Nashandi (2002) who states that in Southern Africa two-thirds of primary caregivers are females. The mothers are overburdened by financial constraints, fear of stigma and discrimination. In addition a lack of support structures for caregivers results in them feeling isolated from family and community.

Laurvick *et al.* (2006:1153) assert that factors that are known to contribute to the physical and mental wellbeing of mothers of physically disabled children include the burden of care, the child's age and behaviour. In addition the family functioning and support they receive reinforces their coping style. The children may need long term care because of challenges with routine daily activities like feeding, dressing, toileting, grooming and bathing. All these can be a burden which can cause psychological and physical stress, as well as personal factors like attitudes and beliefs. Laurvick *et al.* (2006) and Singer (2006) purported that every mother experiences some stress in her life, but studies show that "physical and mental health is significantly worse among mothers caring for disabled children compared with mothers of non disabled children" (Laurvick *et al.*, 2006).

Simeonsson (2008:36-37) stated that the mother automatically becomes the one to be given information on anything concerning the physically disabled child from school, hospital and stimulation centres and has to share it with the family even though most of the time she will not be supported, but stigmatized and blamed for the disability and this may lead to depression. Mothers pointed out that they remain ill-informed about the condition of their physically disabled children; even after various medical and allied professionals have spoken to them about it and this causes shock if they learn about it somewhere else.

Noyes (1999:431) stated that "...mothers clearly have different needs depending on what had happened to their child." Well supported mothers are less restrictive and

punitive with their children than those mothers without good social support. The improvement in social support is directly linked to an improvement in the parent–child relationship, which has positive outcomes for the child such as coping better academically and emotionally. Hungerford and Cox (2006:638) said “The quality of parenting is relevant to understanding how families influence children’s development.”

Yssel *et al.* (2007) emphasized the importance of treating mothers as individuals, because they view their disabled children differently. They face different barriers, each paying attention to a particular barrier. In many cases women in families, where there is a person with a disability, face the additional burden of having to provide an income for the household as well as taking care of the family, including the disabled family member. In addition they have to deal with the disabled as victims of conflict and deal with the social stress that often results from shifting gender roles in the household. This burden affects the mental health of women. The other children in families with disabled children in developing countries are also less likely to get education and have high drop-out rates. It is clear that the economic and social consequences of disabilities are already very high, both for the public, as well as for the individuals with disabilities and their families.

Bruun, Mucabe and Combes (1994:18) provide the background to the origins of social safety nets in Botswana. Historically, Tswana society has social safety net plans for the less fortunate in the community and has contributed to the development of modern social policy in Botswana. The social safety nets were not only taking care of material needs but also providing advice and counselling. The following methods were used;

“*Mafisa*” in which the less fortunate household would acquire resources by borrowing cattle from the wealthy households and once the cattle has multiplied, they then return the cattle they borrowed plus one extra.

The extended family system is the method by which the members of the extended family will take care of the needs of their less fortunate members, though this obligation has changed and is now the responsibility of individual households due to the modern lifestyle that has been adopted.

The traditional Social Safety Nets (SSN) deteriorated due to constraints caused by broad social changes in society. This then shows that the importance of taking care of others' needs was always an important issue. However when assessing from a cultural perspective how society has ill-treated households where there was a disabled child, it shows that the needs of mothers with disabled children and the disabled children themselves have been ignored for long time.

According to Seleka *et al.* (2007:10,19), Botswana currently has social safety nets such as the Destitute Persons Programme, the Orphan Care Programme, Community Home Based Programme, World War II Veterans, Old Age Pension, but none of these specifically target disabled persons. The physically disabled children live with their mothers in rural areas and have poor shelter. This is confirmed by Mpfu *et al.* (2008) when they said that Botswana's Social Safety Nets are not highly developed like in other countries in Southern Africa. Also, Seleka *et al.* (2007:20) stressed that they are not well coordinated like in South Africa and Namibia. Floyd and Gallagher (1997:359) report that "the psychosocial climate of the home affects the social development of children with disabilities." This means that if a mother belongs to a caring environment the social and cognitive adjustment of the child at home and school can improve. Despite the fact that mothers view the disabilities of their children differently, Sloper (1998:88) illustrated that the mothers of physically disabled children need income, education, transport, housing, informal and formal support services. Sloper and Turner (1992:260) indicate that there is a considerable amount of parental dissatisfaction with the help received in managing children with physical disability. Also, many mothers do not have access to professionals who can help them with their needs because, as statistics show, most of the disabled are in rural areas where access to professional support is nonexistent.

Witt, Riley and Coiro (2003), in their research on disabled school children in the USA, showed that physical disability can be a major life stressor to the mother. Meyers *et al.* (2000) articulated that caring for a disabled child requires of the caregiver to devote more time to caring for the child and the cost of medical care has been estimated to be two and a half to 20 times more than what it costs for other children. Even when caregivers try to cope with these costs it may impact on them psychologically and socially. Limitations and long-term dependency of the physically disabled child can overwhelm the mother making it difficult for the mother to help the

child to develop into an independent individual. The World Health Organisation's International Classification of Functioning, Disabilities and Health Framework stresses that the environment is critical to health and wellbeing. It highlights the importance of the caregiver-child relationship. There is a move away from focusing primarily on treating disability in family-centred services to rather focusing on child development, but with active participation of the family. This involves helping the caregivers by providing resources and ensuring that they remain healthy as this makes "good economic sense".

Horton and Wallander (2001:184) and Sloper's (2004) studies showed that mothers of children with physical disabilities, especially psychiatric disabilities, reported more physical health complaints than did the mothers of children with other disabilities. The burden of caring for these children increases stress, which manifests itself in a variety of chronic conditions. Horton and Wallander (2001:184) and Sloper (2004) continue by saying that caring for a disabled child can result in a variety of physical and psychological conditions. For example, a mother of a child with spina bifida may perceive herself to experience a greater level of disability-related stress than a mother of a child with diabetes, primarily because of the differences in disease characteristics and the resultant care giving responsibilities. "However, because all mothers of children who present with greater care giving demands do not perceive this as a source of stress, it is the mother's perception of the strains placed on her that is associated with her adjustment rather than the child's disability as defined by more objective parameters. Without the individual believing that improvement is possible and that she or he personally can achieve some success, it is highly unlikely that learning how to attack problems will be implemented in daily life, much less be effective" (Horton & Wallander, 2001:184). This research lends credence to those problem-solving training interventions that focus in part on establishing hope to enhance coping in individuals experiencing care giving stress. Singer (2006:163) mentions that when support services are provided to manage their stress, most mothers show improvement in their mental wellbeing, as shown by the following remark: "the link between social support and wellbeing is well established for parents of children with disabilities."

Although employment provides material and social resources which most researchers associated with lower stress levels, Sloper (2004) found that families of

physically disabled children experience low income and face extra costs which may not be fully covered by SSN. This is due to the fact that these children need care, which does not allow mothers to work, for example they must meet hospital appointments, transport children to school, and there is a lack of services during working hours. If they do work it is often part time while the child is at school or if the child's disability is not that severe. High levels of distress are also caused by inadequate housing and transport, lack of informal support from families and lack of appropriate education on the management of the child's disability. Witt *et al.* (2003) confirmed that other areas that mothers of the disabled children complain about are work status, sleeping patterns and financial problems. This is supported by Laurvick *et al.* (2006) who assert that mothers working full or part time have "better physical health than those not working at all." In their study Van Dyck *et al.* (2004:889) reported that "having a child with special health care can result in financially burdensome health care expenses, substantial caretaking demands, and lost parental employment opportunities."

Mothers with physically disabled children are often living in rural areas where services are inaccessible. They lack information on the disability of their children. In addition to the need for continuous information about the condition of the child, they also need general information on the rights and entitlement of the child to services. Mothers always want to provide the best possible care for the child and need support with that as well. Mothers always feel they need an explanation every time they meet a new practitioner and frequently seek general medical information both in service institutions and from traditional practitioners.

In Botswana mothers of physically disabled children need counselling and social support. Simeonsson (2008) stated that many researchers indicated that when people are faced with a crisis, specific needs arise and they adopt various coping mechanisms. It was found that black people prefer utilising their extended family systems instead of institutional care as this is based on their belief in "not throwing away" their people. In other words, children cannot be regarded as burdens for parents. This conviction provides positive reinforcement in helping mothers to accept and cope with their disabled children. As stated earlier by Bruun *et al.* (1994) and Seleka *et al.* (2007), the traditional social safety nets in Botswana are not only providing for the material needs, but even offer support and counselling, however

due to the fact that the system is deteriorating “relatives, neighbours and friends may tend to pity, ignore or actively avoid the family.” A study by Simeonsson (2008) revealed that most mothers are not pleased with the reactions of their neighbours and the community at large. The community have a negative attitude towards them. It was reported that the children were being isolated and not perceived as part of the normal pool of children in the community. The mothers felt that they were generally perceived by the community as being “cursed” for deviating from cultural norms.

This isolation and attitude of the community is experienced by others too, such as the mothers of vulnerable children. A study of mothers of children with HIV/AIDS done in Burkina Faso by Hejoaka (2009:869), indicated that mothers face great challenges with the daily care of their children with life threatening illnesses and this may also cause them to become fatigued. Mothers become isolated in their role as caregivers, because they limit their use of potential social support in order to keep the disease a secret. While some mothers disclose their children’s status to gain support from relatives, others do not and must develop strategies to hide the disability and this can hinder the child’s rehabilitation. Botswana has the same problem with the HIV/AIDS pandemic, which is one of the issues the government is giving attention to. The mothers of the physically disabled children could also be facing the HIV/AIDS pandemic, which could lead to more stress and depression.

Stigma can cause further isolation of mothers caring for their children. According to Hejoaka (2009), this is also weakening family bonds, as observed in Burkina Faso and widely seen in other African countries. Isolation of mothers with physically disabled children is worsened by the lack of effective, formal psychosocial support targeting children, policies on voluntary counselling and universal access to treatment for children. As already stated, in Botswana more attention is given to orphans than to disabled children. This may be overwhelming for mothers with physically disabled children. There may be some hope for improvement, because in July 2009 Botswana Television News stated that a coordinator for services for disabled people will be employed in the office of the president by the beginning of August 2009. This may mean that support will be provided to meet their needs.

The State of Governance in Botswana Report of 2004 and the Population and Housing Census Report of 2001, reported that public services do not satisfactorily address the needs of women. Even though the country is developing, the people of

Botswana live in a patriarchal society where tradition influences and defines men and women's roles. This has affected the level of income for both genders. Women are still disadvantaged when it comes to family roles, acquisition of assets, inheritance and incomes. They do most of the household chores including caring for the sick. Married women are regarded as minors even though laws are trying to change this. Tswana laws favour men in respect of inheritance especially with cattle and homesteads. These stereotypes make it difficult for women to have access to public services. If the psychosocial needs of mothers with physically disabled children are not attended to, then it will have a double impact on their wellbeing.

Mothers of physically disabled children are facing challenges in meeting their psychosocial needs, there is also a lack of policies to support them. In addition social services to assist them are not well coordinated.

3.4 SUMMARY

This chapter has outlined the psychosocial needs and challenges faced by mothers with physically disabled school going children. These challenges are not easy to combat without the support of other stakeholders, as there are still a lot of gaps in many of the systems involved in disability programmes. Community based rehabilitation also has many challenges and gaps in their services when working with the disabled children and their families. The chapter has also indicated the importance of the family system when approaching issues concerning the physically disabled client. This is shown through the way in which the extended family assisted their disabled family members in the past. At present, the extended family ties have broken down and the immediate family has to spend more on the special care of the physically disabled children and this has affected them socially, economically and psychologically, as was illustrated in this chapter. There is also a shortage of programmes that are meant to help them, but which are not adequately assisting them.

CHAPTER FOUR

THE ROLE OF SOCIAL WORK IN COMMUNITY BASED REHABILITATION IN ADDRESSING THE NEEDS OF FAMILIES WITH DISABLED PRIMARY SCHOOL CHILDREN

4.1 INTRODUCTION

This chapter is important to the study because it discusses the role of the social worker in community based rehabilitation (CBR) in addressing the needs of families with disabled primary school children. The chapter proceeds as follows: the impact of CBR on the physically disabled children, the impact on the family, the needs of mothers of physically disabled children as well as the role of the social worker.

4.2 COMMUNITY BASED REHABILITATION (CBR)

4.2.1 Overview

Lightfoot (2004:456) finds that childhood disability is mostly caused by malnutrition of the mother and the child, injuries before and after birth, exposure to toxic substances and infectious diseases. This then can result in physical and other disabilities. In developing countries they find prevention and rehabilitation to be the best strategies to assist the disabled persons and their families. Rehabilitation helps to prevent, treat and improve physical disability conditions.

Lundgren-Lindquist and Nordholm (1993:83) defined rehabilitation as described by the World Health Organisation as "...all measures aimed at reducing the impact of disability and handicapping conditions, and at enabling the disabled and the handicapped to achieve social integration." The Disability World Report of 2003, defined community based rehabilitation as "...a strategy within general community development for rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities."

CBR is an approach introduced by the WHO to provide rehabilitation services. According to the WHO Action Plan of 2006-2011 on Disability and Rehabilitation, CBR is practiced in 90 countries around the world and is involved in an inclusive multi-sectoral strategy of providing health care, education and livelihood opportunities. CBR is used by both developed and developing countries. Lundgren-Lindquist and Nordholm (1993:83) continue by explaining that community based rehabilitation involves measures taken at the community level to use and build on the resources of the community, including the impaired, disabled and handicapped themselves, their families and the community as a whole.

CBR aims at assisting people with permanent physical conditions by making the disabled people independent through the provision of special assistance that builds on their abilities.

4.2.2 The need for community based rehabilitation

According to the WHO Action Plan of 2006-2011 on Disability and Rehabilitation, CBR is planned to help people living in rural areas and those in urban areas who cannot reach urban rehabilitation institutions and services. Lundgren-Lindquist and Nordholm (1993) indicated that CBR involves community based resources, works with the community and disability organisations and has successful referral and supporting arrangements for disabled persons.

CBR can be illustrated from the perspective of the social model. Lightfoot (2004) purported that CBR is a three-tiered model because it rehabilitates on three levels: mobilization of community resources, recruiting and training community workers and training family members in basic rehabilitation services, providing the necessary information and offering them support. Most services of the CBR model should be provided to the disabled people at their homes. The services are not expensive, because community resources are natural and simple. Also, because the rehabilitation is community based, it is able to deal with cultural issues that concern the disabled people and their families. CBR entails educating the community and families of the disabled people and forming support groups to strengthen them. Then, according to the WHO, the services are supervised by professional workers like physiotherapists who work with the community. According to Lightfoot (2004) and Trevillion (2007), social workers are ideal for the work as the profession is better

suited to working according to the social model than the medical model. Social workers have experience in working with the community and coordinating services.

CBR is supported by most countries and their governments are including it in their plans. For example, many countries like Zimbabwe, China and Botswana have participated in piloting CBR and have accepted the CBR model. According to the MENA Report of 2005, in order to promote and support the development of the CBR strategy in African countries, the CBR Africa Network (CAN) was established in 2002 with its secretariat in Kampala, Uganda. The Mission of CAN is: "To promote access to appropriate information on disability and development for all people in Africa." Its objectives and activities include: collecting and collating information about disability services from all African countries; facilitating the development of a record keeping and writing skills culture for the purpose of documenting community initiatives and good practice, as well as facilitating the capacity of CBR workers to communicate their experiences between themselves and with other practitioners.

According to Lightfoot (2004:457), in contrast with community based rehabilitation, institutions based rehabilitation follows the medical model. The institutions based rehabilitation is professionally based and uses complicated tools to provide services. It also needs big budgets to provide these services and facilities. Furthermore, the institutions based rehabilitation is mostly located in urban areas rather than in rural areas, thereby isolating their the services they provide. Even though the method is helpful, it has added complications for developing countries, including Botswana, such as budgets, distance and facilities, as discussed above.

Since communities are different, CBR is applied differently in different countries. CBR is therefore a flexible, dynamic and adaptable strategy that aims to increase respect for the rights of individuals with disabilities, improve access to services and increased opportunities for all children, youth and adults with disabilities in the community. CBR is a multi-sectoral strategy that promotes and facilitates access to health services, education, vocational skills training, income generation activities and participation in all aspects of community life.

The above explanation shows the importance of the real idea behind the rehabilitation and why it should be community based. It involves both the disabled and the family by helping them to have a comfortable and better quality of life in the

community. The CBR is needed to assist with the work with physically disabled people.

4.3 PHYSICAL DISABILITY AND COMMUNITY BASED REHABILITATION (CBR)

Lundgren-Lindquist and Nordholm (1993:83) explain that rehabilitation includes all measures aimed at reducing the impact of disability and handicapping conditions, and at enabling the disabled and handicapped to achieve social integration. According to Lightfoot (2004), in developing countries the notion of prevention and rehabilitation are crucial as many disabilities can be avoided. Then according to Lundgren-Lindquist and Nordholm (1993:83), CBR involves measures taken at the community level to use and build on the resources of the community, including the impaired, disabled and handicapped persons themselves, their families and their community as a whole.

Lundgren-Lindquist and Nordholm (1993:83) stated that in **1976** member countries of the WHO decided to include rehabilitation in their goal, namely “Health for All by the Year 2000”. Seven years later it was stated that **90%** of disabled persons in developing countries were totally neglected. Then CBR was launched and, according to Lundgren-Lindquist and Nordholm (1993) and Lightfoot (2004), through the Primary Health Care model (PHC) it was aimed at prevention of the onset of disabilities and primarily to meet the needs of disabled people in rural areas who had no access to the urban rehabilitation institutions, but it is also appropriate for urban people who lack access to rehabilitation services. Lightfoot (2004:458) emphasized that effective CBR has a system for community involvement, promotion of appropriate technology and an effective referral and support system in cooperation with disability organisations. The model is usually provided by community based workers such as community health nurses and social workers.

Ingstad (1990) stated that CBR is an approach practiced in more than 90 countries, including many African countries. According to the WHO, CBR promotes collaboration among community leaders, health care personnel, social workers, people with disabilities and their families and other concerned citizens to provide services and equal opportunities for all children, youth and adults with disabilities in a community. “CBR is a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with

disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families, organizations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services” (WHO, 2004).

The World Bank Report on disability issues in the Middle East and North Africa of 2005 stated that physical rehabilitation services by government-sponsored programmes vary significantly among countries in the region. Djibouti, Egypt, Morocco and Syria reach less than five percent of the disabled population, while Jordan and Lebanon cover somewhere between six and 20 percent of their respective disabled populations. Iran covers from 41 percent to 60 percent of the population with disabilities. In Djibouti, rehabilitation services are provided essentially for individuals with mobility impairments. In most other countries, services are available for deaf and blind individuals, the handicapped, individuals with learning challenges and individuals with disabilities due to chronic diseases and mental illness. In Yemen, government sponsored rehabilitation programmes cover mobility impairment and the blind. Several local NGOs have established rehabilitation programmes for deaf and mentally handicapped children. However, almost all governmental and NGO rehabilitation services in Yemen are urban based and do not reach individuals with disabilities in rural areas.

According to Lightfoot (2004:461), CBR has been piloted in many countries like China, Jamaica, Zimbabwe and also Botswana and has shown success with improvement in most disabilities. For example in China it showed a 90 percent improvement for people who had a physical disability. Ingstad (1990) stated that CBR was launched in Botswana in 1977 and, like other countries, provides rehabilitation services through the Primary Health Care model, which in Botswana is under administration of two ministries: Ministry of Local Government, Housing and Land and Ministry of Health.

Mpofu *et al.* (2008) stated that in the seven countries (Botswana, Zambia, Zimbabwe, Cameroon, South Africa, Tanzania and Rwanda) in Sub-Sahara Africa that were reviewed in respect of their rehabilitation services, only three have disability related legislation and they are Zimbabwe, South Africa and Cameroon. Disability related policies in most countries do not show many results because they lack coordination. Also, most governments under fund rehabilitation and disability related agencies,

which is the case in Botswana with the national budget allocation for the disability budget. None of the abovementioned countries have policies for family supported rehabilitation or those provided by traditional healers or faith-based organisation. There may be laws or acts like in South Africa and Zimbabwe, but such activities are never addressed. If mothers are expected to provide rehabilitation for their children, then they will not cope because they are not supported. The World Bank Report of 2005 on disability issues in the Middle East and North Africa indicated that many local NGOs do not adequately employ a community based approach to interact enough with the affected families. They often use old rehabilitation techniques and are not sufficiently exposed to inclusive education policies, pedagogical methods and practices. Government programmes often lack the mandate, knowledge and resources to guide and monitor local NGO activities and support their transitions towards inclusive community based services, which integrate education, primary health care and early intervention. The existing legislation and programmes reflect governmental commitment. However, as enforcement remains limited and implementation capacity weak, legislation alone does not guarantee benefits for individuals with disabilities.

Feldman *et al.* (2002) asserts that the goal of rehabilitation is to improve the functioning of the disabled child. It reduces the disability and handicap by the provision of appropriate aids and adaptations, for example sitting devices, bathing devices and walking devices. If it takes long to produce these, children and their mothers or families will be unable to participate in normal daily activities, in schools and in social activities, isolating them even more. The decision to refer the children for rehabilitation services is often related to the severity of the problem and may also depend on the parents' ability to persist in articulating their needs and to manoeuvre within the system. This underscores the need for rehabilitation officers to help families to learn how to seek assistance, request instruction on the care of their children and find appropriate services suitable for children. Botswana could be one of the countries with effective CBR, but as Mpfu *et al.* (2008) stated the programmes provided by the rehabilitation services lack coordination.

In a review which was done on CBR by Lundgren-Lindquist and Nordholm (1993) in Botswana, they identified a lack of community participation, lack of resources and education. This shows that a large number of physically disabled children are either

not assisted or it takes a long time for them to receive assistance. In addition the needs of their mothers never surface because of a lack of community participation and education by professionals to motivate them to identify their needs. According to Barnes, Griffiths, Ord and Wells (1998:61), provision of services by professionals should be based on the assessment of an individual's need and be provided in partnership with users, their families and carers through interagency involvement to ensure quality and cost-effective care. In this way they can give assistance to the individuals and their families to maintain their physical, psychological and social wellbeing, even when the individual carer is unaided. It is important for social workers in CBR to help families of disabled children to achieve the abovementioned goals, which is in keeping with the intentions of the Botswana Government in its vision and mission for 2016 which states that "...we will be a compassionate nation and productive. Most of Botswana must be healthy by then." MacKenzie, Lee and Ross (2004:40) confirmed that the rehabilitation goal can be achieved through a multidisciplinary collaboration. It is important for social workers to play their role so that they can complement other professionals and help the mothers of the disabled children. MacKenzie *et al.* (2004) shows that the psychosocial needs identified include emotional strain, instability, helplessness, poor self image, feelings of poor self-worth and low self esteem, social isolation, difficulty in coping with stress and depression. This is why it is important for social workers to attend to the psychosocial needs of mothers who are responsible for the long-term care of their children. MacKenzie *et al.* (2004: 41) discovered that the results of psychosocial interventions were disappointing.

Raghavendra, Murchland, Bentley, Wake-Dyster and Lyons (2007:587) in Australia found that the philosophy of family-centred practice indicated that parents are experts on their child's care and needs. Hence they are to be supported in the rehabilitation process so that they can do what is best for their disabled children. In addition they showed that the families of the disabled were given a lot of respect and support even though the services providing information (both general and specific) were limited. The importance of psychosocial support for mothers is described by Uluikin, Vedmed and Voronin (2003:1151) in their study of mothers with HIV-infected children in Russia, where these mothers experience long term crises and need active psychosocial support and medical aid. They emphasized that these mothers need to be helped financially as approximately 80 percent of them are not working. In Botswana,

the report on the state of governance in Botswana of 2004 and population and census report of 2001 indicate that many women are in rural areas and are also economically disadvantaged, therefore showing that many mothers are disadvantaged including those of the physically disabled children. They are more disadvantaged because they care for children with special needs at home and in school. Gittelman (1997:404) in his studies on rehabilitation of the mentally disabled found that a system with access to needed services, adequate follow-ups, education, stress management and other appropriate activities is an important part of the psychosocial rehabilitation programme.

Whereas Schneider (1998:16) showed that in the South African a baseline survey on disability undertaken in 1998, 76 percent of the disabled received health services while only 22 percent received welfare services, 22 percent received counselling and six percent of the families of disabled persons received counselling and only 33 percent received primary education. He also indicated that lack of services is an issue in developed countries like Australia and is worse in remote areas, quoting the Australian Institute of Health and Welfare on the use of aids and the role of the environment (2003).

Brehaut, Kohen, Raina, Walter, Russel, Swinton, O'Donnell and Rossenbaum (2004:183) stated that few studies have examined the community based groups of caregivers of children with disabilities or compared their health with that of samples of parents from the general population. In Botswana they can be assisted by social support groups as they can also help the rehabilitation officers with counselling and identifying the needs of both the disabled school going children and their mothers. According to Burger (1990), social support groups assist rehabilitation programmes by making its services accessible and available to those affected by disabilities.

In his 2009 budget speech, the Minister of Finance of Botswana, Baledzi (2009:11) announced that in order to increase the level of the social protection system, social security benefits and alleviate poverty and destitution through existing programmes and projects, they are targeting the vulnerable and less fortunate in society like orphans, the elderly, the needy and the war veterans. He continued by mentioning that 49 852 orphans, 31 300 vulnerable children, 40 525 destitute persons, 3 530 home based care patients, 3 202 World War II veterans and 89 471 old age pensioners are benefiting. No mention was made of programmes for disabled

children and their families as no such programmes exist for them. They could be included as vulnerable children, but the emphasis is on vulnerable children who are abused and abandoned and need a place of safety.

Local NGOs play a key role in MENA countries in reaching out to persons with disabilities through a combination of own funding, donor financing, or public funding. Local NGOs providing rehabilitation services are, in the majority of cases, dependent on donor or public funding. The interaction between government agencies, NGOs and communities often lacks a clear governance system. Coordination between NGOs, communities and local governments requires an institutional framework geared for cooperation, which is not always evident, and for capacity building of all stakeholders. CBR is needed in most countries including Botswana. The next section will discuss CBR in Botswana.

4.4 CBR IN BOTSWANA

According to Ingstad (1990), CBR was introduced in 1976 when Botswana requested a consultant on rehabilitation services from the WHO. In 1979 the programme was ready for field testing, but this was only done in 1982. The field testing showed much improvement in programmes for those disabled persons who were involved. Then CBR was introduced in Botswana under the Ministry of Health with the relevant stakeholders being trained, but in 1998 it was transferred to the Ministry of Local Government, Housing and Land (MLGHL). According to Lundgren-Lindquist and Nordholm (1993), CBR in Botswana is implemented under the strategy of Primary Health Care (PHC) with its components of services being promotional, preventive, curative and rehabilitative. The implementation is done through the rehabilitation services division in the Ministry of Health, which has units such as a rehabilitation appliances unit, physiotherapy unit, audio logy and speech therapy unit and the social welfare unit. PHC assists by coordinating, training, supporting and supervising the implementation in the districts. The outreach in the districts is done through rehabilitation social workers who fall under the MLGHL.

The rehabilitation social workers are based in districts throughout the country and do their work in the community by collaborating with other stakeholders like non governmental organizations, health workers, village committees and support groups and government organizations. Their duties are to identify the disabled persons and

their needs, to do registrations, referrals, dissemination of disability information, as well as to facilitate and organize projects, special activities and to do home visits.

In all of the abovementioned duties, the social workers should not attend to the disabled child alone, but rather use a holistic approach so that they are able to identify the child and all the problems in his/her environment which he/she encounters at home, school and in society. The immediate environment is the family and if it is not functioning well, then the disabled child will not function well and the same applies to the other environments. This is reinforced by the National Policy on Care for People with Disabilities of 1996, established under the directive of the president of Botswana, as it outlines roles of various sectors in caring for the disabled persons, which include government ministries and departments, private organisations, non-governmental organizations, community based organisations, community leaders, disabled persons and their families. Some of the policy objectives are supportive of rehabilitation, which according to Mompati (2000:21) are as follows:

To strive for an environment within which all people, including those with disabilities can develop their abilities to the fullest possible extent.

To ensure that the person with a disability has a responsibility and a right to determine his/her own wellbeing.

To ensure that the integration of the person with a disability into society is actively promoted.

To recognize that care of people with disabilities is a continuous process requiring more family participation, community involvement and less institutionalization.

To aim for equal opportunities for all people in society, but that these will vary according to the needs and abilities of the individuals.

The above objectives show that CBR is the best way of assisting the physically disabled children and their families.

4.5 THE ROLE OF CBR FOR PHYSICALLY DISABLED CHILDREN

Helander (1992) quoted by Cook *et al.* (1997:207) said “one approach that is increasingly being applied to promote greater community integration of children with disabilities is community based rehabilitation, which consist of programs run by

governments, non-governmental organisations, communities, families, and persons with disabilities that attempt to address the divergent needs of people with disabilities within the context of a particular community.”

As already stated, CBR works with different sectors to identify, assist and refer, and then CBR will help to assist in identifying the physically disabled children, register them and refer them to relevant organizations and services such as hospitals, schools and welfare services. Through the family, especially the mothers who are the caregivers, the needs of the disabled school going children can be identified. Therefore, they need relevant training for these children, formulation of different committees and groups to ensure care of the physically disabled children. The importance of integration and inclusive education in accordance with relevant policies is recognized in order to assist these children. Then, according to Lundgren-Lindquist and Nordholm (1993), the knowledge and understanding of the physical disability and coping strategies will increase in the children, their families, their teachers, colleagues and society in general. All this is done through involvement of all sectors and the community. As Lightfoot (2004) already stated, social workers are known for working with the community and coordinating services, they are the leaders in CBR and it is their role to see that the physically disabled are assisted. Moreover, Evans (2004) highlighted that social workers must note the importance of care and management of disabling physical conditions and early intervention with children because it can correct and build self-worth and competence.

4.6 THE IMPACT OF THE SOCIAL WORKER IN CBR

4.6.1 The impact of the social worker in CBR on the families of physically disabled children

According to Karren (2006:68) “individuals do not live in a vacuum but in a complex and social environment. Rehabilitation professionals should not be allowed to do only medicine or administration but to work with the disabled person and the community.” Fieldman et al. (2002:355) emphasized that rehabilitation professionals should assist families to seek help and to find appropriate services for their physically disabled children. Lang and Oppenheimer (1968:166) and McCarthy (1992:46) expressed that the social worker must make sure that there is information from other stakeholders involved, because a valid multidisciplinary service must attend to the whole family as

they often overlook the psychological and social aspects of disability within the family. In other words information must be available on housing, finances, employment, clothing and coping strategies. McCarthy (1992) highlights the fact that the mothers of the physically disabled children are depressed because the social workers fail to observe that they lack traditional family support, appropriate services, employment and adequate housing. The following figure will explain the need for the multidisciplinary team.

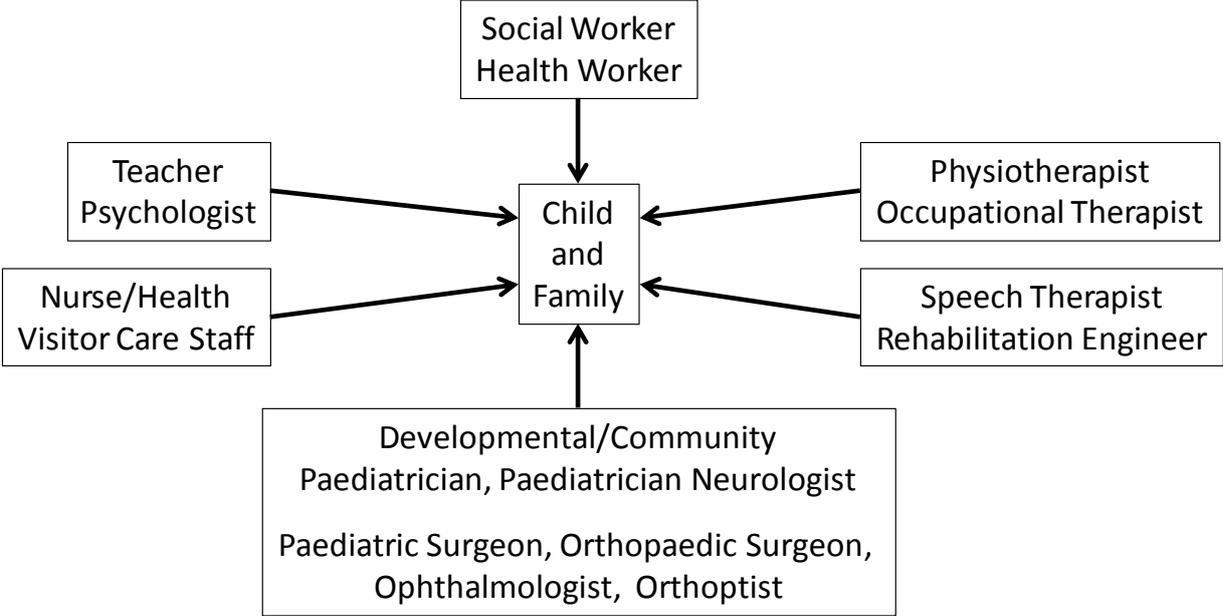


Figure 4.1: The multidisciplinary team for disabled children and families

According to figure 4.1 the social worker must approach the needs of all the children and the parents, bearing in mind the impact of the disability on the child and the family by including information previously known about the family from other professionals. As well as the relationships in the family as it shows the family strengths and weaknesses and their needs, this can be derived from the information from other professionals.

4.6.2 The impact of the social worker in CBR on the mothers of physically disabled children

Many researchers have indicated in their studies that mothers constitute a large number of caregivers. In a study done by Brehaut *et al.* (2004:189) on primary caregivers of children with cerebral palsy, for 90 percent of the children, the person most knowledgeable about the disabled child was the biological mother while in 10

percent of the cases it was the biological father and non biological parent. Mothers are the centre of the family, as the men are usually busy providing for the material needs of their families. In CBR there is contact with the family of the physically disabled child and in so doing the needs of the mother as primary caregiver will be identified. This will be done through assessment, home visits, follow-ups and feedback from referrals from other professionals. CBR will assist professionals especially the social worker to understand the importance of a holistic approach to the family rather than concentrating only on the correction of the disability of the child. They will also identify other needs of the child and his/her family like clothing, schooling and psychosocial support in general. As many researchers have shown that the child can cope well in a well functioning family which has all the necessary resources to provide for the needs of the child.

Hammell (2006) explained that mothers of the physically disabled children suffer as there are many demands on them, their families and extended families. Therefore, the rehabilitation social workers are to attend to their needs by:

Working on the needs of both the physically disabled children and their mothers.

Assist them with the demands imposed on them by the disabilities and how to cope with traumatic and challenging situations.

Support the mothers of the physically disabled children by looking at their needs, which when fulfilled will enable them to adequately care for the disabled children.

Educate the mothers of the physically disabled children and their families about CBR, its activities and preventative methods which can help their children. They usually have insufficient information about support services.

Develop programmes that can assist the mothers of physically disabled children to improve life at home. Assist and motivate them to deal with anxieties, fears and uncertainties. Cook *et al.* (1997:214) expressed that mothers of the disabled children experience cultural and social barriers, feelings of isolation, marginalisation and stigmatisation which can result in them failing to access rehabilitation resources and can lead to poor participation in community activities.

Provide equipment for physically disabled children and refer them to welfare programmes that can assist with their psychosocial needs, for example housing and feeding programmes,

Encourage voluntarism by initiating the formation of support groups or self-help groups, which also fulfil many other roles such as counselling, socialising, practical help and being part of professional decision making (McCarthy, 1992).

Initiate income generating projects as most researchers have indicated that these mothers have financial constraints due to the burden of special care for their disabled children.

Hammell (2006) supported by McCarthy (1992:46), states that continuous, lively counselling, support and appropriate services for mothers can reduce their trauma and psychological needs by improving "...parental acceptance and enjoyment of their children."

The evaluation of CBR in Botswana by Mompati (2000), shows that the working conditions for rehabilitation social workers are unimpressive. There is one rehabilitation social worker in every district despite these being large and rural areas. They do not have vehicles, budgets are low and they also have to share most of the resources and facilities with health clinics and priority is given to health clinics. In many areas there are no officers or they are away on leave or study leave and nothing is being done to attend to the key duties of that office. Most social workers lack training on rehabilitation services. Despite the good work the social workers are trying to do in CBR, rehabilitation activities are not adequately dealt with, coordinated and monitored due to lack of resources, manpower, transport and administrative issues. Mompati (2000) further illustrated that most rehabilitation activities which are active are done by non governmental organisations, but they also have their own limitations in terms of resources and need to be assisted. Ingstad and Whyte (1995:188-189) described, with reference to the same conditions, how CBR is not a priority in the government budget, despite these NGOs being the pillar of CBR in Botswana.

There are a lot of issues concerning disability and the family, so social workers have a role to play in attending to the psychosocial needs of the mothers of the physically disabled children in CBR. Philpott (2006:291) states as follows: "The lack of coordinated strategies means that service provision focusing on children, continues to be fragmented and thus available resources have limited impact".

4.7 SUMMARY

As already stated in this chapter, the World Health Organization (WHO) supports rehabilitation as the best method to help prevent, treat and improve physical disabilities if practiced in the community as Community Based Rehabilitation (CBR). This is because the method involves measures implemented at community level using community resources, involving the disabled persons and their families and the community as a whole. It can also reach people living in both urban and rural areas. CBR is described as multi-sectoral because it includes services like education, vocational skills training and income generating activities. As it involves the disabled persons and their families, community resources and the community, it can be viewed from the perspective of the social model. It is best suited to being coordinated by social workers as they have experience in working with communities and coordinating services. CBR is unlike institution based rehabilitation, which uses medical professionals, high budgets and is mostly located in urban areas. Institution based rehabilitation therefore follows the medical model. In most countries including Botswana, the CBR method has proved to be fruitful and can reduce physical disability except where disability policies are not well coordinated, not budgeted for, do not support families and is not linked to policy on education. In Botswana there is a lack of coordination, resources and education.

Most mothers of physically disabled school going children need psychosocial support because they are not working but are caring for children with special needs at home and school. The CBR support system should consider the immediate environment of the disabled child, which is the family, so that they can function well in other environments like school and the community. CBR provides appropriate aids and adaptation in the environment. It is then the duty of the social workers in CBR to assist the physically disabled children and their mothers to achieve this. If however the social workers in CBR lack resources, then the activities for physically disabled children and their mothers will not be well coordinated and monitored.

CHAPTER FIVE

SITUATIONAL ANALYSIS OF THE PSYCHOSOCIAL NEEDS OF MOTHERS WITH PHYSICALLY DISABLED PRIMARY SCHOOL CHILDREN

5.1 INTRODUCTION

Sheafor *et al.* (2000) stated that a family as a system has subsystems, which when affected impact on the whole system. The presence of a physically disabled primary school child affects the whole family. This is confirmed by the literature, Gulliford and Upton (1992) and Bartman (2007) state that physically disabled school children have special needs which are caused by the challenges related to disabilities both at home and at school. Due to the fact that these children have special needs, which are social, psychological and physical in nature, they need committed mothers to fulfil their mothering role effectively to ensure the child's adaptation at school and home. These mothers need support from the whole family, relatives and the community so that they can develop and be well integrated in society. It is clear therefore that mothers have their cultural, physical and psychological needs which need to be supported in order for them to fulfil their role.

Literature confirms that in Botswana psychosocial programmes do not support the mothers of the disabled children and this in turn affects the support they provide to their disabled primary school children. Pirila *et al.* (2005) confirm that families cope positively and adapt to a crisis situation if they have received assistance, especially psychosocial support. Literature (Landsman, 2006) shows that mothers of disabled children suffer from social and psychological disturbances due to the challenges of coping with disability such as caring for and loving these children and facing societal attitudes.

Wishart *et al.* (1981) and Lemes and Barbosa (2007) confirmed that mothers of the disabled children lack psychosocial support like a conducive, welcoming and

accepting environment, without stigma and discrimination. Also, they lack emotional and financial support.

The Botswana government has therefore adopted CBR to address the needs of the physically disabled children and their mothers through services provided by different professionals. The social workers provide the psychosocial support, but due to certain circumstances faced by social workers in CBR, they are not able to fulfil this role effectively.

The objectives of this study were to discuss the psychosocial needs of mothers who are responsible for the care of different physically disabled primary school children and to identify the role of social workers in CBR in addressing the needs of the mothers with physically disabled primary school children. In addition it aims to develop guidelines for social workers which can assist in addressing the needs of the said mothers.

This chapter discusses the results of the study on the psychosocial needs of mothers with physically disabled school going children and the role of social work in Community Based Rehabilitation.

5.2 EMPIRICAL STUDY

The results of the empirical research that was undertaken will be presented in the following sections.

5.2.1 Research method

Generally, as the mothers are the primary carers of their families and are familiar with the challenges facing the family, the focus of study was on the biological mothers of the physically disabled primary school children who care for their children at home. This was explained in more detail in chapter one. The study was limited to Letlhakeng village in Botswana. The study used both quantitative and qualitative research methods and an exploratory and descriptive research design.

5.2.2 Sampling and data collection

A purposive sample was used. The sample was selected from Letlhakeng rehabilitation office. The sample consists of 20 biological mothers (N= 20) of different physically disabled primary school children ranging in age from five to 12 years. The mother's information was taken from the register of their disabled children. A semi-

structured questionnaire (Appendix D) was used during interviews, it focused on the following information: location, demographic information of both the mother and the child, type of disability of the child, assistance provided, type of assistance needed by the mother, services provided by social workers (the role of CBR) and information about the mother as a carer. The questionnaire solicited information from mothers with children with different physical disabilities.

This empirical study is related to the aim and objectives of the research, which are described in chapter one and is supported by the literature review as presented in chapters two, three and four of the study. The respondents participated voluntarily after being guaranteed confidentiality by signing a consent form (Appendix C). The ministry of Local Government, which gave the permission for the study (Appendix B), and Letlhakeng Rehabilitation Office (on behalf of clients) requested access to the results.

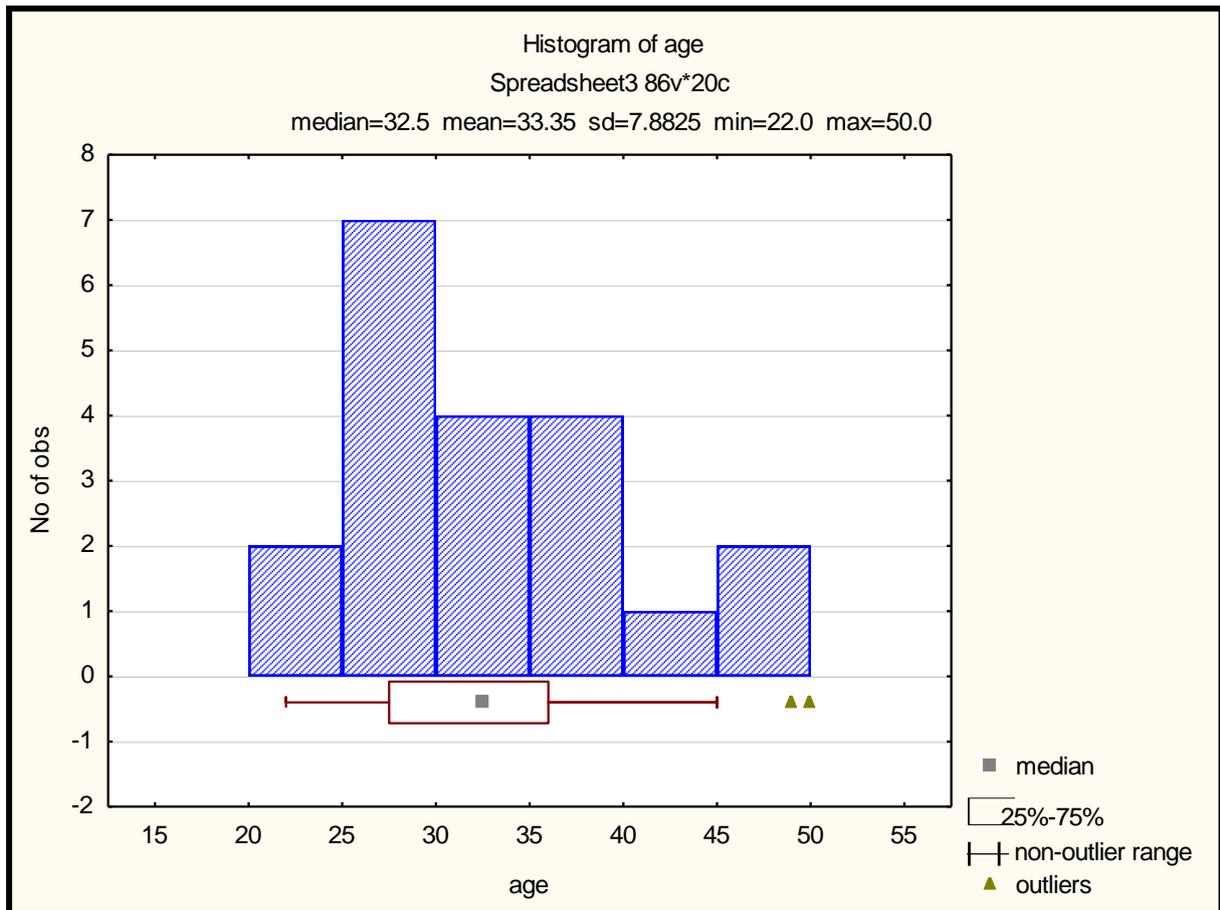
The research is quantitative with the results presented in tables and figures, but a qualitative approach was also used to capture the perceptions and emotions of these mothers. The mothers were interviewed using a semi-structured questionnaire with open-ended questions so as to explore their psychosocial needs as well as to determine the services that are offered by the social worker to help them. The mothers were interviewed at their homes in order to observe their home environment and their interaction with the child when he/she is at home. The researcher was shown the homes by the family welfare educator and the physiotherapist. The interviews lasted six days and took place from 7-10 July 2009 and again from 13-14 July 2009. Three to four mothers were interviewed on each day and each interview took 50-60 minutes, sometimes longer depending on the emotional reactions of the mothers.

5.3 RESULTS OF THE STUDY

5.3.1 Identifying details of the respondents

5.3.1.1 Age

The age of the participants, namely the biological mothers of the physically disabled primary school children was investigated.



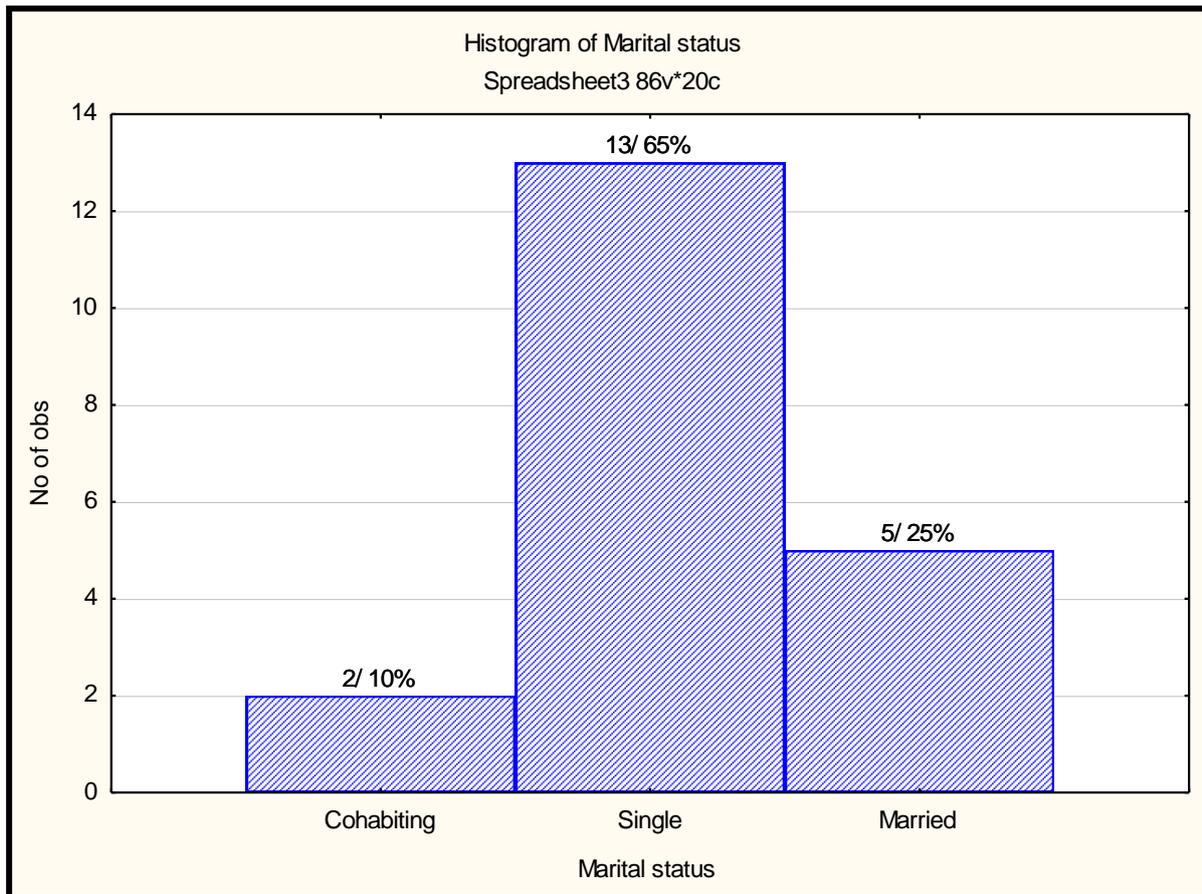
(N=20)

Figure 5.1 Age of respondents

The graph above shows that the mothers range in age from 20-50 years with a mean of 33,35 years and a median of 32,5 years. According to the Botswana Population and Housing Census (BPHC) Report of 2001, childbearing is mostly evident among the 15-49 year age group. It also reveals that having a physically disabled child can be found in any age group and that the causes are not age based. Furthermore, it was determined that mothers in any age group have psychosocial needs whether living in urban or rural areas even though this study was undertaken in a rural area.

5.3.1.2 Marital Status

The respondents' marital status was investigated.



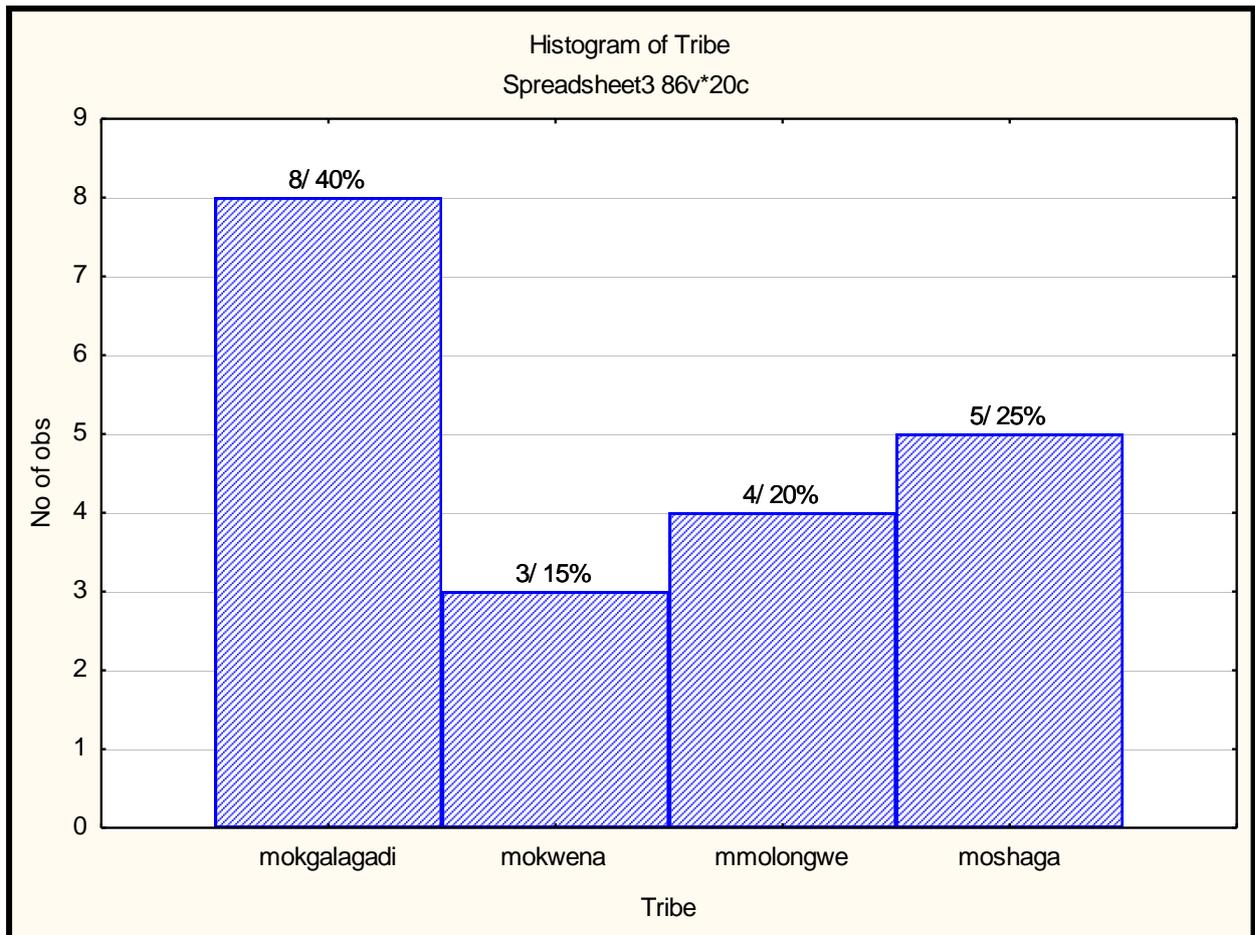
(N =20)

Figure 5.2 Marital status

The graph shows that most participants are single mothers. Single mothers are found in large numbers in Botswana. This is compatible with what was recorded in the BPHC Report of 2001, which indicates that there are larger numbers of unmarried females in the country than there are married females. They comprise 46.5 percent and 17.9 percent of the population respectively.

5.3.1.3 Tribe of household

The tribe to which participants belong were investigated.

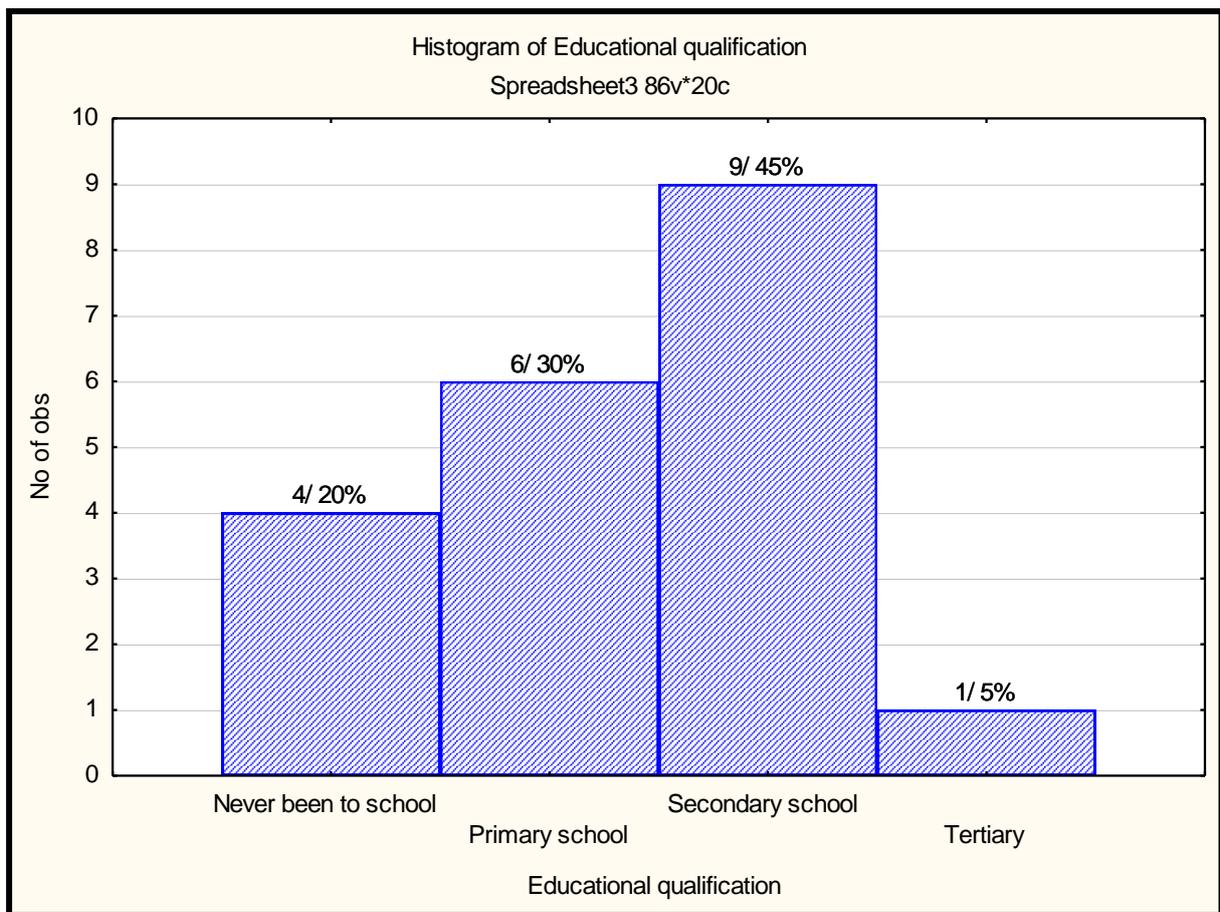


(N = 20)

Figure 5.3 Tribe

The graph shows that more participants belong to the Mo/Bakgalagadi tribe than to the other tribes, with the second largest number of participants belonging to the Mo/Bashaga tribe. Letlhakeng is an area where people of the Mo/Bakgalagadi tribe and other small tribes live. The main tribal language is Sekgalagadi but the official local language commonly used is Setswana.

5.3.1.4 Educational qualifications



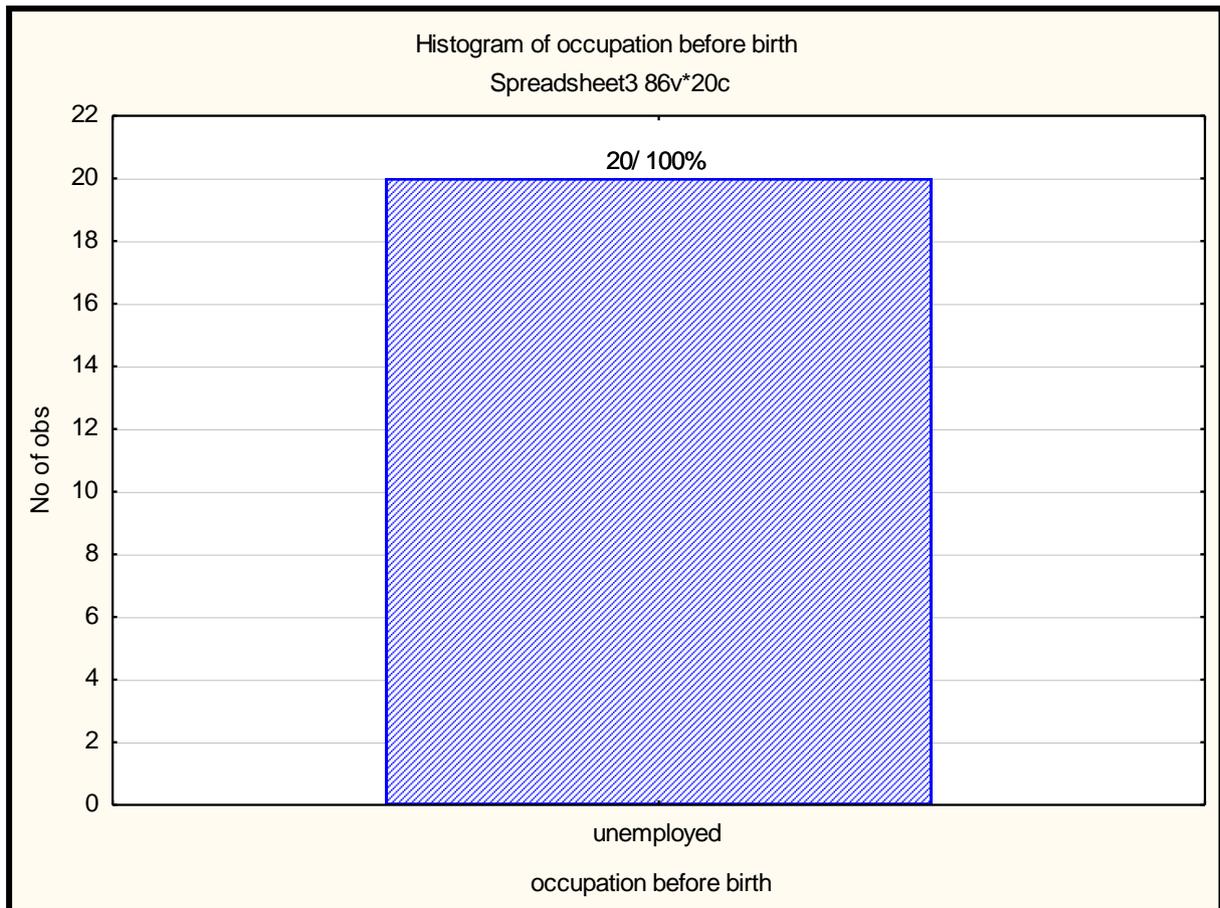
(N = 20)

Figure 5.4 Educational qualification

There were different levels of educational qualifications acquired by the mothers and most of them obtained a secondary school qualification. This is in line with the BPHC Report of 2001 that showed that most women dropout at secondary school level. With this qualification, even if they were to be employed, it would be in the low income jobs. This indicates that they would then still need financial assistance as most jobs today require trained people with better skills.

5.3.1.5 Occupation before giving birth

The occupation of the mothers after the birth of their disabled children was investigated and the results are presented in figure 5.5.



(N = 20)

Figure 5.5 Occupation before giving birth

All the mothers (20 or 100%) were unemployed even prior to the birth of their disabled children. Even though most mothers claimed that having a disabled child does not allow them to look for a job, it would appear that Letlhakeng does not offer regular employment opportunities. Most of the mothers survive by farming, doing nominal small scale jobs and they often migrate to look for jobs in other areas. In most cases having disabled children has denied them of the opportunity to work.

5.3.1.6 Occupation after giving birth

The occupation of the mothers after the birth of their disabled children was investigated and the results are presented in figure 5.6.



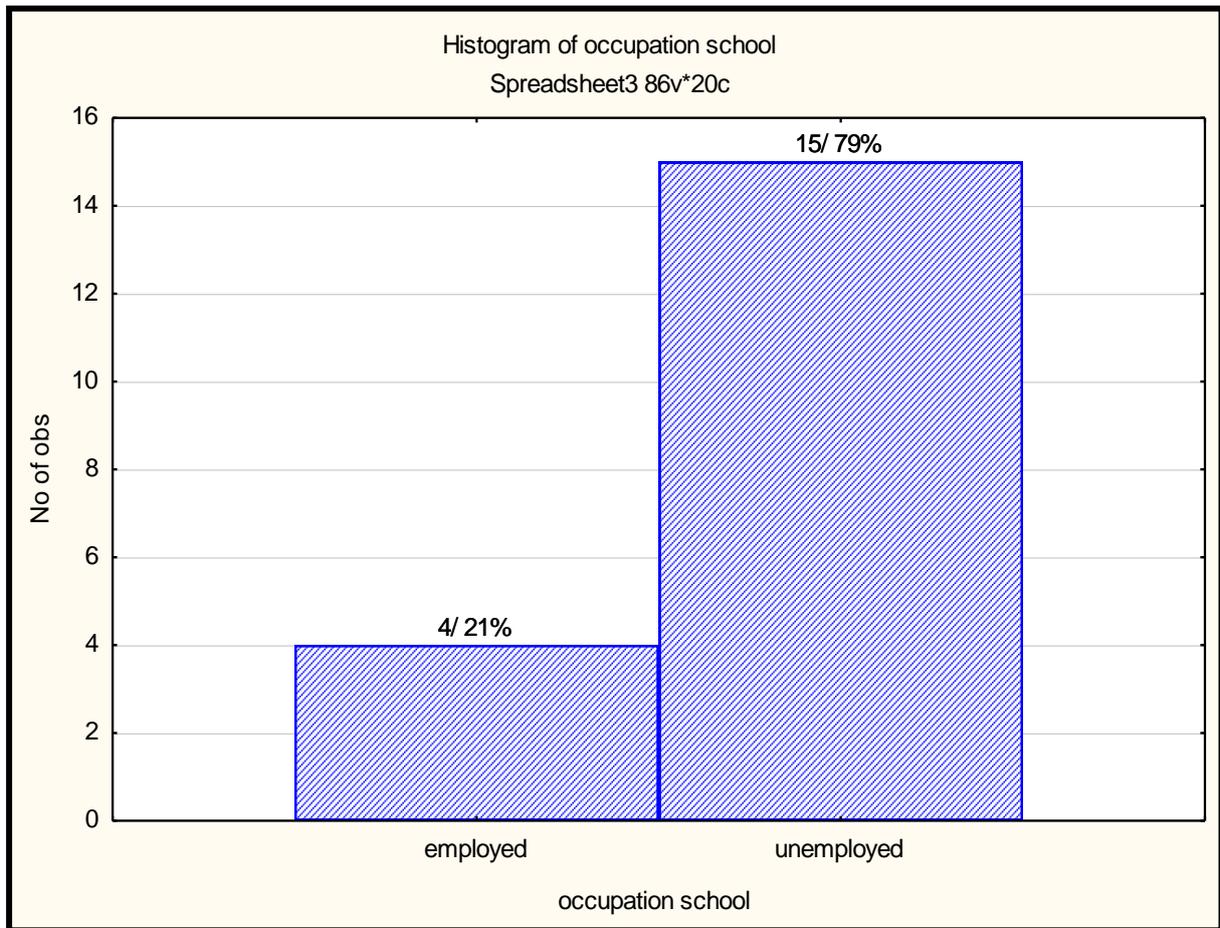
(N = 20)

Figure 5.6 Occupation after giving birth

Only four (4 or 20%) of the mothers were employed after the birth of their child and most of them said they were not able to look for employment opportunities, nor other means of survival.

5.3.1.7 Occupation when the child is at school

The occupation of the mothers after the birth of their disabled children and when the children were at school was investigated and the results are presented in figure 5.7.



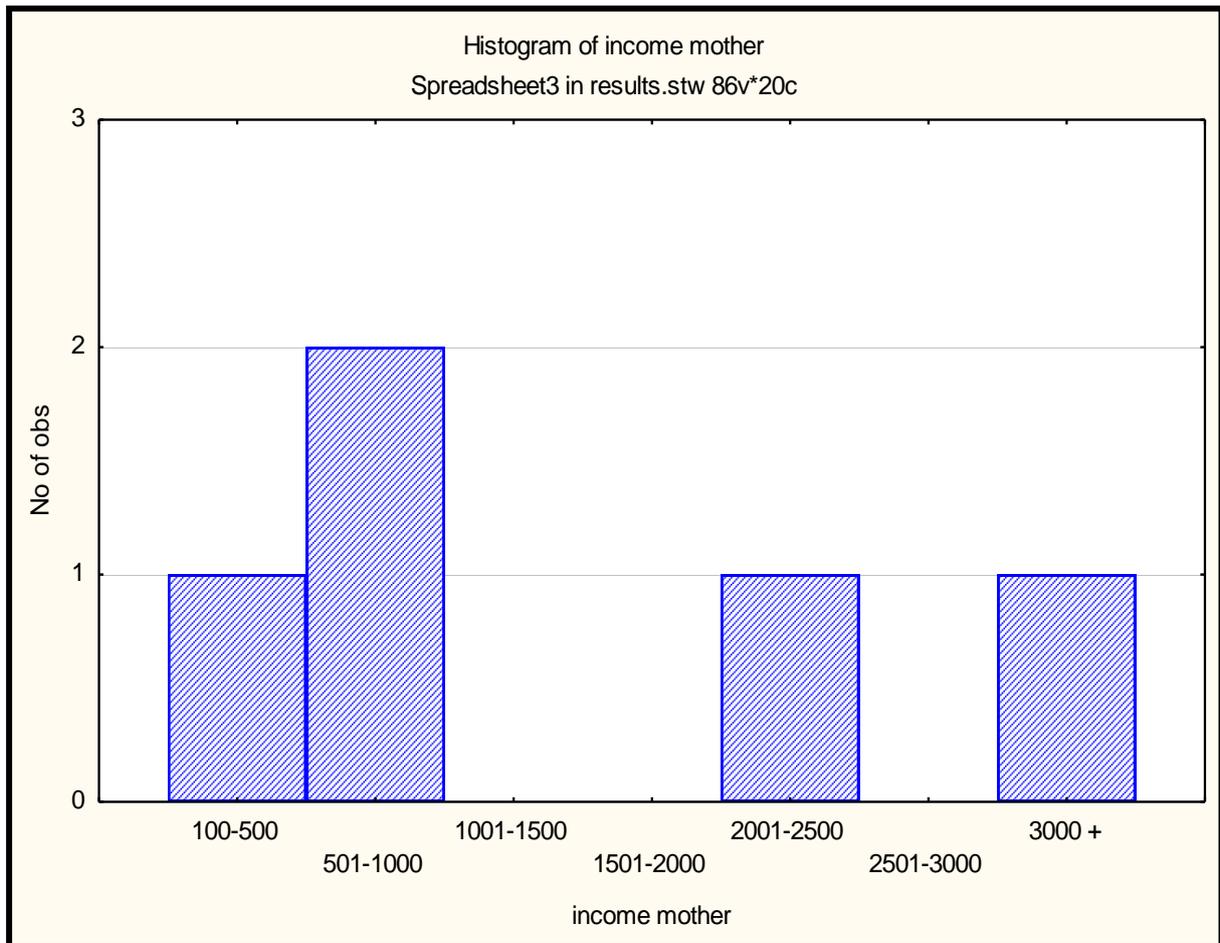
(N = 20)

Figure 5.7 Occupation when child is at school

As can be seen from figure 5.7 the number of mothers employed has not changed that much from the results presented in the previous figures. This is because they claimed that they cannot work as the disabled children needs to be attended to after school.

5.3.1.8 *Income of the mothers*

The income of the mothers was investigated.



(N = 20)

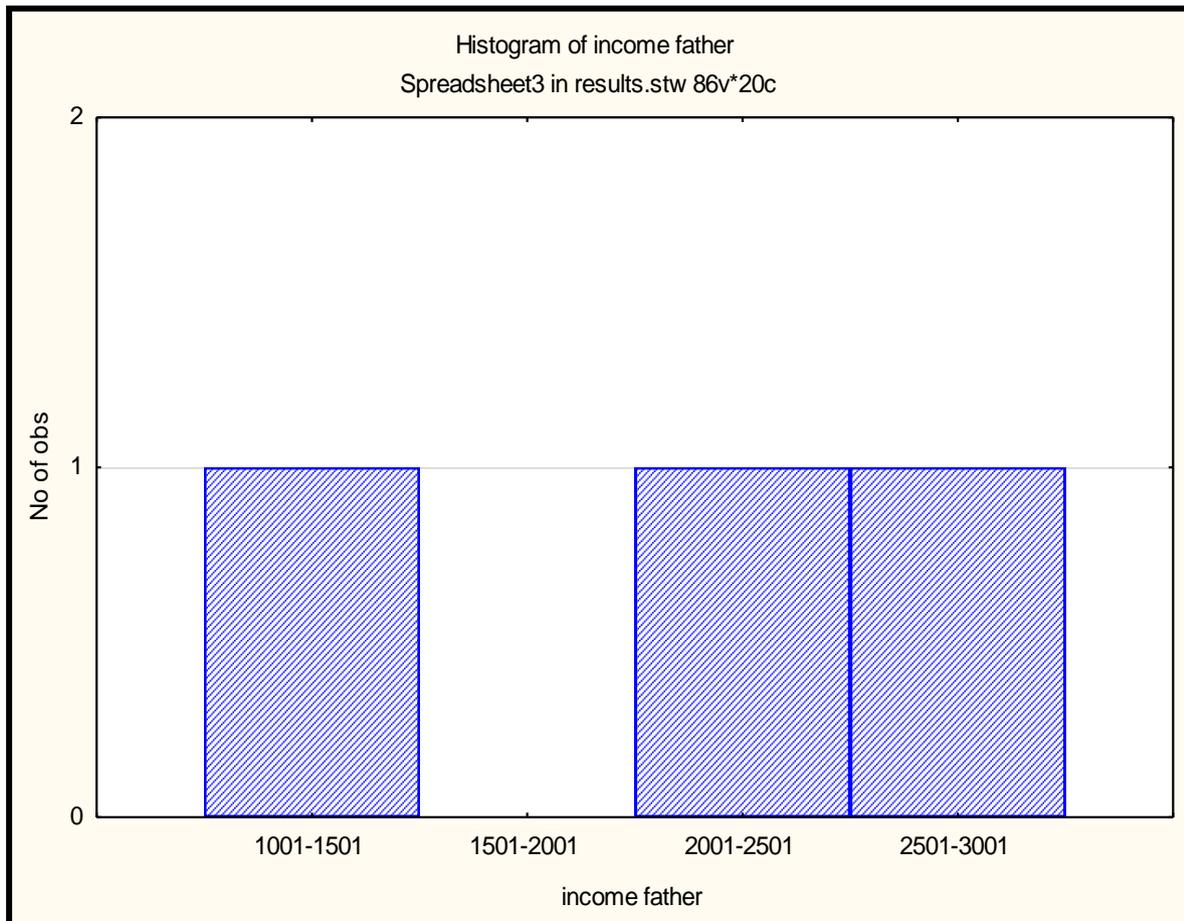
Figure 5.8 Income of the mothers

Figure 5.8 shows that the highest income earned is P3000 and only one mother earns this amount. The lowest income earned is P500. According to the BPHC Report, the largest sector of the population is employed and paid in kind. Also, females are mostly unemployed especially those without training.

Lack of income may have an impact on the psychosocial needs of mothers as they need to provide for their children. Nashandi (2002) stated that in Southern Africa, two thirds of primary caregivers are females. The mothers are burdened by financial constraints, fear of stigma and discrimination.

5.3.1.9 Income of fathers

The income of the fathers was investigated.



(N = %)

Figure 5.9 Income of fathers

In this study only five mothers were married and out of them only three of their husbands were working and their income was less than P3000. Arguably, an income of this amount is not enough to maintain a family. According to Seleka *et al.* (2007:10-19), Botswana has social safety nets for different groups, but none of these are specifically targeting the disabled persons. This then has an impact on the psychosocial needs of mothers if both the mother and father or partner have low incomes.

5.4 THE CHILD WITH A DISABILITY

5.4.1 THE DIFFERENT PHYSICAL DISABILITIES FOUND IN PRIMARY SCHOOL CHILDREN

Table 5.1 below shows the different disabilities that were found in primary school children involved in this study.

Table 5.1 Type of disability in primary school children

| Type of disability | No of children |
|---------------------|----------------|
| Deaf | 1 |
| Difficulty walking | 1 |
| Epilepsy | 1 |
| Hunched back | 1 |
| Muscular dystrophy | 1 |
| Paraplegia | 1 |
| Cerebral palsy | 2 |
| Club foot | 2 |
| Deformed limbs | 2 |
| Hemiplegia | 2 |
| Multiple disability | 6 |
| Total | 20 |

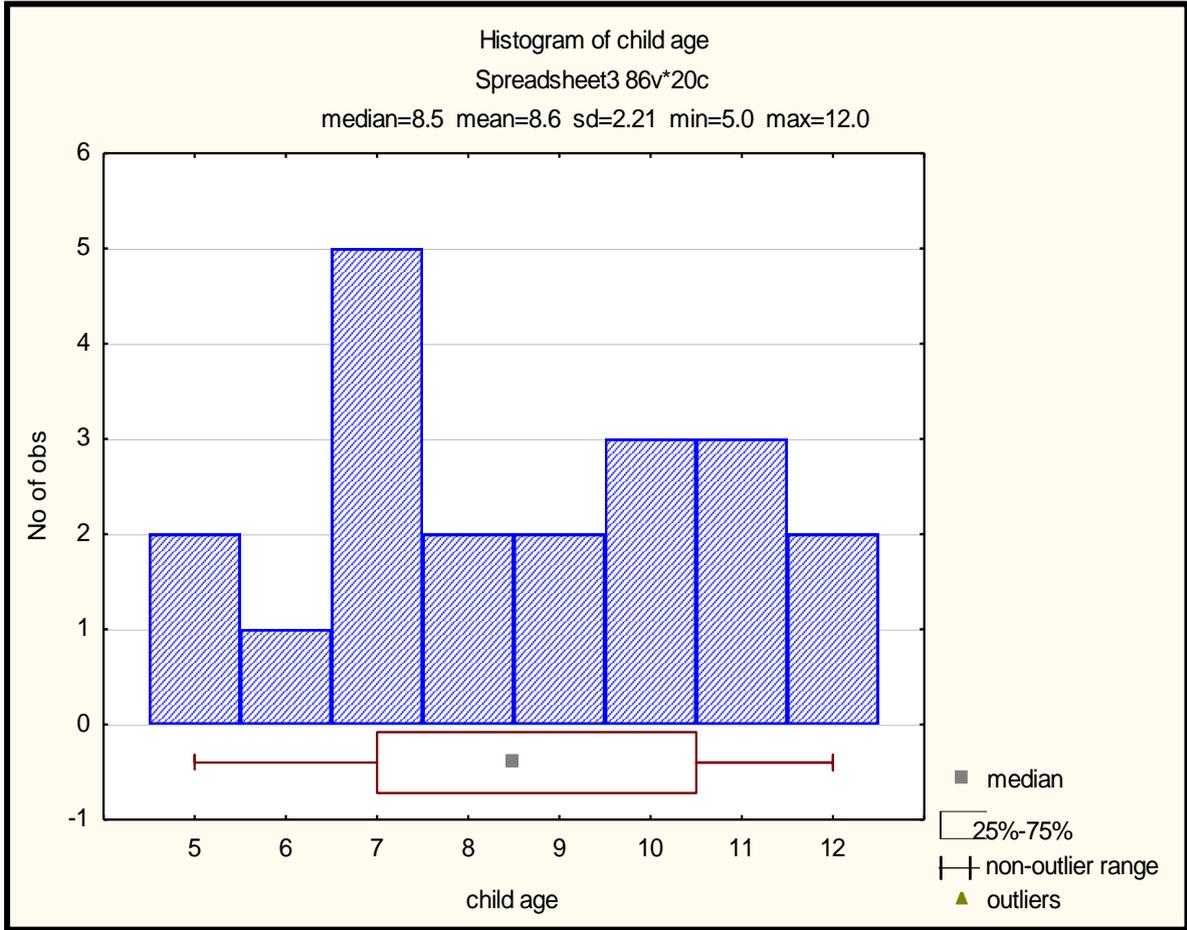
The multiple disabilities that were found in six children were a combination of a hunched ribcage, deformed limbs, walking on toes, deafness, a hand without fingers, delayed milestones with shaky body muscles, cerebral palsy, quadriplegia and mental retardation.

According to the results in table 5.1 the most common disability found was deformed limbs (2), cerebral palsy (2), club foot (2) and hemiplegia (2). Disability can be a complex issue, so the mothers of these children need information from the professional on the nature of the physical disability of their children. When assessing the child a multidisciplinary team should be involved so that the social worker can give a full report to the mother. As seen in chapter two, physical disability is caused by a number of conditions that mothers should know about. This is why it is also important to assess, both the parent and the child or the whole family to gain knowledge of the family history so that the root cause or issue can be revealed. Disability is influenced by issues such as nutrition, medical aspects and the environment. According to McCarthy (1992) and Evans (2004:246), by giving the family information about available resources, the mother's confidence in her ability to deal with her child can be reinforced. In addition, Collins, Jordan and Coleman (2007)

argued that according to family systems theory, challenges like disability puts the family in a state of disequilibrium as there is then a need for additional care.

5.4.2 Age of the child

The age of the disabled children whose mothers participated in the study was investigated.



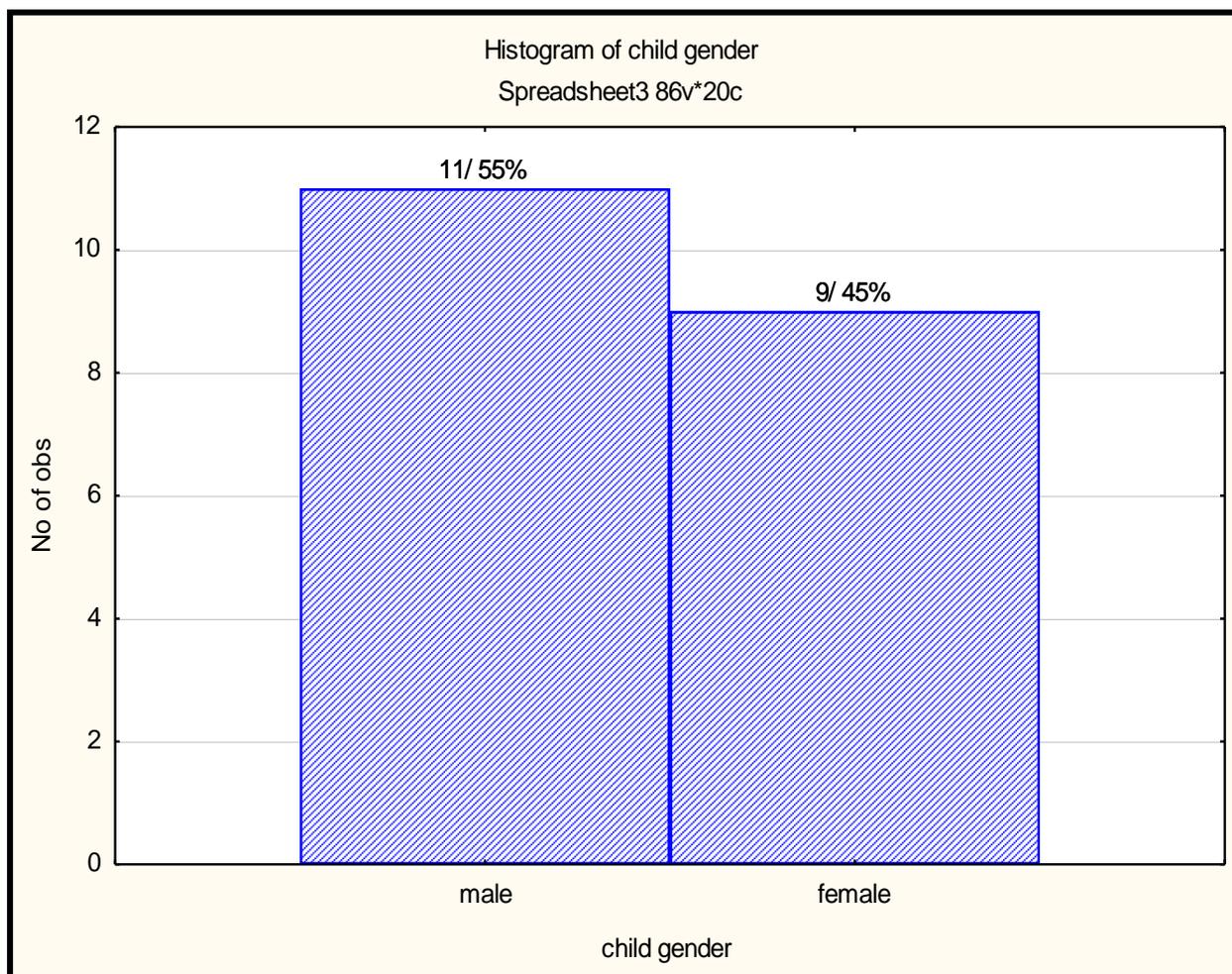
(N = 20)

Figure 5.10 Age of the child

Figure 5.10 shows the number of children of the respondents who are in primary school. Their ages range from five to 12 years. Most of them fall between the ages of seven and 11 years as most of them are in primary school.

5.4.3 Gender of the child

The gender of the disabled children whose mothers participated in the study was investigated.



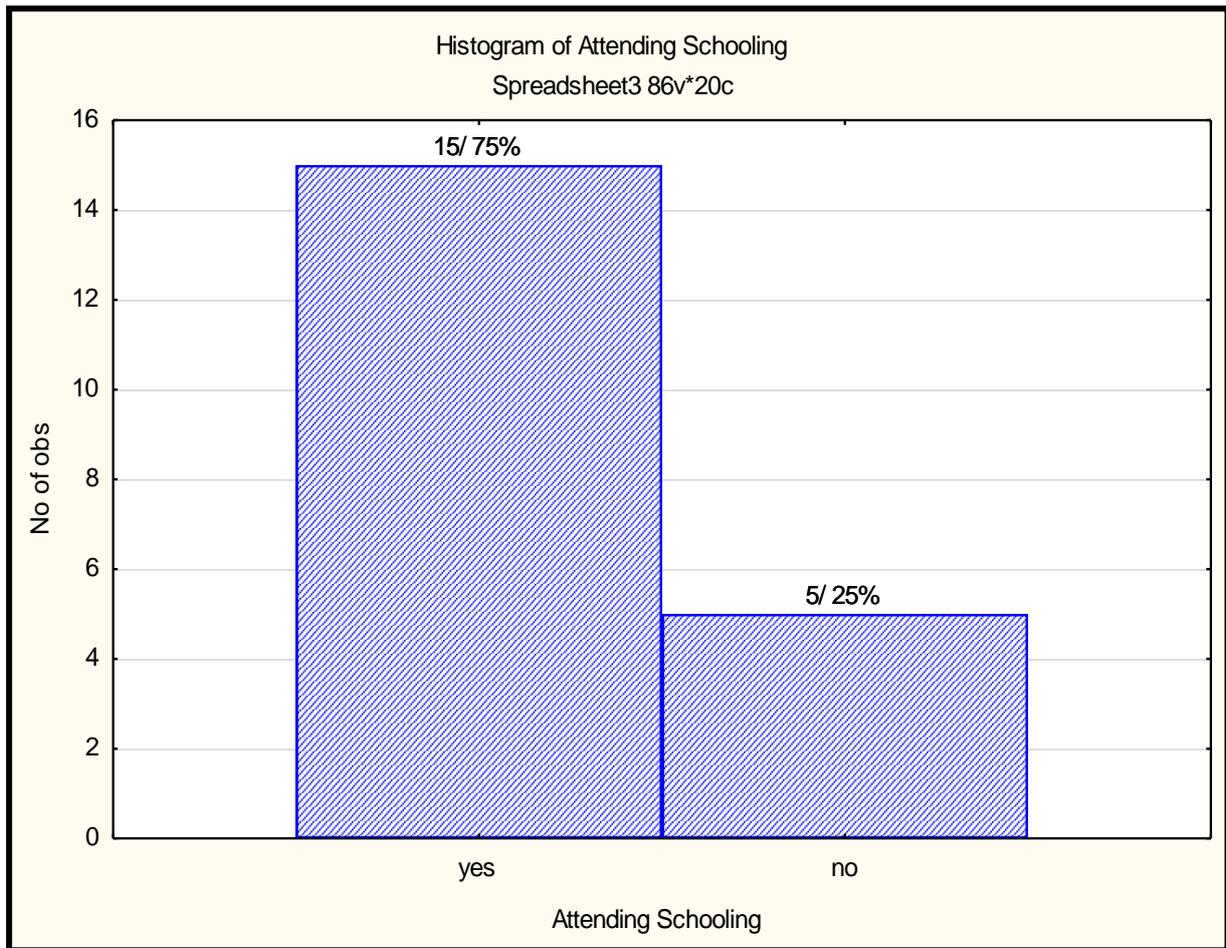
(N = 20)

Figure 5.11 Gender of the child

Figure 5.11 reveals that the highest number of primary school children (11 or 55%) with a disability, are males. The results correspond with that of a study done in USA by Van Dyck *et al.* (2004) where there was a high prevalence of disability among boys, school age children and children in lower income families.

5.4.4 School attendance of the child

The graph below illustrates that 15 children are attending school while five are not attending school.

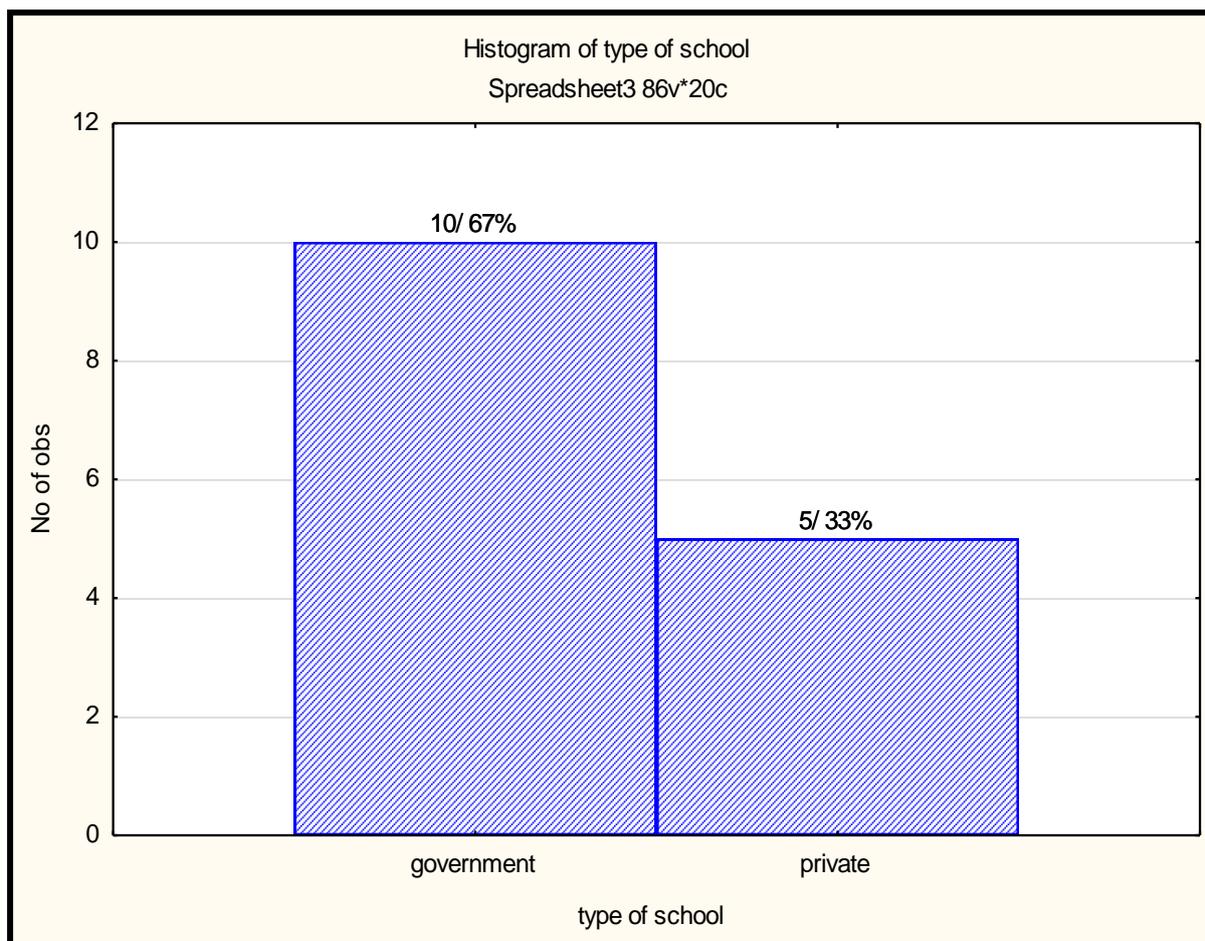


(N = 20)

Figure 5.12 Attending School n=20

5.4.5 Type of school

The type of school the disabled children attend was investigated.



(N = 20)

Figure 5.13 Type of school

The findings show that most disabled children (15 or 75%) attend school. This corresponds with the findings of the United Nations Enable Programme of Action (UNEPA) 2005 that states that many countries have taken action to eradicate barriers to participation in education for disabled persons. In Botswana for example, although there is a Revised Education Policy (1994), most of the children reported to be in school were in lower grades or standards showing that they start school late. Furthermore, mothers expressed their dissatisfaction with the schooling of their children citing barriers such as sandy surfaces, no ramps and teachers' attitudes. This shows that even if they are in school there are still barriers with regards to resources and facilities. Similarly, Hopkins (2004:99) notes that special education is committed to social inclusion but operational practice offers exclusion.

There are children who still do not attend school and the mothers provided the following reasons for this situation:

The child drops out of school because he/she complains about being teased by other children.

The mother feels the child is immature.

The child does not want to go to school which shows that there is something bothering him/her at school.

The child does not feel like going to school and the mother does not care.

The mother feels that the child is still too young.

The child was not enrolled at any school.

Even though there may be various reasons why the children do not attend school such as the education system, physical or emotional barriers; the mothers are also influential as they are often overprotective, believe that the child is too young and immature and do not care if the child is not attending school. The education system can also have a negative influence by not admitting the child to any school and this can affect both the child and the mother psychologically.

Also, most mothers whose children are at school are unsettled about it. This shows that they are not happy with the education system or do not understand it. These feelings of over protectiveness and uneasiness contribute can have a negative impact and can exhaust them both physically and psychologically. This indicates that the mothers need counselling before their children can go to school in order to prepare them psychologically for this and to reassure them about the school environment. They also need to be provided with the basic items the child requires for school.

As can be seen in figure 5.13 most of the disabled children in primary school are in government schools (10 or 76%). They are in the mainstream education system because the government education policy stipulates that there should be special classes but that those teachers had to integrate them into mainstream education. Most private schools also have special classes for disabled children and the children who go there are also assisted by the government. In this study five (33%) children were in private schools.

5.4.6 Age of the child when starting schooling

The ages of children when starting school were investigated.

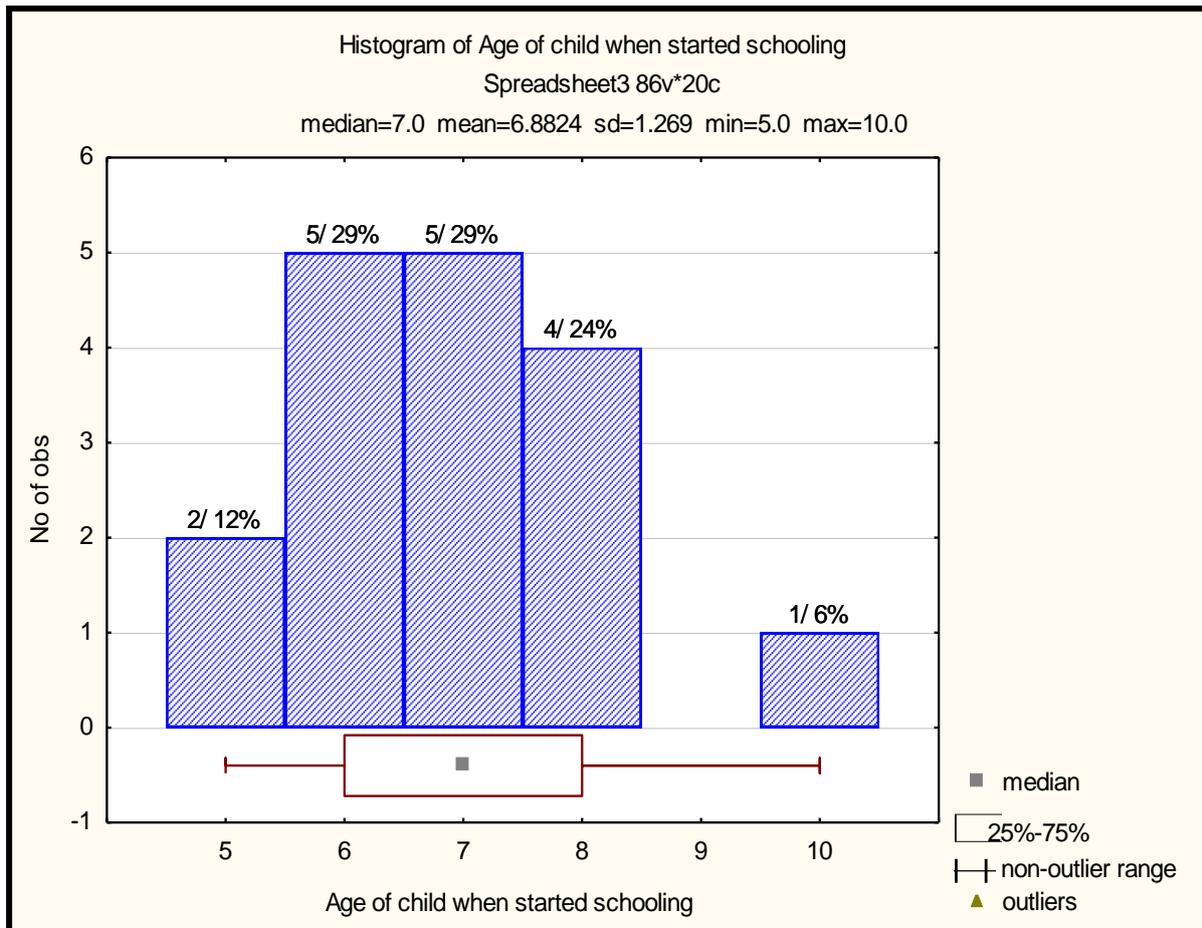
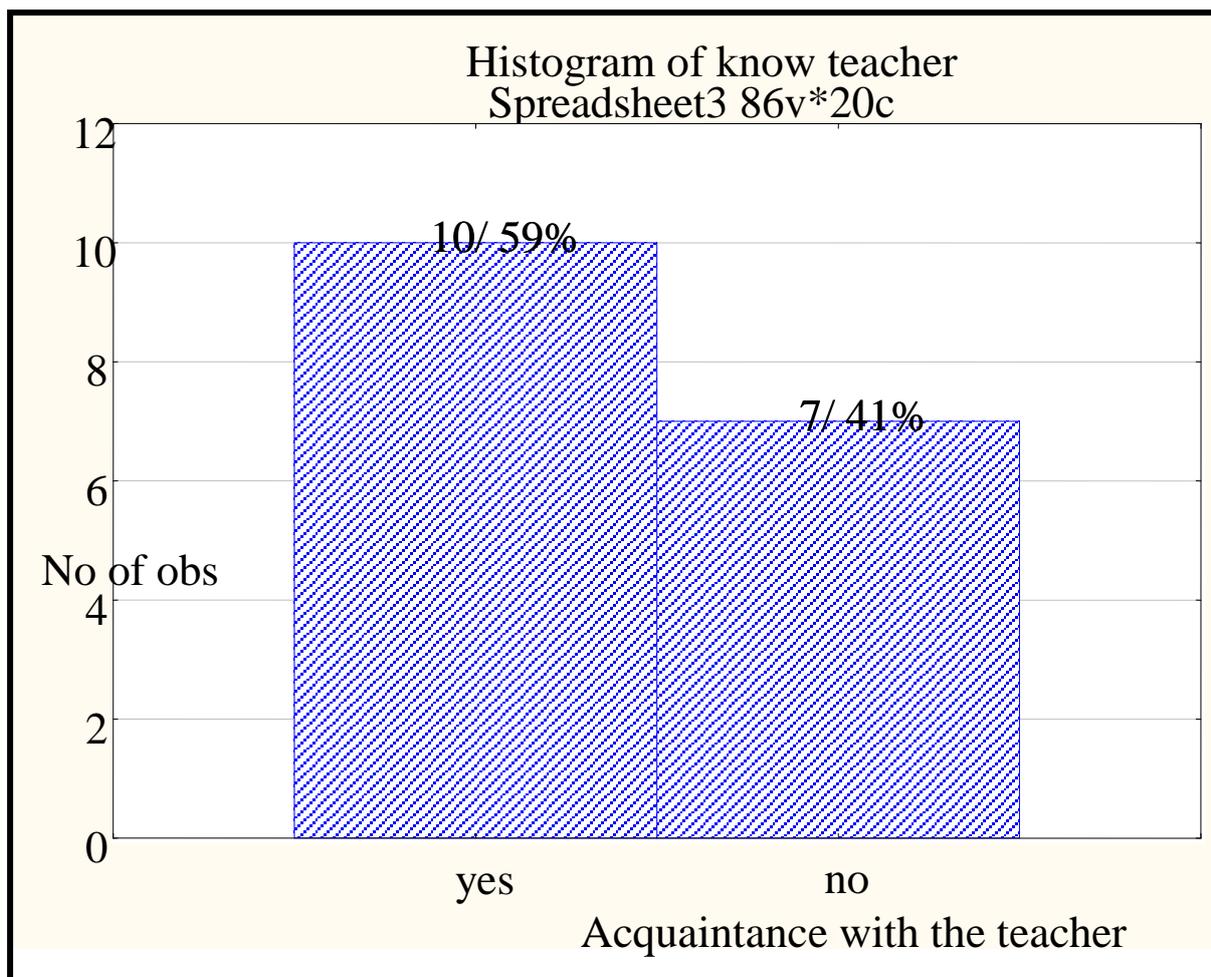


Figure 5.14 Age of child when starting school

The graph shows that some children in the study (two or 12%) start school at the age of five, but mostly between the ages of six and nine years. The recommended age to start primary school in Botswana is six to seven years.

5.4.7 Mothers' acquaintance with the school teacher

The mothers' acquaintance with the school teachers of their children was investigated.



(N = 20)

Figure 5.15 Mothers' acquaintance with the teacher

Most mothers (10 or 59%) indicated that they have met the teachers in the respective schools, but when the researcher checked how they know the teachers it was established that it was through school invitations and registration. Their knowledge therefore is not through their own initiatives or any form of interest in their child's school work.

The mothers' knowledge of the teacher is presented in table 5.2.

Table 5.2 Mothers' acquaintance with the school teacher

| Acquaintance with school teacher | No | Acquaintance with school teacher | No |
|----------------------------------|----|------------------------------------|----|
| Through registration | 3 | Decide to visit at end of the year | 1 |
| Visiting school by invitation | 6 | No reason | 6 |
| Special school invitation | 2 | | |
| Child's sibling | 1 | | |
| Child's grandmother | 1 | | |

| | | |
|-------|----|---|
| Total | 13 | 7 |
|-------|----|---|

N=20

Table 5.2 shows that most mothers know the school teachers as result of invitations from the school (six), special school invitations (two) and registration (three) and those who did not know the teachers (six) had no particular reason for it. This indicates that as much as they want their children to be at school, the parents do not know the importance of coming to school at their own initiative to find out about the progress of their children. The teachers can educate the parents in this regard during orientations and parent meetings by showing them the importance of the parent-teacher partnership. The social workers can also educate them on the importance of this issue. Hakim and Jaganjac (2005) expressed the importance of combining CBR and Special Education Programmes that can benefit all. The integration of the disabled child into the education system can be easy if mothers are also fully involved and share their views. This is essential as it reduces the stress mothers experience due to feeling unsettled, overprotective and fearful for their children. McCarthy (1992:49) highlights the importance of providing clear, coherent and relevant information to mothers as well as acknowledging the trauma and pain involved in identification and assessment of special needs in their children.

McCarthy (2007:49) further stated that “parents frequently under utilise opportunities for participation in their children’s education and development because of perceived inequality as decision makers.”

Even though there could be challenges in the education system, the teachers are doing their best to invite the mothers to school and giving them feedback on the children’s progress. The following comments were given to the mothers by the teachers about their children:

The child is doing well or has the potential to learn.

The child attends well at school but try to encourage him/her.

The child’s performance was not good.

The child is playful and the teacher cannot cope with this.

The teacher complained about the child’s condition and behaviour.

The child has learning difficulties.

The child shows an interest in sport even though he/she has difficulty moving.

One mother said the grandmother went to see the teacher but that she never bothered to ask her what the teacher said.

The above comments reveal different issues about the relationship between the teacher and the child. They can assist both the teacher and the mother to work on the progress and integration of the child in the school. But McMichael (1971), Lonsdale (1978), Yim *et al.* (1996), Quinn (1998), Heinman (2002) and McKeever and Miller (2004) believe that disabled children have an impact on the emotional and social life of their parents and some studies indicate that this can cause a positive or negative reaction in them depending on the situation. The mothers of these children had mixed feelings about what the teacher had said to them about their children:

Some mothers were happy about the progress of the child.

One mother said even though the child is disabled, she is consoling herself with the child's school work.

The other mother said the teacher is impatient and has a negative attitude towards the child.

At least the child is interested in something.

The mother was not happy and feels the teacher is not doing his/her best as the child is disabled.

The other mother was so upset that she took the child out of school as she felt that the child is immature and because of the disability it is difficult to assist him/her.

The other mother was very upset and felt it is the teacher's duty to help her.

5.4.8 Relationship of the disabled children with other children

Another way to find out how the disabled children are integrated at school and in the community is to ask about their relationships with other children. As stated by Antle (2004:173), the physically disabled children lack social skills and friendships. This can be attributed to their physical appearance and to cultural beliefs, as Abosi and Koay (2008) state that disability is always associated with something evil. If they make friends they are labelled with names that are not socially acceptable. The children experience this treatment at school and then take out their frustrations at home. This can then reveal the needs of the disabled child and their adjustment difficulties. The social workers can then assist both the child and the mother.

Table 5.3 Mothers' responses as to how their children relate to their peers/among themselves

| Type of relationship | How the child relates | Number | Reason |
|--|-----------------------|----------|--|
| Relationship of disabled child with others | Relates well | 4(20%) | |
| | Do not relate well | 9(45%) | Cries easily Does not feel free Likes younger children Other children tease him/her Not interested in most games Plays alone among other children Others shun or do not want him/her |
| | Do not relate well | 4(20%) | Isolated |
| | Do not relate at all | 1(5%) | Only wants the mother |
| | Do not know | 2(10%) | Do not know |
| Total | | 20(100%) | |

The findings indicate that even though the children may seem to relate well (65%) to other children there are physical and emotional challenges that these children face, which are ultimately the issues that their mothers have to deal with, with their children once back at home. Family systems theory explains that if one subsystem is affected within the family system, it will be felt by others in the system. According to Collins *et al.* (2007), the social worker should attend to the whole family when dealing with the problem. The mothers of disabled children need assistance with their psychosocial needs.

5.4.9 Barriers at school

There are several barriers at school which were reported by the mothers.

Table 5.4 Barriers at school as reported by the mothers

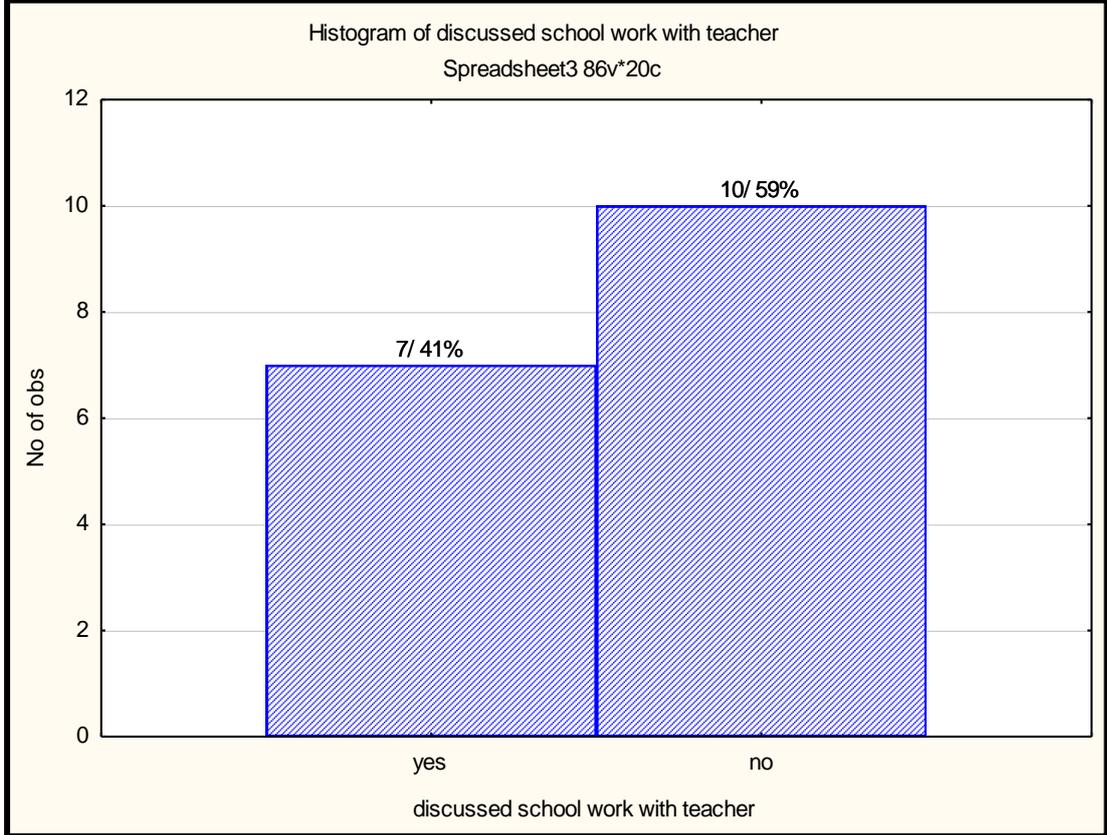
| Nature of barriers at school | Reasons for barriers |
|------------------------------|---|
| Environmental | Sandy, few ramps, uncomfortable furniture, cold classrooms. |
| Attitudes of people | Other children teasing and laughing, teacher not friendly, mothers not trusting the teacher |
| Medical conditions of child | Children using equipment and medication, swelling body parts, pains, pressure sores and learning problems |

The findings reveal that the physical disability is exacerbated by other conditions like learning difficulties, pressure sores and swollen body parts. Therefore, the children need extra care and special attention as they have special needs.

This indicates that neither the school nor the parents can meet the needs of the disabled children alone as there are physical, social and psychological challenges involved. This therefore is where a partnership between the mothers, social workers and teachers is needed in order to support the mothers to deal with their psychosocial needs so as to enhance their disabled children’s integration at school.

5.4.10 Discussion of school work with the teacher

The mothers were asked whether they discuss the school work of their children with the school teacher.



(N = 20)

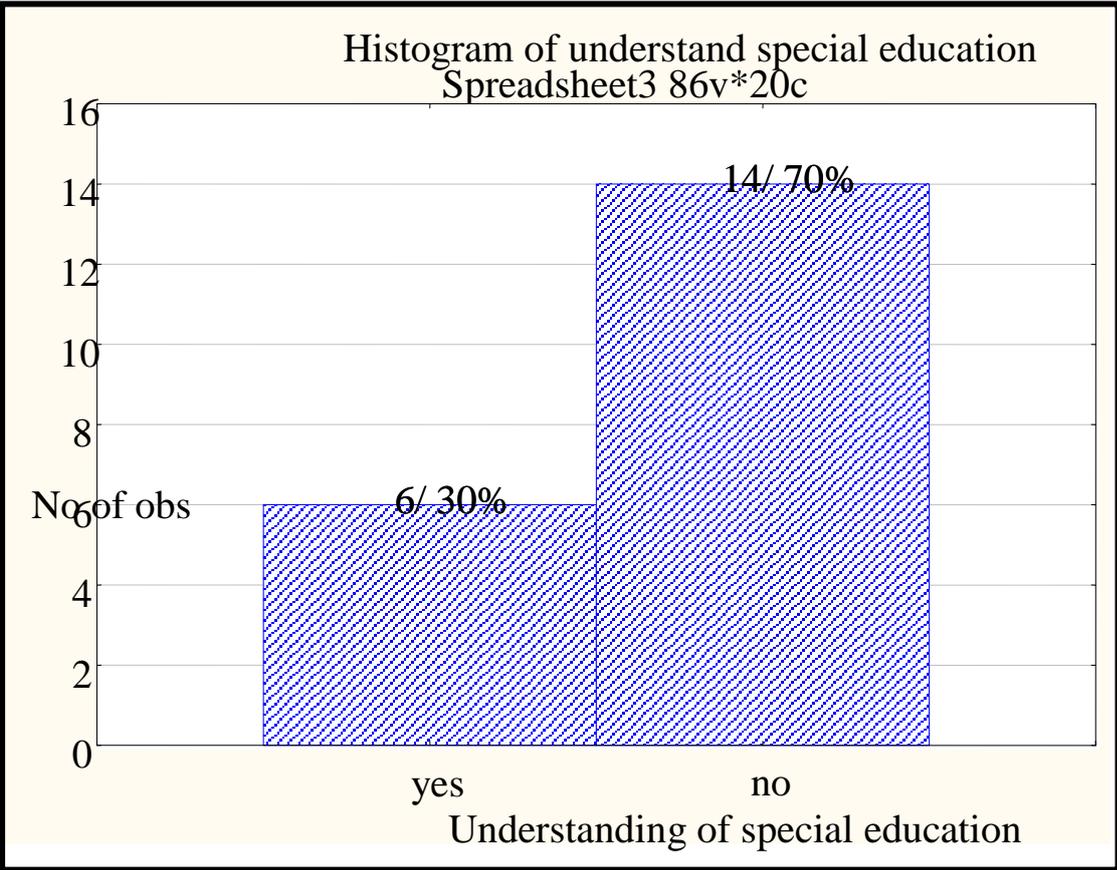
Figure 5.16 Discussion of school work with the teacher

The findings in figure 5.16 show that a high number of mothers (10 or 59%) do not discuss their children’s school work with the teachers. The reason being the negative

feelings they experience like being overprotective of the child and unsettled about the child, as previously discussed.

5.4.11 Understanding special education

The mothers' understanding of special education offered to their children was investigated.



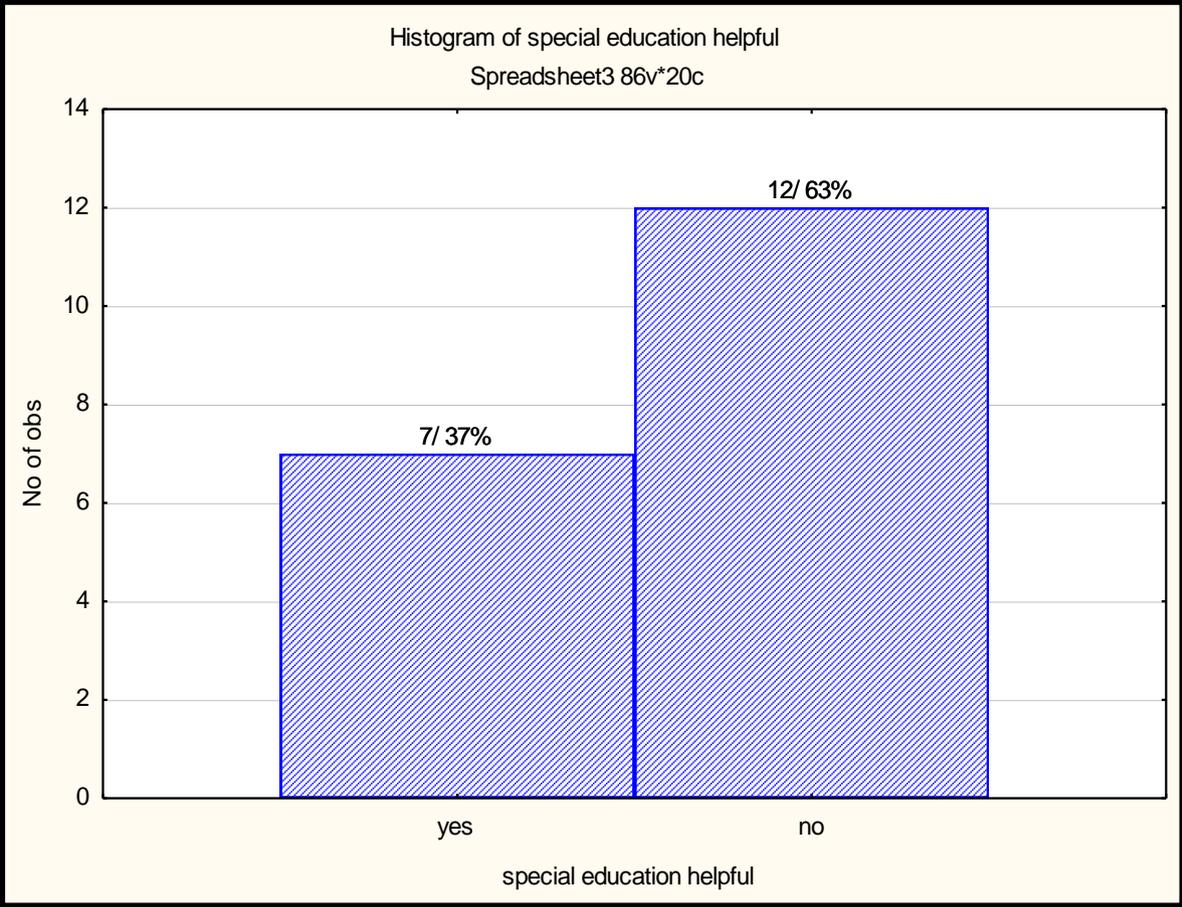
(N = 20)

Figure 5.17 Understanding of special education

The figure above shows that a high number of mothers (14 or 70%) indicated that they do not understand special education programmes. This shows that the special education programmes need to be explained to parents. This will help mothers to understand the special programmes which can assist their disabled school going children, and in so doing reduce a lot of confusion and stress among them.

5.4.12 Helpfulness of special education

Figure 5.18 shows that a high numbers of mothers (12 or 63%) do not know how helpful special education is. The reason may be that they do not understand the programme as indicated above in figure 5.16.



(N = 20)

Figure 5.18 Helpfulness of special education

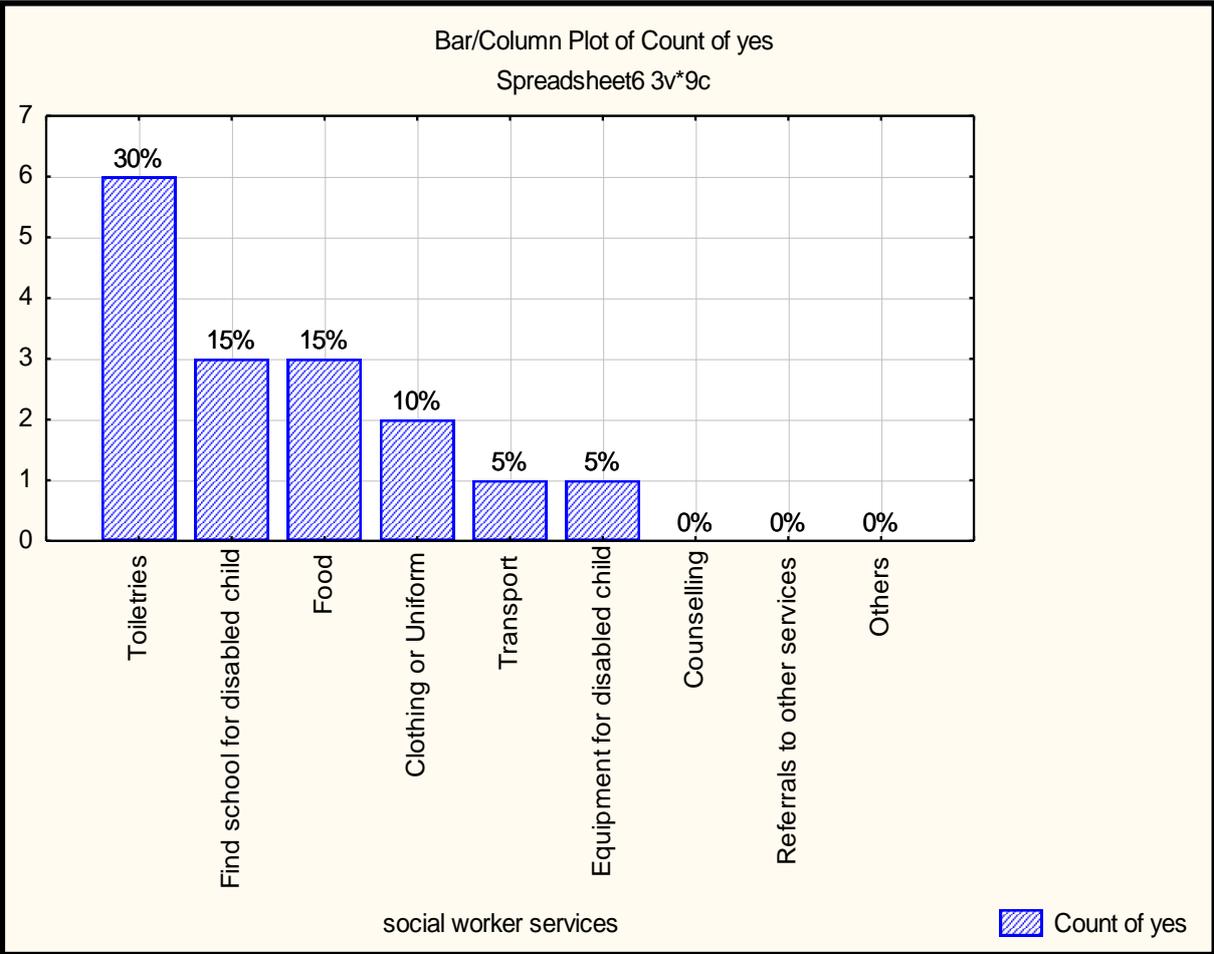
As illustrated in figure 5.17 there are fourteen (70%) mothers who said they do not understand anything about special education, and figure 5.18 shows that twelve (63%) did not find special education helpful. These findings indicate that the special education programme is not accessible to those living in the districts. Letlhakeng is however not that far from Gaborone, which is the seat of education in Botswana, there are education offices in each district and they have education guidance and counselling programmes, there are social workers and special education teachers as well as parent and teacher associations who could be reaching out to mothers and educating them about this. This shows that no matter how well established the

special education department is, with all its policies in place, these are not well implemented practically. Mothers are not aware of the services which can help their children and this lack of information can result in confusion and exclusion from the very services intended to help them, leading to stress and uneducated children. This could be justifying the problem cited by Hopkins (2004) that special education may be well established, but makes little progress due to factors like low budgets, lack of teacher’s interest and shortage of manpower.

5.5 SERVICES OF THE SOCIAL WORKER

5.5.1 Services rendered by the social worker

The participants were asked about the services provided by the social worker for the family as well as about the school necessities provided for the child. The participant’s responses are presented in figure 5.19.



(N = 20)
Figure 5.19 Social Work services

Figure 5.19 demonstrates services provided by social workers to disabled school going children. In the case of all the services rendered, less than 50 percent of the participants received the services. This indicates a lack of support for disabled children by social workers. The school is the environment where social interaction begins and development of children occurs so that they can integrate well with others. If they do not have the necessities for school and other basic needs, this impacts negatively on their wellbeing and the frustration is felt by both the child and the family especially the mothers. As stated earlier, physical disability does not affect the child alone, it also affects the family as they have to support the child. This study has shown that most mothers of disabled children are unemployed, therefore it is difficult for them to provide for the family. Meyers et al. (2000) stated that unless families are supported by government with material aid, they will face hardships which will lead them to poverty. This is supported by the fact that traditional support mechanisms have eroded over the years.

There were only five children who were assisted through the provision of social work services. They were given school necessities and food. None of the five children were fully supported through the provision of services that they needed. None of the parents indicated that their child had received counselling. Two had been on a waiting list for a long time and in the case of the other mother, her child was admitted to hospital due to malnutrition. The remainder of the mothers had not been assisted and most of them are not employed. Only four mothers are employed and one has a better job and can support herself and the child. Almost all parents indicated that they need help with their physically disabled school going children because even if they are working disabled children have special needs which need to be attended to. The children also need counselling so that they can fully understand the school environment and be well integrated. Literature consulted in this study supports the fact that there is no policy which caters for the special needs of the disabled children; they are means tested and then lumped together under the Destitute Policy (2002), which is why they are not assisted and placed on waiting lists. Those assisted are not fully supported. There is a need for serious advocacy for the special needs of the disabled children so that their families can be relieved or supported, particularly the mothers who are worried, desperate and stressed by their lack of material resources. Another important aspect is the provision of a disability grant, like in South Africa, which can be of assistance to these mothers.

The mothers want their physically disabled children to be assisted with food, clothes, toiletries, counselling, school uniforms, special schooling when it's difficult for them in the mainstream schools, information about disabilities, transport and equipment.

5.6 PSYCHOSOCIAL NEEDS OF MOTHERS

Some aspects of the psycho-social needs of mothers with disabled children were investigated.

5.6.1 Housing

Most of the mothers own homes. This could be due to the fact that in Botswana it is easy to get a plot in rural areas through the tribal land boards, but not easy to develop these plots because of lack of funds as most of the mothers are unemployed. Most of the homes are not conducive to the special needs of the disabled children. Nine of the participants indicated that the type of housing they have is modern, while the rest have a mix of traditional houses and shacks. Even the modern homes are not of the standard required. The only distinctive feature is that they have used modern materials. The homes have one to three rooms with an average number of six people staying in a house. They do not have other areas for cooking, living, bathing and studying and the houses are also overcrowded.

5.6.2 Number of people living in a house

The findings show that the number of people living in the house ranged from four to 13 people per house and most of the homes were overcrowded. The figure below represents the number of people per house and as already stated the highest number of occupants per house is six to seven people.

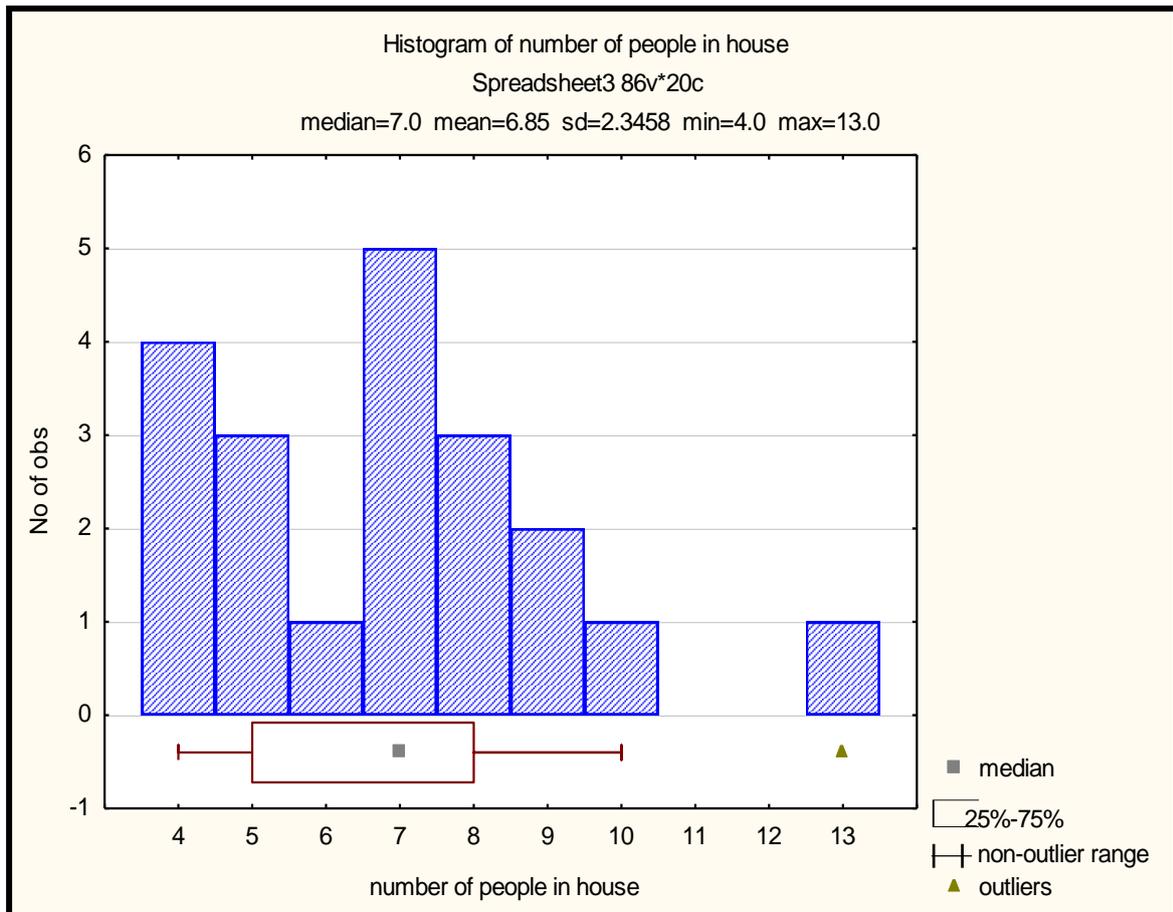


Figure 5.20 Number of people in a house

5.6.3 Electricity supply

Electricity is needed for a lot of activities in the home. An essential activity for which the disabled child would need electricity is light for studying. Most homes however do not have electricity. Lack of these necessities frustrates and stresses most mothers. The participants also used paraffin for lighting. The BPOCH Report confirmed that a large number of people living in villages in Botswana use wood and paraffin for cooking and light. Electricity is common in urban areas and in villages for those who can afford it. If a person is not employed it is however difficult to access this resource.

5.6.4 Water supply

The findings indicate that most homes have a supply of water. The type of water supply indicated is a stand pipe in the yard. The water is however not connected to the house. To operate with this type of system, when the children have special needs, is strenuous especially for bathing, doing laundry and going to the toilet. The fact that the water was not connected to the house meant that these mothers had to

lift their disabled children into the bath, had to use a pit latrine for the child and without electricity had to cook on fires outside regardless of the weather.

5.6.5 Accessibility of the home to the disabled child

Most mothers indicated that their homes are not accessible to their disabled children due to the reasons stated in table 5.5 below that indicate what is needed for their shelters/homes to be more accessible to their disabled children. Other barriers include sandy homes, a lack of ramps, electricity and water as well as poorly built homes.

Table 5.5 Participants’ opinions on what is needed for their shelters/homes to be more accessible to their disabled children

| Item | Amount | Percentage |
|--|--------|------------|
| Well built modern house | 20 | 100 |
| Fitted windows and doors | 20 | 100 |
| Electricity | 20 | 100 |
| Water connected to the house | 20 | 100 |
| Ramps and rails | 20 | 100 |
| Plumbed bathroom and toilet | 20 | 100 |
| Fitted special equipment where necessary | 20 | 100 |
| Special furniture where necessary | 20 | 100 |
| Total | 20 | 100 |

(N = 20)

Table 5.5 shows the challenges the families with physically disabled children face in the provision of adequate shelter for them. As discussed previously in this section the findings show that the conditions of the houses were not satisfactory. The environment was not conducive to meeting the needs of the disabled children and the researcher observed that the mothers were struggling as most of them were unemployed. A shelter with the essential necessities like electricity, water, a safe and accessible environment are very important for every person, especially for parents with disabled children. According to Butler and Roberts (2004:59), a shelter with basic amenities like water, heating, sanitation, cooking facilities, sleeping facilities, which is clean, hygienic and safe contributes to the well being of a person. As this findings in this section of the study show most of these amenities were not available in the housing of the mothers of disabled children. This indicates that it will be tough for them as their wellbeing is affected, both physically and emotionally. Consequently, this has a negative impact on the wellbeing of both the child and the mother.

There are policies which deal with housing needs like the National Housing Policy (1999), which addresses the housing needs of the population especially those in the low income category. The National Population Policy (1997) ensures safe, sanitary and affordable housing and so an increased number of citizens can own houses. Also the Vision 2016 of Botswana stresses that by 2016 all citizens of Botswana should have access to adequate shelter, including privacy, security and space, light, ventilation and basic infrastructure at a reasonable cost. Under these policies there are programmes like the Self Help Housing Agency (SHAA) which develops houses for people with a low income. The programme further provides housing materials and the owner of the house has to pay a certain amount to the SHHA every month depending on the cost of the housing material. If a person is not working, like these mothers, the utilisation of the programme is not easy. There is also provision of shelter under the Destitute Policy (2002), but only if someone has a plot can the council build a house for that person. The programme is however only meant for registered destitute people. For a disabled person to qualify, he/she must undergo a means test in terms of the Destitute Policy. This is the only way these mothers can be helped and if they do not qualify for either, it means struggling with their children unaided, as was the case with the mothers in this study.

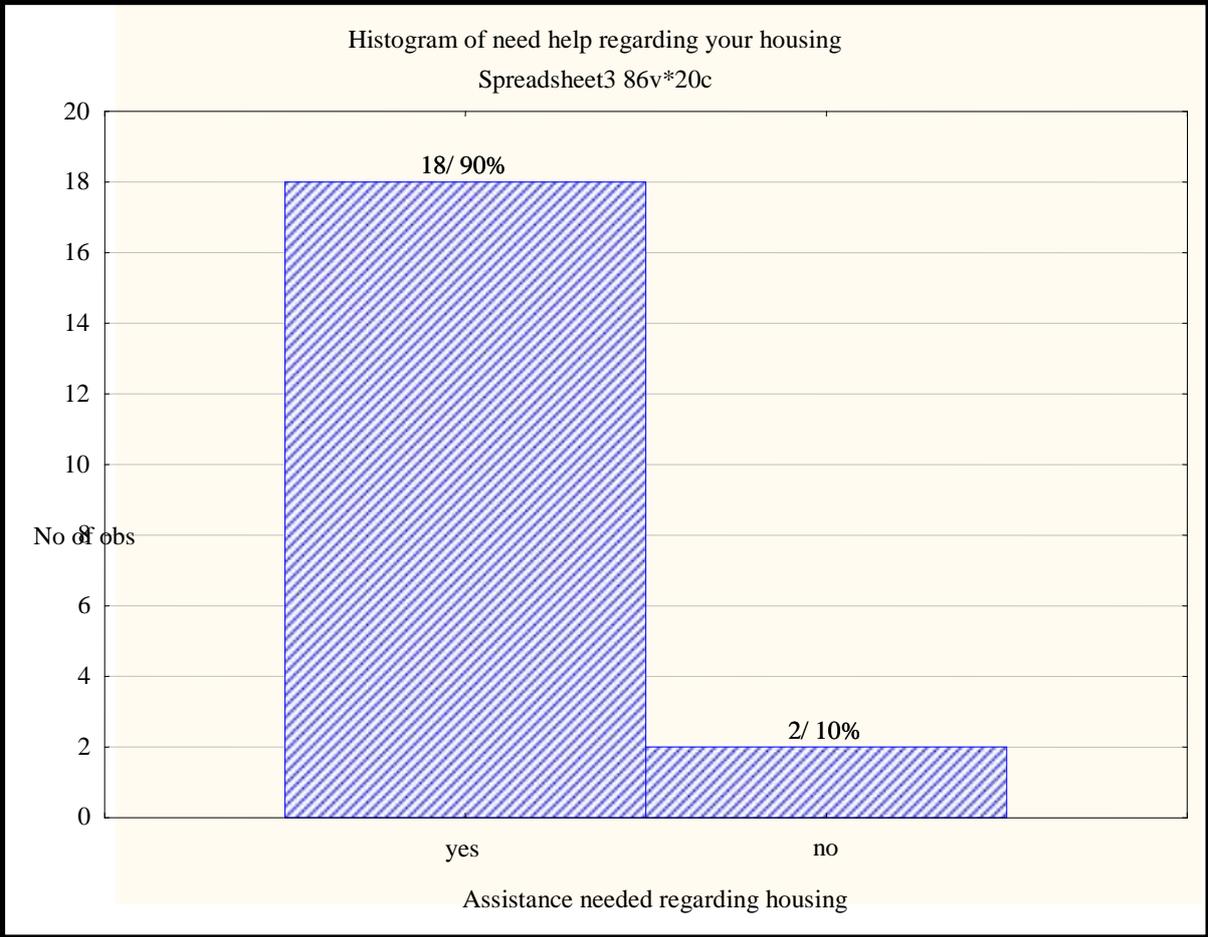
An accessible home is very important for the children as it promotes their growth, enables them to study, heal, be protected, keep warm and to do most of their chores more easily. It even reduces the effect of the disability because the child does not struggle as much. If the shelter is not conducive to meeting these needs the mother and the child become stressed, depressed, desperate, anxious and hopeless and lose confidence. Only eight of the mothers reported that their homes were accessible to their children, but that the standard of the house was poor such as a weak structure, small, broken or no windows and doors at all, no door locks, no ramps, no ceiling and unpainted, rough or no floors.

One mother said “if the government could not give us anything but provide well built two-roomed houses at least. We can struggle with other necessities.”

Of these twenty mothers, either with or without shelter, eighteen of them need help with their homes. Six asked for assistance but did not receive help, of which one is working and only one husband is working. The rest did not ask for help because they did not know the programmes existed, or did not qualify for them or they felt hopeless about the prospect of receiving assistance. This indicates that they do indeed need shelter.

5.6.6 Assistance needed regarding houses

The figure below shows that due to reasons stated in figure 5.23, most mothers indicated that they need assistance with their homes.



(N = 20)

Figure 5.21 Assistance needed regarding housing

As already shown, a large percentage of these participants are not employed and not married, but they have to provide for their families. They need to provide food, clothes and other necessities. Letlhakeng is not an area with employment opportunities and farming is the main mode of survival. As these mothers are taking care of their disabled school going children, they are not able to farm and those who do work in the fields are helping relatives and friends so that they can have something to survive from. The following are ways in which mothers indicated that they are providing for their families:

Eight of the participants have a member of the family who is working, either the husband, the mother herself or the elder child. The highest amount earned is P2000 – P3000 and only by two people. The rest earn a meagre wage of less than P1500.

Four are assisted by the Social and Community Department (S&CD). Only two are fully assisted, one only gets food and one receives food for her deceased sister's orphans and she helps herself by selling sweets.

Eight are surviving by helping relatives on farms during the farming season, selling liquor, doing nominal jobs, and begging from friends and relatives during those hours that their children are still at school.

One mother said "*re ithusetswa ke Modimo. Mo go mmaboipelego re itlhobogile.*" (We are surviving by God's mercy. As for social workers we have given up.)

Those mothers who are farming only do so part time in order to buy food, but mostly those who do farming have funds. There is a farmers' programme which assists farmers, but they have to pay a certain percentage to the tractor driver in order to be assisted. There is also a destitution programme, but beneficiaries must do a means test to qualify. It is unclear how it works as most mothers were complaining about not receiving services. Some said they were waiting for the social work assessment; others were on the waiting list, while others were turned down because they were considered young and fit enough to fend for themselves. There is also a home economics officer under the welfare programme who is supposed to help with income generating programmes. One mother indicated that they once formed a group and went to see the physiotherapist about an income generating programme. The physiotherapist approached the said officer but she told the physiotherapist that it is the responsibility of the rehabilitation social worker, who must also budget for the programme.

According to Butler & Roberts (2004) and Collins *et al.* (2007), families should provide for their children's basic care like their physical needs, appropriate medical care, food, warmth, shelter, clean and appropriate clothing and personal hygiene. This makes them feel proud of their role as carers, but if they fail to do so they feel inadequate about their parenting abilities when the children enter school. Most parents then need assistance from the social worker in Letlhakeng, because they lack material resources.

5.7 Equipment for special needs of children

Equipment for physically disabled children is part of the material equipment that mothers should provide for their children because, as stated in chapter two, equipment assists them to carry out their daily activities and also brings some relief to the mothers with the physical care of their children.

Of the 20 mothers interviewed, 14 stated that their children are using special equipment which includes hearing aids, special shoes, corner seats, standing boards, crutches, walking frames, prostheses and wheelchairs. The equipment is very expensive and also needs maintenance. Most mothers could not afford these and were either assisted by the orthopaedic hospitals, physiotherapists, charity organisations, schools or the rehabilitation officer. Most of the participants have waited a long time for these services with the waiting period ranging from months to years, as shown in the table below.

Table 5.6 Provision of equipment and waiting period

| Mother | Equipment | Waiting period | Provider organisation |
|--------|---|--|--|
| 3 | Special shoes | 6 months | Charity organisation |
| 4 | Hearing aid | 1 year | Hospital |
| 5 | Bilateral splints + walking frame | 1 day (waiting for walking frame) | Hospital To be provided by rehab office |
| 6 | Hearing aid + hand prosthesis | 6 years | School + hospital |
| 7 | Wheelchair, corner seat, standing board | 3 years | Rehab office |
| 8 | Wheelchair | 7 years (child was still under therapy) | Rehab office |
| 9 | Hearing aid | 2 years | Hospital |
| 10 | Walking frame | 1 year (still waiting, child uses homemade wooden frame) | Rehab office to provide |
| 11 | Hearing aid, chair, bed or mattress | 1 year (still waiting for chair + mattress) | School (to be provided by rehab office) |
| 12 | Walking frame | 1 year | Clinic |
| 14 | Crutches + wheelchair | 3 years (was still waiting) | Decided to buy it themselves from private clinic |
| 18 | Wheelchair + walking frame | 3 months Still waiting | Rehab office to provide |
| 20 | Walking frame | 1 year | Self |

(N = 20)

The use of equipment depends on the type of disability and some children with disabilities cannot do without equipment and if the waiting period for the equipment is long the disability can become more severe. Mothers or family members can suffer from the demands that daily care giving like feeding, carrying and bathing of children places on them. The equipment also helps the child to do certain activities, cope at school and in the community. The goal of the rehabilitation social worker is to assist the mothers with provision of these services relatively quickly so as to avoid more damage, as expressed by Feldman *et al.* (2002). McCarthy (1992), Barnes *et al.* (1998) and Mackenzie *et al.* (2004) believe that the social worker should play his/her role in multidisciplinary collaboration so that they can complement other professionals and assist mothers of the physically disabled children. In the reviews and evaluations of the work of authors like Lundgren-Lindquist & Nordholm (1993) and Mompati (2000) it seems all these problems in Botswana are due to lack of resources, community participation, community education, coordination and monitoring of services.

Lack of materials and resources can have different effects which can be physical and psychological. The following are the views expressed by the mothers regarding the lack of materials:

It makes life difficult as everyday they need to stay in an environment that is conducive to good health, receive sufficient food and medication to ensure good health, as well as clothing and good equipment.

It brings poverty to their homes and makes them dependant on other people, relatives, families and NGOs or government.

It makes them feel hopeless, depressed, neglected and desperate.

It brings financial and emotional stress because of extra care and attention that must be given.

It makes them blame the child, the family, partner or themselves.

Almost 90 percent of mothers mentioned that they are experiencing poverty, depression, dependence and stress. According to the BPCH Report of 2001,, data at international level reveals that female-headed households tend to be poorer than their male counterparts, because of low access to assets and participation in low

income jobs and having a high ratio of dependant people like caring for the young and the elderly.

5.8 MEDICAL ASPECTS

The participants' opinions with regards to medical aspect of their children were obtained.

Table 5.7 Opinions of mothers regarding problems with medical aspects

| Medical aspects | Examples of problems |
|---|--|
| Attending checkups (84%) | -Mostly monthly checkups |
| Distance to travel for the checkups (75%) | -Providing transport -Informing mothers about the checkups -Preparing the child -Mothers go with the child to the checkups -Informed about the progress of the child -Most mothers not prepared for the news |
| Need for transport (94%) | -Mothers checking for availability of transport with the social worker - Social workers provide transport but not comfortable with disability situation -Mixing patients with the disabled children in the same transportation |
| Feelings about the checkups (99%) | -Mixed feelings of depression, strained, not helpful -Some mothers said it is helpful |

(N = 20)

Participants could mention more than one problem.

The table shows that most children (84%) go for medical checkups. These mothers have to prepare for these checkups both physically and psychologically. As most of them are unemployed, they need assistance. The longest distance they have to travel is between 110 and 140 km and a large number of children go for checkups. They need their parents to accompany them. Mothers need assistance with this.

The feelings of participants with regards to issues relating to the medical checkups were explored. The findings are presented in table 5.8.

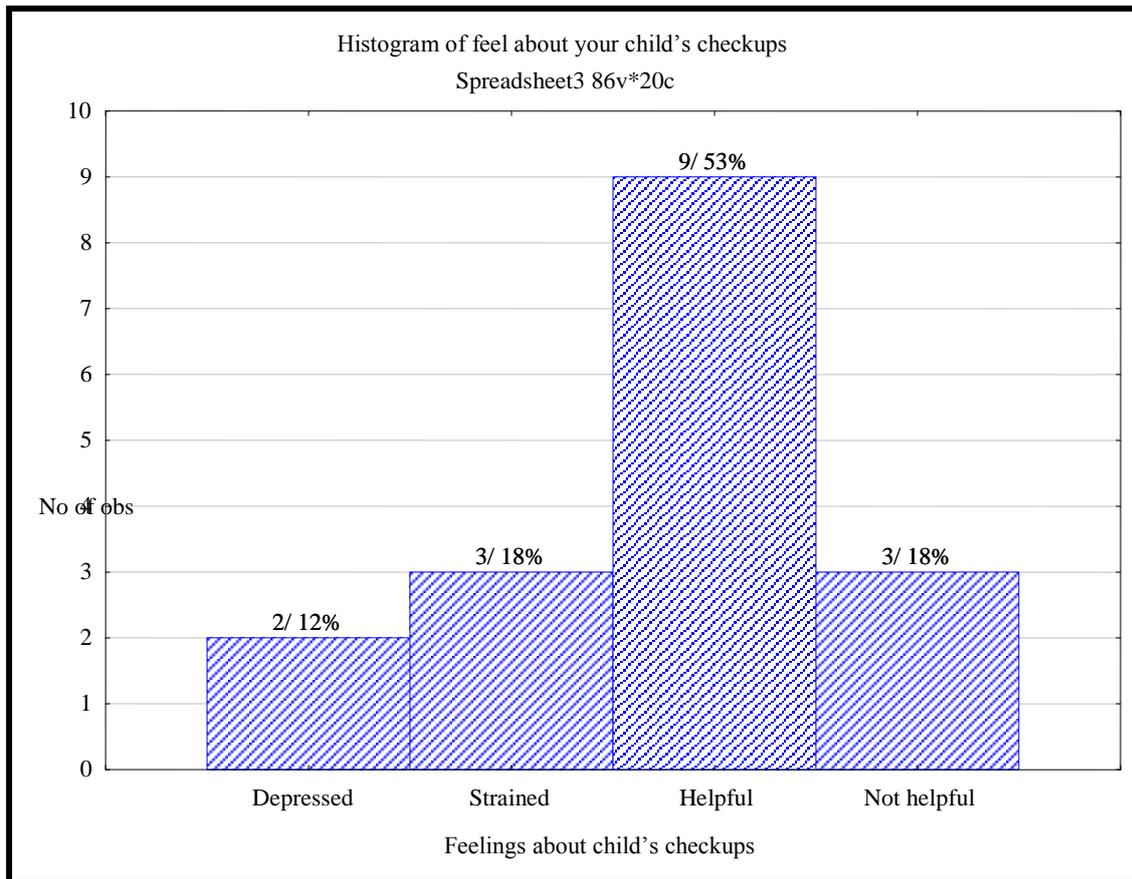
Table 5.8 Parents' feelings about issues relating to the checkups

| Issues | Amount | Percentage |
|--|--------|------------|
| Combi bus instead of van | 4 | 20 |
| Special transport catering for the disabled children | 4 | 20 |
| Preparations before the checkups | 4 | 20 |
| Cater for those on public transport | 4 | 20 |
| Not to be mixed with sick people | 4 | 20 |

| | | |
|-------|----|-----|
| Total | 20 | 100 |
|-------|----|-----|

5.8.1 Feelings about child’s checkups

Mothers mentioned that they find these checkups helpful to their children. Most of them however, even those who find them helpful, stated that the checkups can be strenuous and depressing. Findings about their feelings are presented in figure 5.22.



(N = 20)

Figure 5.22 Feelings about child’s checkups

Tables 5.7, 5.8 and Figure 5.22 demonstrate resources needed by the disabled children that go for checkups, how far they travel, how often, how they feel and if they need transport.

Of the 20 mothers interviewed, 17 of them take their children for medical checkups. The checkups are at the village clinic or places surrounding the village that are between three and 140 km away. They need transport to get to the checkups and checkups are done anything from weekly to yearly depending on the situation of the child. On average the checkups took place on a monthly basis. The transport is

provided by the rehabilitation office or the clinic or the family themselves. There are nine mothers who are assisted by the rehabilitation office or clinic, six provide for themselves and one gets assistance from both, either the rehabilitation office or her husband helps.

Even though most mothers found the checkups to be helpful, they said they are strained and depressed by them due to the fact that they have to think, prepare and keep dates for these checkups which stress them. They have to do the following:

Have money for either transport or food.

Prepare physically and psychological for the trip as some children use special equipment

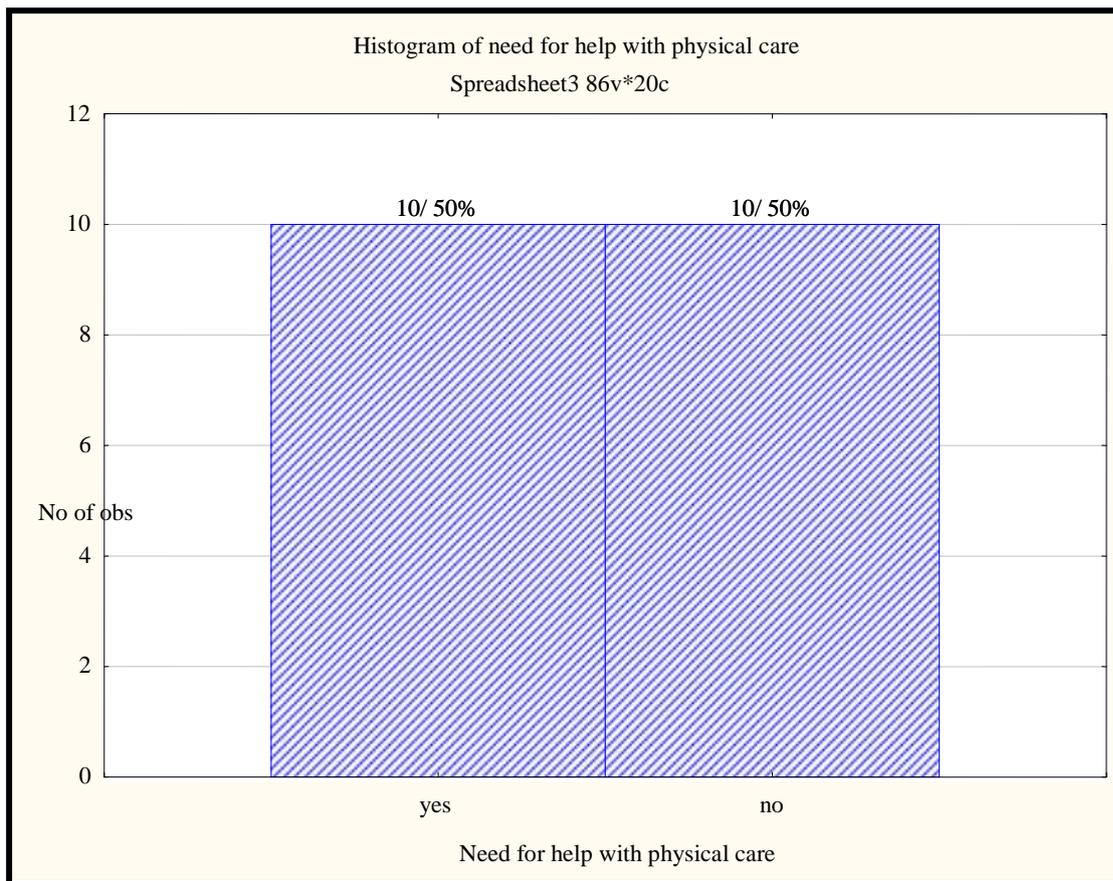
Prepare the children for the checkups as they see the physiotherapist or social worker in the morning if he/she is available.

Notify the school

The rehabilitation office shares resources with health clinics. This includes sharing of transport with the result that the rehabilitation office, which is currently being partly managed by the physiotherapist, grouped the clients together for the monthly checkups so that it would be easy for her to take them there. There were 14 mothers going for monthly checkups. The mothers complained because they were taken in vans with mattresses and covered with a canopy. They all get on the van with their children and their equipment. Sometimes they have to go with other sick people from the clinic because they have to share the transport. Those using public transport also complained because they have to struggle with the children and their equipment as the public transport in Botswana does not have facilities for disabled persons. They also have to deal with the negative attitudes of the other people using public transport.

5.9 Need for help with physical care

Figure 5.23 shows that there are an equal number of mothers who need assistance with the physical care of their children as those who do not need assistance. This could be due to the fact that some need special equipment and some do not need special equipment.



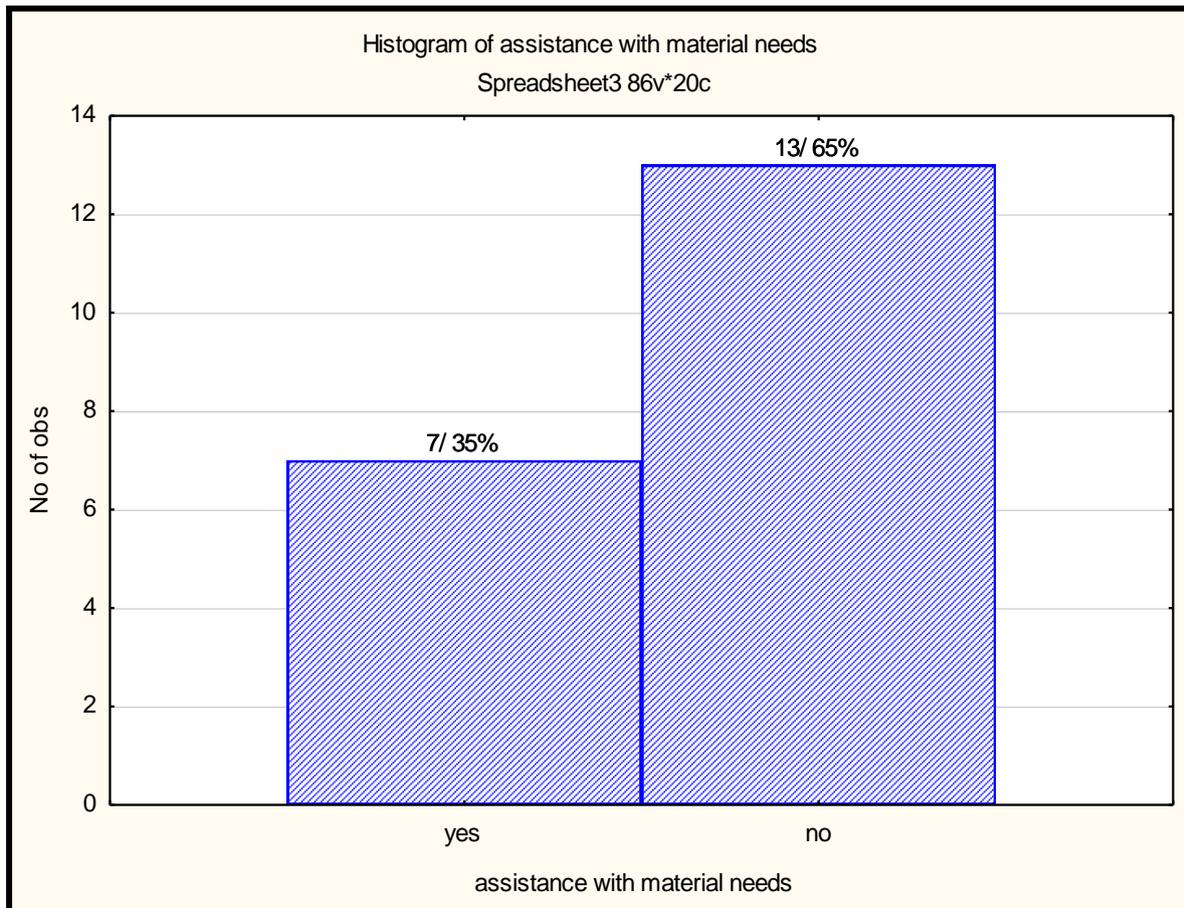
(N = 20)

Figure 5.23 Need for help with physical care

When there is someone with a disability in a household this can have ongoing repercussions especially with regards to time and the need for special care. Depending on the severity of the disability, the physically disabled children may need assistance with daily activities, for example bathing, toileting and dressing.

5.9.1 Need for assistance with material needs

Figure 5.24 shows that a large number of mothers require assistance with material needs. This could be due to the fact that most of them do not have regular incomes. They also do not get assistance from social services or are still waiting to be assisted.



(N = 20)

Figure 5.24 Assistance with material needs

It is apparent from the above information that the mothers of the physically disabled children need food, clothes, adequate shelter and counselling, transport and financial assistance in order to survive and provide for their disabled children. If the participants do not receive these services it is the duty of the government and social workers to be the key role players in the provision and administration of social services. When the disabled child starts school, the whole family should be assessed so that the needs of the family can be determined and both the child and family can be assisted. A holistic approach will assist with detecting these psychosocial needs. Meyers *et al.* (2000) expressed that the physically disabled child requires more time from the caregiver and the costs of their medical care may be twice as much as for other children.

5.9.2 Obstacles in caring for a disabled child

Horton and Wallander (2001), hold the view that the severity of the disability will determine the effect on the family. For example a child with a club foot will place a different burden on the family than a child with cerebral palsy. Some mothers, due to the type of physical disability their children have, experience obstacles to performing their daily activities.

The study found that of the 20 mothers interviewed, 15 mothers experience obstacles in performing their domestic activities while five 5 said they experience no obstacles. This can be due to many reasons. Those that carry out the chores without difficulty, usually have a child with a single disability, not multiple disabilities, nor do they have severe problems like an impaired limb or club foot. In most cases the disability is not accompanied by mental disability which can cause a child to behave in a strange way, or they are difficult to understand. Such children always need a lot of attention and special care, such as being carried, massaged and medicated, so it is never easy for their mothers to do the daily chores freely unless the children are at school or asleep.

The mothers of the physically disabled children have social problems as they face many issues like caring for the children, dealing with negative attitudes and stigmatisation in the community and are unable to socialise and interact easily. There is a lot of information on disability, policies, societies and departments that work with disability issues. More has to be done to sensitise people by means of community and public education. As mentioned earlier, there is a need for more support from the government, families and society in general to address this problem. Therefore that is where the social workers as community workers and advocates of people with problems should fulfil their role.

One of the main obstacles in caring for a disabled child is the impact of it on the welfare of the mother. The participants views on this issue is presented in table 5.9

Table 5.9 Impact of caring for disabled child on the welfare of the mother

| Item | Amount | Percentage |
|-------------------------------|--------|------------|
| Child is dependent on mother | 3 | 15 |
| Child needs high special care | 6 | 30 |
| Reduced hours of work | 1 | 5 |
| Not assisted by relatives | 3 | 15 |

| | | |
|---|----|-----|
| Unable to socialise | 4 | 20 |
| Not trusting others with the child | 2 | 10 |
| Grandmothers too old to monitor high special care | 1 | 5 |
| Total | 20 | 100 |

(N = 20)

The presence of a physically disabled school child has an influence on the welfare of their mothers. Most researchers associate employment with low distress, because then household needs can be provided for. Sloper (2004) has stated that families of physically disabled children experience low income and face extra costs, which may not be fully covered by the social safety network (SSN).

The mothers had the following answers about how their welfare is affected by having a disabled child:

Even though there is a need for financial support they cannot look for a job because the child needs high quality care, medication administered and attention.

One mother whose child uses bilateral splints and a walking frame said:

“ke tlhokana le didirisiwa tsa go tlhokomela ngwanake mme ga ke kake ka mo tlhogela le mme yoo tsofetseng ke ya a go batla tiro.” Meaning that:

“I need to care for the child but I do not have resources and I cannot leave the child with my old mother while I work because he needs extra care.”

Those who are working, work reduced hours because they have to be home after school to attend to the disabled child.

They are depressed because they are not assisted but they need help.

Mother 10 said: “I was referred for food rations because of the child’s malnutrition but the social workers put me on a waiting list until the child was admitted back to the hospital due to the malnutrition problem.”

They cannot work or socialise freely because they always think of themselves as the only and best provider and carer of the child.

The child always wants to be with the mother.

Grandmothers are too old to care for, lift, read medication and equipment too complicated for them.

Another mother said: “I just take each day as it comes.”

They have become dependent on relatives and the community, but they have accepted the situation even though it is lowering their self-esteem.

Most of the mothers (15) do their daily activities hampered by these obstacles. Some wished that the children could be taken to special boarding schools, but they also said that they feel unsettled when the child is at school. This indicates how these mothers feel confused, depressed and unsettled by the situation they are in with their disabled children, so they need assistance from social workers such as counselling to accept their situations. "Poverty, poor housing and unemployment add to the stress of child rearing and may limit a person's ability to parent adequately" (Butler and Roberts, 2004:88).

5.10 Mother to child relationship

Most mothers showed that they relate well to their disabled children except for two, of whom one said the child controls her too much and the other one said she is disturbed by her child as she is studying. Of the other 18 only seven relate well to their children without any problems and 11 relate well but the relationships are disturbed by the following issues:

They are strained because they require more attention than the other children.

Strained due to a breakdown in communication as the communication at school is different from the communication at home.

They sometimes feel hurt and depressed and think "why me?"

They are exhausted and depressed.

They are worried about the child's condition and behaviour.

They have no choice but to love the child.

They sometimes have no feelings for the child and the grandmother has to intervene.

The above indicates that mothers with disabled children love their children, but due to certain circumstances they are faced with having disabled children, they develop mixed feelings towards the children, which can be positive or negative and affect the relationship with the child.

The family relationships are also affected as some need more love and attention than other members of the family. So the mothers need to be encouraged socially to deal with the situation. Social support networks are important here. The fact that the social needs of mothers with disabled children are affected is also reinforced by their

relationship with their partners. Most of the mothers are single (13) and most of them do not want to talk about their relationships, stating how painful it is to be left with a small child especially one with special needs requiring special care. Even under normal circumstances it has been proven that single headed households are faced with more social issues. Out of seven mothers with partners, five are married and two are cohabiting. They state that their partners are loving and supportive, but they do not spend more time with children, they are unhappy about the situation, and complain about a tight budget.

Collins *et al.* (2007:66) confirmed that the nature and severity of the disability affects the family and their coping systems. So the families need support so that they can fulfil their roles and love their children fully.

5.10.1 Relationship with family members, relatives and friends

The relationship the mothers have with their family members, relatives and friends is a very complicated one. This depends on the situation of the child and how other people perceive it. Mothers had mixed answers regarding this situation, as seen from their comments below. This shows that the community of Letlhakeng has to be sensitised about disability and needs public education on disability and stigma. The social workers need to provide this education. People have to change their attitudes.

Eight mothers said they were relating well without any problems.

Three were not relating well.

Nine were relating well, but there were issues which indicated that they were not as fully accepted as they had thought.

The mothers expressed the issues as follows:

Mother 1 "I relate well even though I am stressed by the child crying a lot."

Mother 2 "I relate well even though I am not comfortable with others."

Mother 3 "They ignore us."

Mother 4 "Relationship is not good because they laugh at her."

Mother 5 "It is good but they feel I am a burden."

Mother 6 "Relate well."

- Mother 7 "Relate well and ask about his health."
- Mother 8 "Relates well but with uncertainty because they are not settled when I am with the child."
- Mother 9 "Relate well"
- Mother 10 "Relates well"
- Mother 11 "Relates well but they feel she does not help them with house chores."
- Mother 12 "Relates well but not patient with her."
- Mother 13 "Relate well but strenuous as the child is a bully and harasses me and their children."
- Mother 14 "Supportive even though children don't play that much with my child."
- Mother 15 "Do not relate well."
- Mother 16 "Relates well."
- Mother 17 "Relates well."
- Mother 18 "Relate well."
- Mother 19 "I am fine at home but shameful with friends."
- Mother 20 "They have accepted me."

These comments show that the mothers are not fully accepted by others because of their disabled children. They are faced with the challenges of being looked down upon and isolated, so they need support.

5.10.2 Community interaction

In view of the above results it seems the relationships with family, relatives and friends is much better than with the community. The results show that even though they may be dysfunctional families, family members are important because of the attachment they have with the person.

The results of interaction with the community show that two mothers have not seen any change, three mothers were interacting very well, three were interacting well but did not find the community accommodating and 12 found the interaction poor. This has resulted in them leaving their children at home when they travel and only

spending short periods away from home. So they spend most of their time at home and do not attend most of the community activities unless the child is at school. They cannot even discuss the problems they encounter with rearing their children or ask for help unless they are with other mothers of disabled children at checkups.

The results indicate that the community still have negative attitudes towards mothers of disabled children. This could be linked to cultural beliefs whereby disability is associated with something bad or a physical disability. Conversely, Mattsson (1972) believes that the mothers are overly concerned about the child’s disability. Either way, they need intervention from the social worker.

5.11 PSYCHOLOGICAL NEEDS

5.11.1 Feelings about the child’s school attendance

The mothers were asked about their feelings about having a physically disabled school going child and other psychological challenges that come with having such a child. The mothers expressed different psychological feelings. The 20 mothers that were interviewed have different feelings about having a disabled child. The highest number feel depressed, followed by those who do not feel affected by it, then those who consider themselves unlucky, as well as those who are overprotective and those who experience fear. The findings are presented in table 5.10.

Table 5.10 Mother’s feelings about having a disabled child and sending the child to school

| Having a disabled child | No | Sending the disabled child to school | No |
|-------------------------|----|--------------------------------------|----|
| Not affected | 3 | Not affected | 3 |
| Depressed | 6 | Unsettled | 14 |
| Overprotective | 3 | Overprotective | 1 |
| Unlucky | 4 | Uncertain | 1 |
| Fear | 2 | Guilt | 1 |
| | | | |
| Total | 20 | | 20 |

(N =20)

Table 5.10 demonstrates that mothers feel differently about sending their disabled children to school, but a large number feel unsettled due to different reasons. The above results show that mothers react differently towards the challenges of having physically disabled children. Most of them have problems as a large number showed negative psychological reactions such as depression, over protectiveness, feeling

unlucky and unsettled when their children are at school. The reaction of an individual depends on his/her coping mechanisms and on the support he/she is getting. Some cope well and some do not. This illustrates that mothers of physically disabled children must be attended to, by determining their needs and helping them with them.

5.11.2 Husband's feelings about the disabled child

The findings of the study indicate that most of the mothers feel that their partners (70%) accept their disabled children, but they have different views (30%) concerning their welfare. They accept the child but do not spend more time with him/her. The results also reveal that some mothers feel that the children are being accepted in their homes but the husbands are unsupportive, then blame and reject the child. The mothers however said that even if they have mixed feelings about their husband's acceptance of the child at home and outside, there are issues associated with these feelings.

Mother 1 – “I am happy my husband is supportive but he does not spend time with the child.”

Mother 6 – “I am not happy because my boyfriend does not show interest.”

Mother 9 – “I am happy he is helpful when there are means.”

Mother 12 – “I am unhappy because we are a burden to him and I cannot work.”

The mothers also expressed what they feel when they are in the community.

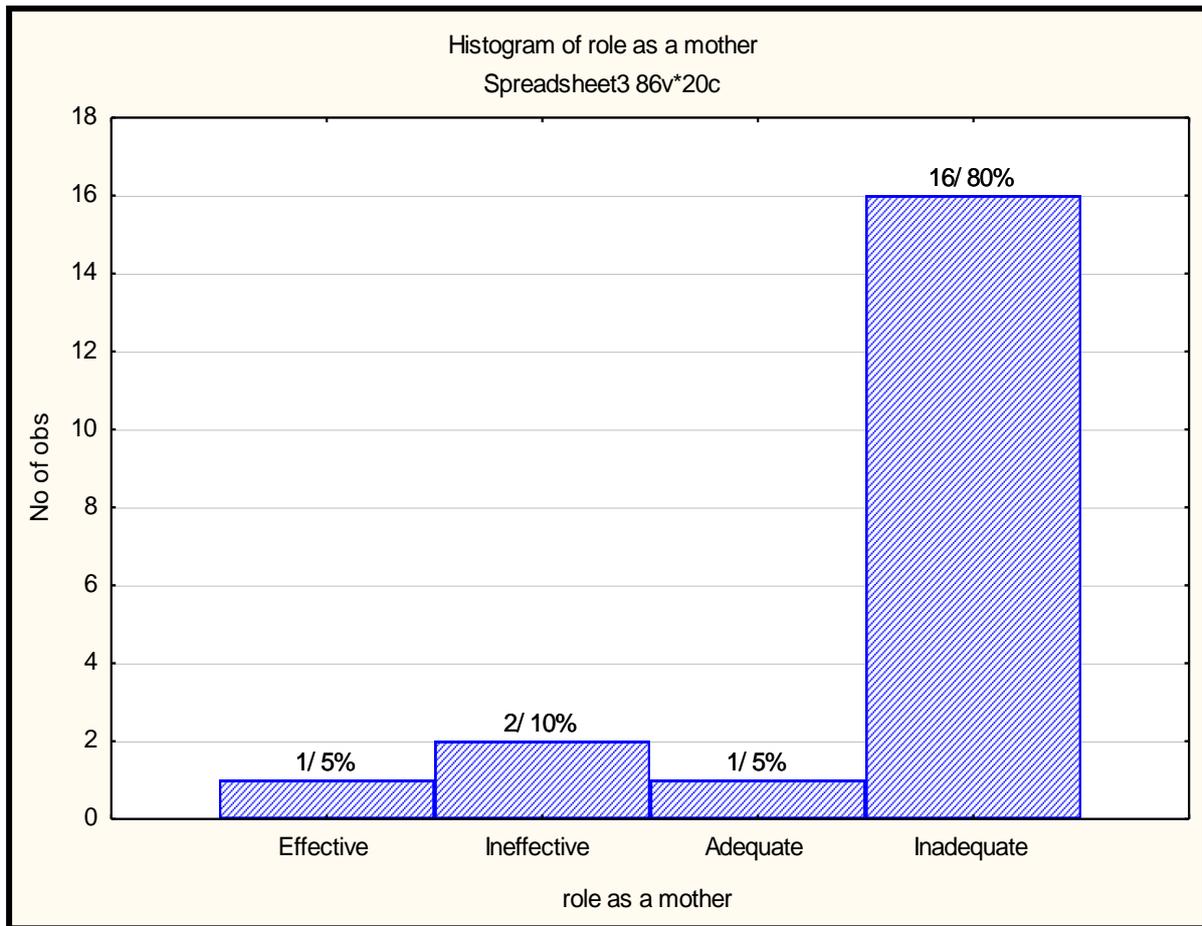
Mother 4 – “People have a starring attitude and laugh at my child.”

Mother 9 – “People accept me well when I am not with the child.”

Mother 18 – “I feel partly comfortable when I am at the church, but at the village they are not supportive.”

5.11.3 Role as a mother

Figure 5.25 shows that most mothers feel inadequate in their role as mothers, as well as ineffective. There are reasons that make mothers feel this emptiness and this in turn makes them feel they are not providing enough for their children because they are unemployed. Arguably, some social, economic, and psychological needs are difficult to separate because they impact on each other.

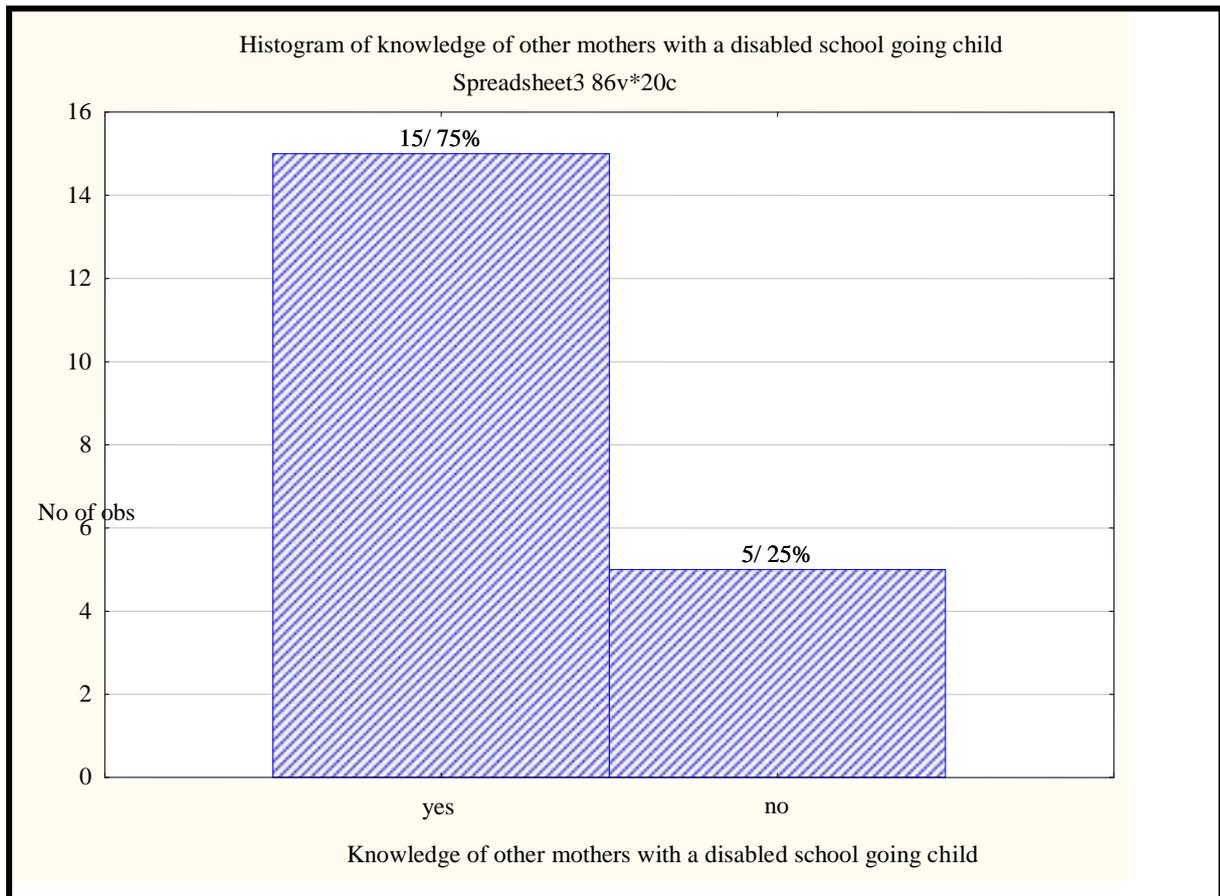


(N = 20)

Figure 5.25 Role as a mother

5.11.4 Knowledge of other mothers with disabled school going children

The figure below shows that most mothers stated that they know other mothers who have disabled children as they stay in the same yards, go to checkups together and have children at the same schools.



(N = 20)

Figure 5.26 Knowledge of other mothers with a disabled school going child n

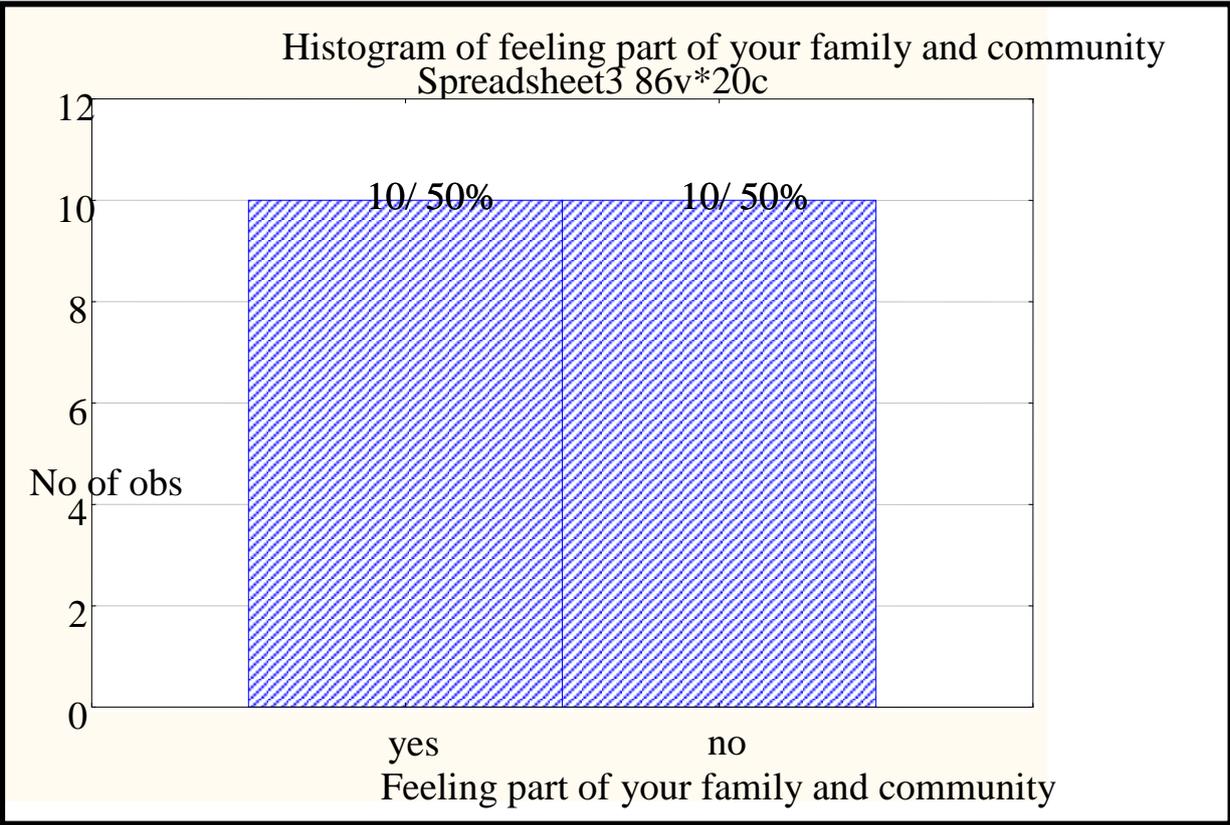
The mothers of physically disabled children face challenges alone. They need to encourage each other as the mothers of disabled children. Many (15) mothers reported that they know each other from staying in the same ward, meeting at checkups, being related and their children going to the same school, but the interaction among themselves is poor. They only meet when they go for checkups and then there is little time to talk to each other about the good things and the challenges that they face in caring for a disabled person. They need a professional like a social worker to motivate them and offer guidance on how to cope with their feelings.

Hammel (2006) stated that there is a need for programmes that can contribute to improving the lives of mothers of the physically disabled children by assisting and motivating them to deal with anxieties, fears and uncertainties. Cook *et al.* (1997:214) expressed that mothers of the disabled children experience cultural and social barriers, feelings of isolation, marginalisation and stigmatisation which can result in them not accessing rehabilitation resources and limited participation in community

activities. Arguably, this indicates that they will have no interaction among themselves unless they are going for checkups, as was found in this study.

5.11.5 Feeling part of your family and community

Figure 5.27 shows that an equal number of mothers felt part of the community to those who did not feel part of the community.



(N = 20)

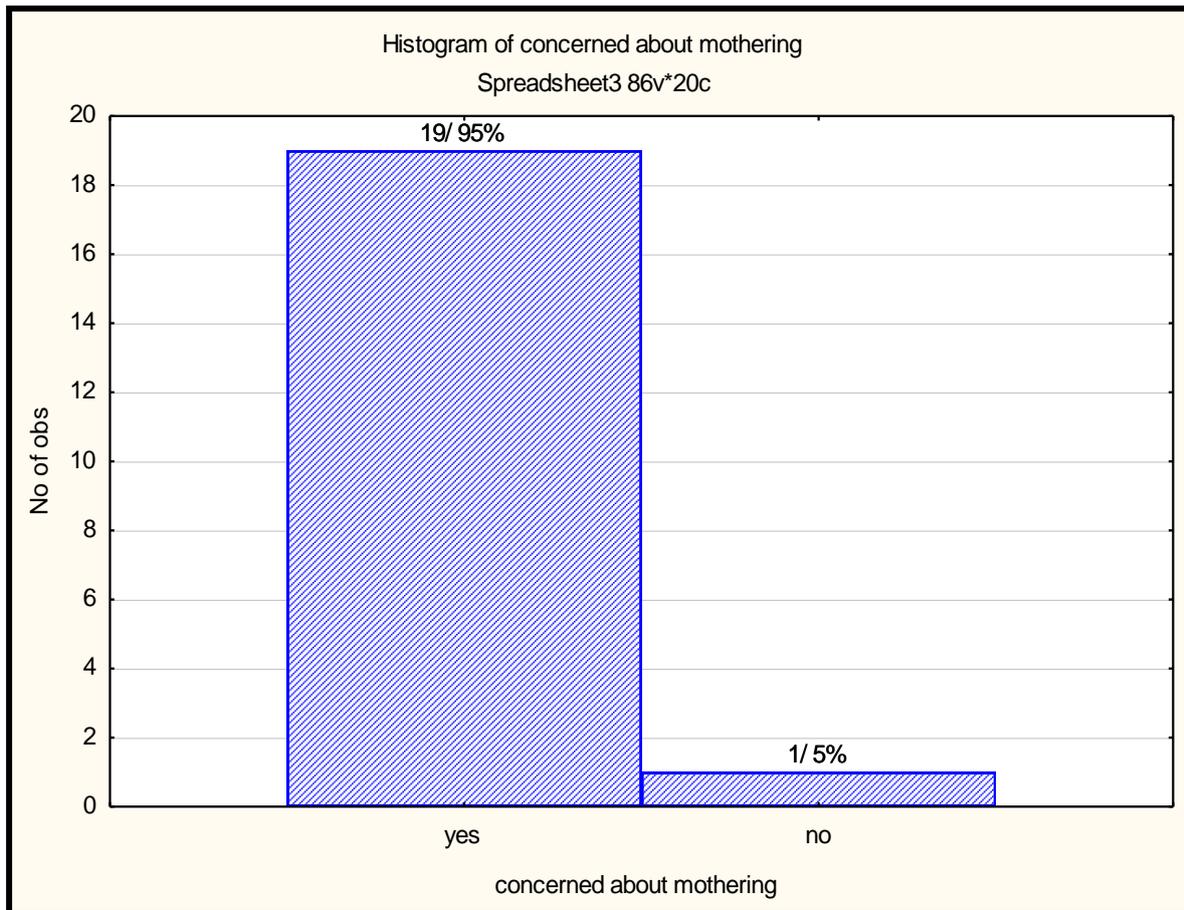
Figure 5.27 Feeling part of your family and community

The community also contributes to the psychological problems of these mothers because they are not as supportive as they should be. They have shown that they do not accept them in that they label and stigmatise them and have negative attitudes towards them. Others have accepted them wholly whilst others have mixed feelings about them like only accepting them when they are at church and caring about them when they are not with the child, which is inconsistent with how they react to them in other situations. Liewellyn (2000:106), Abosi and Koay (2008:4-5), report that the average person in the world (including Botswana) associates physical disability with something bad.

The physically disabled children are usually isolated by family members, relatives and peers at school. According to Antle (2004: 173), they lack social skills and the ability to form friendships, which impacts on the mothers, thus isolating them from family members and the community. Abosi and Koay (2008) confirmed that this is done through negative attitudes and beliefs that exist in Africa whereby disability is associated with evil and a disabled person is regarded as hopeless and helpless. They further explained that people should understand causes of disability as more physiological than cultural. All these issues impact socially, physically and emotionally on the child and they then take their frustrations home. This then impacts negatively on the family and they feel isolated, inadequate and need more information and guidance. The situation is worse in rural areas than in urban areas. William and Argent (1981) stated that it is easy for other children to be negative or sensitive to limitations associated with physical disabilities because cues of physical disabilities are easily seen and this also happens with the mothers when they are with them in the community. A study by Simeonsson (2008) revealed that most mothers are not pleased with the reactions of their neighbours and the community at large. The community have a negative attitude towards them. It was reported that the children were being isolated and not perceived as part of the normal pool of children in the community. The mothers felt that they were generally perceived by the community as being “cursed” for deviating from cultural norms.

5.11.6 Concerned about mothering

Figure 5.28 illustrates that mothers are concerned about mothering a disabled child and stated that this is due to the fact that disability has challenges of its own as discussed in previous chapters.



(N = 20)

Figure 5.28 Concerned about mothering

All the above issues about mothering that relate to caring for a disabled child and the challenges this poses are experienced as more negative than positive and this has lead mothers to be concerned about having disabled children. Almost all of them (19 or 95%) are concerned and they feel that they are inadequate in their roles as mothers even though this could be due to a number of different reasons like:

Not being able to provide for the child.

Not working.

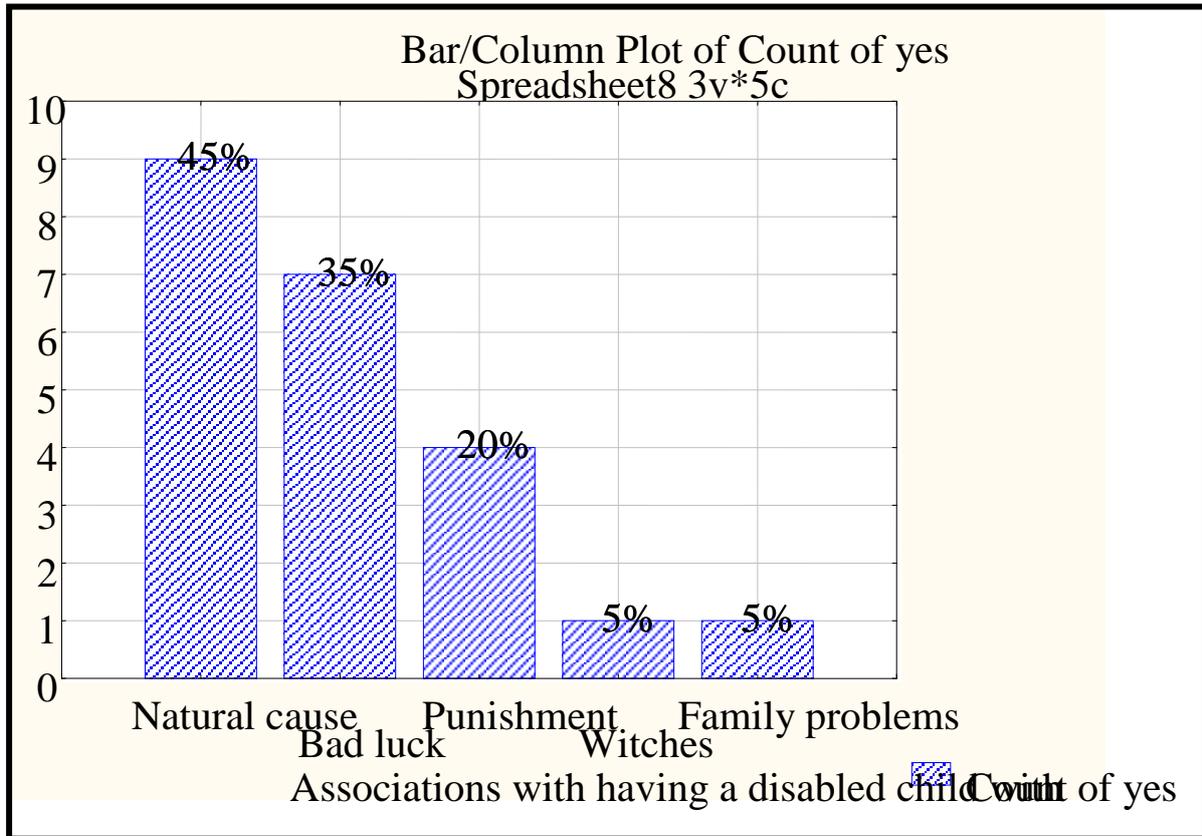
Having many roles to play in the family as the mother.

Associating having a disabled child with something negative.

5.11.7 Associations with having a disabled child

The figure below demonstrates that most mothers (45%) believe that the reasons for having a disabled child are due to natural causes, followed by bad luck (35%), then

as a form of punishment (20%) and other causes (10%). Even if shown these results, mothers emphasize that disability is associated with something bad.



(N = 20)

Figure 5.29 Association with having a disabled child

As the findings show mothers often associate having a disabled child with something negative. During interviews the researcher observed from their facial expressions that even though they were trying hard to be positive, they feel that there is something behind this disability. Their feelings are as follows:

Nine think it is due to natural causes

Five feel it is bad luck

Two feel it is punishment

Two feel it is a mix of punishment and bad luck

One feels it is due to witchcraft

The mixed feelings these mothers have regarding disability as something negative could also be encouraged by the way society feels about disability. This is based on a cultural perspective, as discussed in chapter two, whereby disability is believed to be something bad.

Seligman and Darling (2007:5-6) view disability as an illness, which is in accordance with the medical model. The model is professionally dominant and views disability as a negative condition that needs treatment, rehabilitation or cure. Despite this situation, mothers of the physically disabled children usually seek ways that will improve their children’s ability to be included in society. In Botswana the medical model used to understand the causes of physical disability is still dominant even though society and environment are trying to change (Ingstad, 1990). However the changes are still only in theory. The medical perspective reinforces this because it encourages the correction of disability in the individual and ignores other issues beyond the disability. The mothers are always called in to be told what is going to be done for their children. How she reacts is attended to while she is still with them in the consulting room, but the reaction of the mother afterwards is not followed up. She has to face her family, relatives and other community members alone without any moral support. Van Dyck *et al.* (2004) and Laurvick *et al.* (2006) explained that families with a disabled child would experience the professionals who help them as being child-centred and focusing on correcting the disability of the child, forgetting that parental and family efforts in addition to the professional input can improve the outcome for both the family and the child. The mothers need the support and encouragement of social workers in dealing with such issues. According to Llewellyn (2000), social support networks beyond the family are helpful in aiding responsive parenting and positive development of the child.

5.11.8 Help needed concerning psychosocial problems

The participants were asked about the help they need concerning their psychosocial problems. The findings are presented in table 5.11.

Table 5.11 Mothers’ opinions on the help they need concerning their psychological problems

| Nature of help | Number | Percentage |
|--|--------|------------|
| They need counselling | 20 | 100 |
| They need encouragement and support | 20 | 100 |
| They need assistance with basic needs to boost their self esteem | 20 | 100 |
| Assistance with equipment to encourage and give self empowerment | 20 | 100 |
| Total | 20 | 100 |

(N = 20)

All the mothers (20 or 100%) indicated that they need help with the issues mentioned in the table above.

The table illustrates that all mothers indicated that they need assistance with their psychological problems requiring encouragement, counselling and support and that they need this for both themselves and their children.

They also indicated that they need assistance with their social needs such as the need for shelters, education about their children's disabilities, equipment and financial assistance. They said the following:

Mother 1- "I need counselling to accept my children and more information on disability."

Mother 4 - "I need food, clothes, shelter, counselling and encouragement and education on sign language."

Mother 14 - "I need serious support and counselling."

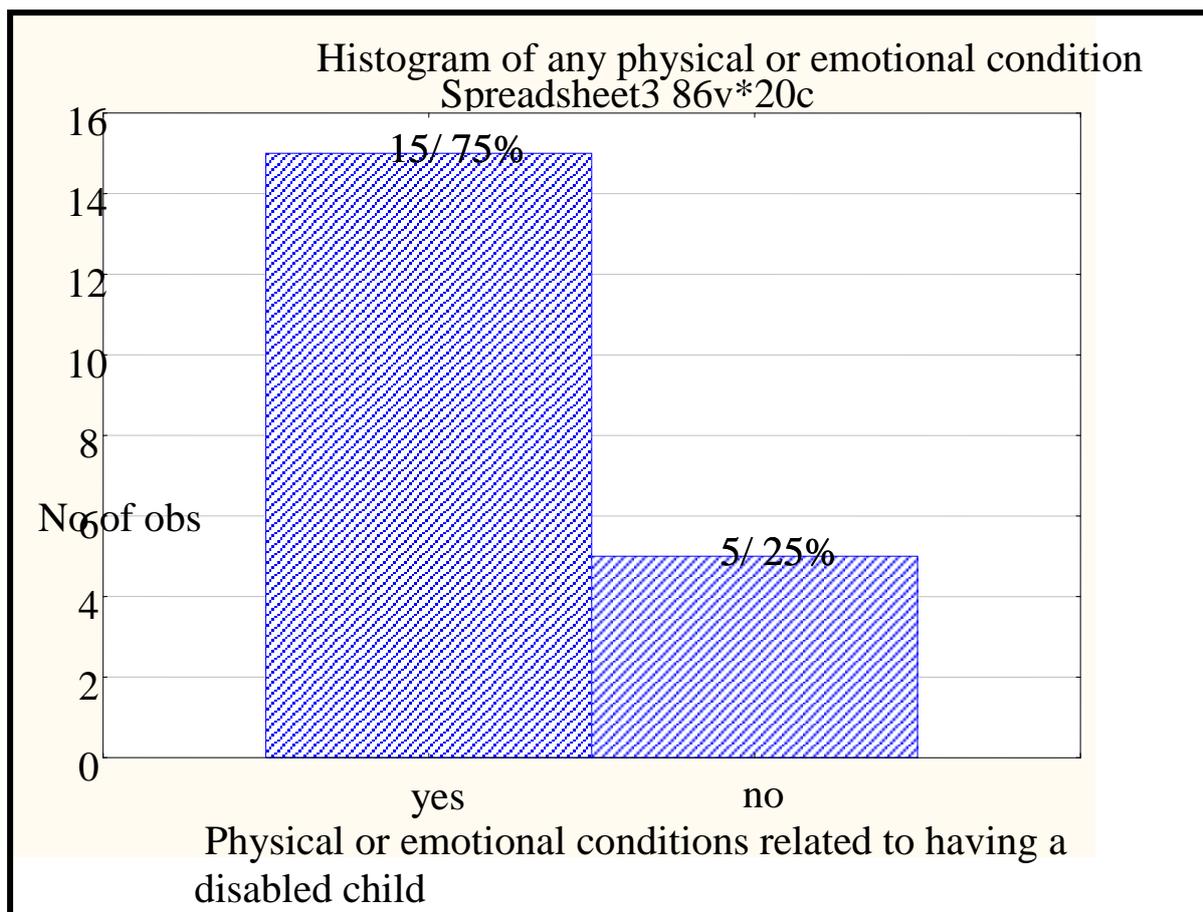
Mother 15 - "I need counselling and employment support to reduce dependency."

Mother 17- "I need encouragement, shelter and education on her condition."

Even though they specify other needs on the questionnaire about their psychological needs, the results showed that they are really in need of the above.

5.12 PHYSICAL OR EMOTIONAL CONDITIONS EMERGING AFTER HAVING A DISABLED CHILD

The figure below demonstrates that a large number of mothers (15 or 75%) have developed a physical or emotional condition like blood pressure, depression, backache and chest pains after having a disabled child.



(N = 20)

Figure 5.30 Physical or emotional conditions related to having a disabled child

Laurvick *et al.* (2006) believes that factors like the burden of care, a child's age and behaviour of physically disabled children can affect the mental and physical wellbeing of their mothers. Long term care like daily activities of bathing and giving medication can be a burden which can cause physical and psychological stress. Lonsdale (1992) and Gulliford and Upton (1992) stated that physical and mental health is more significant in mothers caring for the disabled than mothers caring for non disabled children. The burden and challenges of coping with a disabled child manifest themselves in physical and emotional conditions in the mothers. Mothers have indicated that they have developed major or minor emotional and physical conditions after they had a disabled child, even though it cannot be confirmed whether this is due to the child's disability or not. Fifteen mothers reported to having some or other condition while five did not have anything. The conditions range from depression, blood pressure, palpitations, loneliness, emotional stress, backache, chest pains and waist pains to headaches. Some of the mothers genuinely believe that these

conditions are due to being too worried, lifting the child, lack of necessities and financial problems. The mothers stated as follows:

Mother 5 – “I have depression because I think my child was bewitched.”

Mother 8 – “I am emotionally unsettled and have chest pain because I am always worried.”

Mother 10 – “I have palpitations from thinking and worrying too much.”

Mother 12 – “I have back and chest pain from providing too much care to this child.”

Mother 13 – “My whole body is aching and I am stressed.”

Mother 18 – “I have blood pressure.”

5.13 COMMUNITY BASED REHABILITATION (CBR)

5.13.1 Services of CBR by social workers

The CBR programme is the main one with the responsibility of attending to the needs of the disabled persons and their families and to sensitise the family and the community regarding the disabilities and challenges they face. The social workers are the ones who attend to the psychosocial needs of these families. This is because other members of the rehabilitation team such as physiotherapists, speech therapists are specialists who attend to problems specifically related to their area of speciality. Some of these specialists do not operate in the same areas as these mothers and that is why they have to accompany their children when they go for checkups.

The social workers are professionals delivering services to disadvantaged people, which include the field of disability. Families who have a disabled member are serviced by rehabilitation social workers under the programme of community based rehabilitation. It should be noted that Letlhakeng school children with physical disabilities are registered with rehabilitation social workers. The services of the social workers should be provided in order to assist these children and their families.

This section of the study was more concerned with the opinions of the participants concerning social work services in community based rehabilitation. These social work services are as follows:

To provide services to the disabled and their families and refer where possible (already discussed under social work services).

- To provide community based rehabilitation information.
- To provide support services to the disabled and their families.
- To promote community based rehabilitation.
- To provide other services where possible.

The responses of the participants regarding the services they received will be discussed and analysed. Fieldman et al. (2002:355) emphasized that those rehabilitation professionals should assist families who seek help with care and appropriate services for their physically disabled children. Lang and Oppenheimer (1968:166) and McCarthy (1992:46) expressed that the social workers must make sure that there is information from other stakeholders involved, because a valid multidisciplinary service must attend to the whole family as they often overlook the psychological and social aspects of disability within the family. What this means is that information about housing, finances, employment, clothing, coping and so on must also be provided.

5.13.2 Nature of CBR services

The following table shows the kind of CBR services the participants wanted to be informed about.

Table 5.12 Provision of community based rehabilitation information

| CBR services | Percentage |
|--------------------------------------|------------|
| Information about functioning of CBR | 30 |
| The role of social worker | 70 |
| Total | 100 |

(N = 20)

Most of the participants (70%) would like to receive information about the role of the social worker, while a about a third (30%) wanted to know more about the functioning of CBR. The findings indicate that information regarding the BBR programme is not taken to the community in a satisfying manner.

5.13.3 Provision of support services

The following table will show the need for support services.

Table 5.13 Provision of support services to the mothers of the disabled

| Supportive services | Percentage |
|---|------------|
| The need for support by the disabled children and their families especially mothers | 90 |
| Support groups existing for mothers of disabled children | 0 |
| Uncertainty of mothers regarding services | 10 |
| Total | 100 |

(N = 20)

With regard to the question about who is their main source of support, the mothers indicated that they were supporting themselves with the help of their families, relatives and children. The families and relatives were mostly supporting the mothers with some material assistance rather than with emotional support.

About 14 mothers indicated that they were supported by way of transport for checkups and school and equipment. Two mothers said they received home visits and two received nothing. All these services were provided to help the disabled children, but little or nothing was done to help the mothers. This indicated that they see the physiotherapist when they are picked up for their children's checkups or for school, or when they are at the clinic for massage or assessment and provision of equipment. The mothers said this does not make them part of the rehabilitation programme, because they do not have time with the officer to share their issues. Out of the 20 mothers, nine said they feel involved in CBR through the equipment and transport that is provided, nine said they do not feel they are involved and two said they do not know. Sloper and Turner (1992) indicated that mothers are dissatisfied because they do not have access to professional workers to help with their needs, because as statistics show most of them are in rural areas where professional support is limited. In addition, Hejoaka (2009) expressed that mothers of physically disabled children are isolated because they lack effective formal psychosocial support. Arguably, this is why mothers do not feel as part of CBR because they are not involved in most activities.

5.13.4 Contacts with the CBR office

The following table will present the findings about the contact of the CBR office with the mothers.

Table 5.14 Contact with community based rehabilitation office

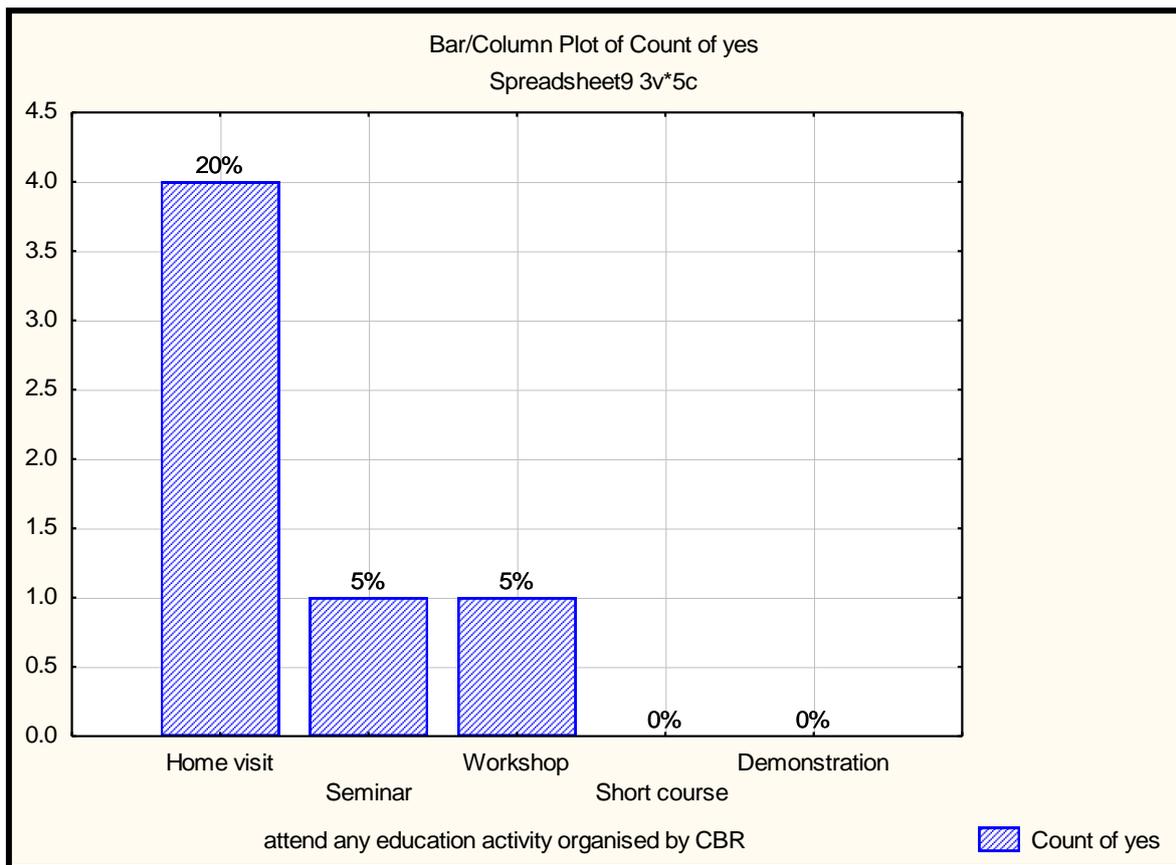
| Contact with CBR office | Percentage |
|----------------------------------|------------|
| No continuous contact | 65 |
| Home visits | 20 |
| Educational activities contacted | 10 |
| Does not visit at all | 10 |
| Total | 100 |

(N=20)

Lack of contact can lead to poor monitoring and coordination of provision of services, as supported by Mpofu *et al.* (2008) who stated that Botswana could be one of the countries with effective rehabilitation service programmes, but it lacks coordination. Most of the mothers (65%) indicated that they do not see the rehabilitation social worker often and 20% indicated that they received home visits. The officer does not visit the mothers unless there is a checkup or maybe if the child is going to school. The low number of education activities organized by CBR proved that the CBR office has limited contact with the mothers, as seen in figure 5.31 below.

5.14 EDUCATION ACTIVITIES ORGANISED BY CBR

Figure 5.31 shows that the highest number of educational activities that the mothers do receive (20%) from CBR is day home visits. This again shows that the CBR programme is not taken to the community.



(N = 20)

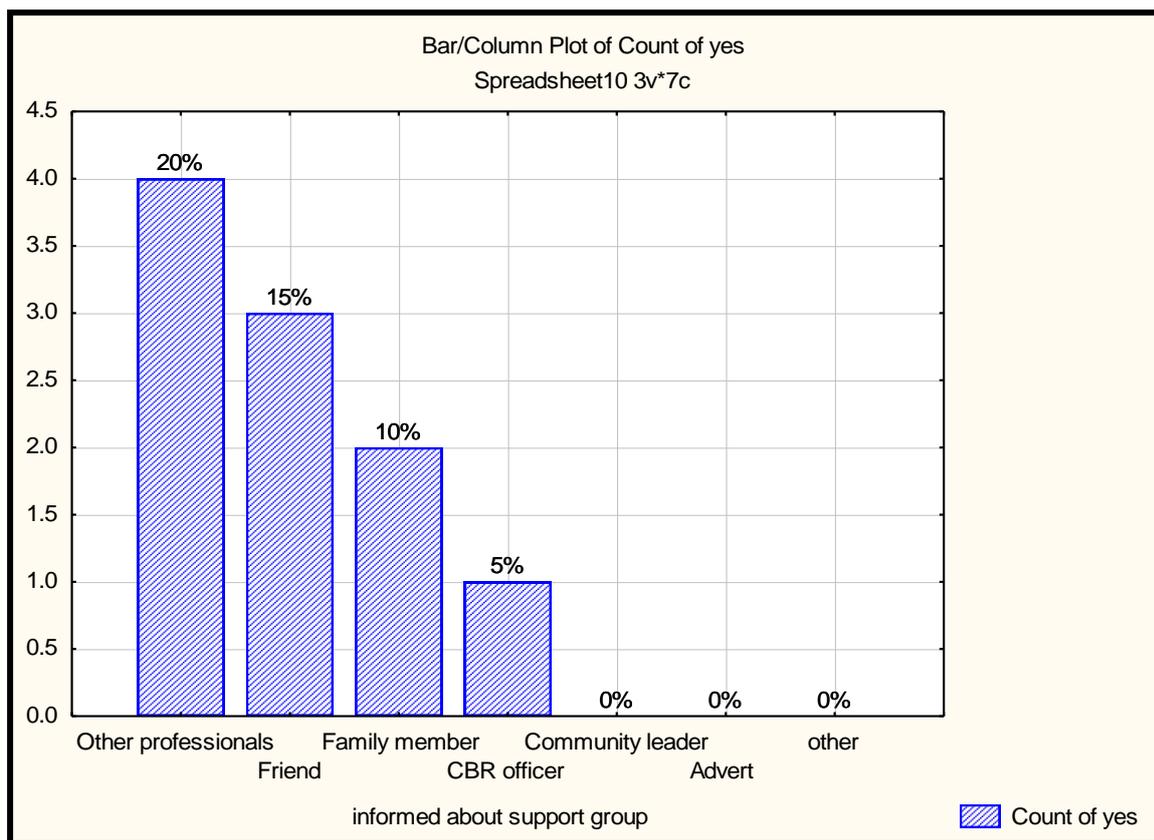
Figure 5.31 Education activities organized by CBR

5.15 KNOWLEDGE ABOUT SUPPORT GROUPS

5.15.1 Informed about support groups

By asking the question about how they were informed about support groups, the researcher tried to determine the mothers' knowledge of support groups, attendance of these groups and the benefits they gained from the support groups.

Figure 5.32 displays how mothers have been informed about support groups. Most of them were informed by other professionals (20%) and not the CBR officer.



(N = 20)

Figure 5.32 Informed about support group

The findings show that half (50%) of the mothers knew about the support groups and half (50%) did not know about these groups. Those that knew about the support groups got the information from other professionals not social workers. Only 20 % attended the support groups which were not part of rehabilitation. This shows lack of support services from the CBR programme. The CBR had no support group, which is why the mothers could not say anything about the support groups being useful, or about the benefits of attending them. They cannot benefit from the support group if they are not part of it and not informed about it.

According to Burger (1990), a support group is essential as it makes rehabilitation services accessible to the needy. Mothers can also discuss their problems amongst each other (group counselling), share information about emergency services like Care Line, discuss their rights and empower each other with knowledge about laws, engage in community services, and receive professional guidance.

It is therefore important for the social worker from the CBR programmes to educate, assist and guide the disabled persons and their families about support groups. These

support groups will help them to discuss their issues and challenges and how they can overcome them. Only 10 (50%) of the mothers knew about support groups and 10 (50%) knew nothing about them. Of the 10 that knew about the support group four had heard from other professionals like nurses and family welfare educators. The support was related to home based community care and orphans. Three mothers heard about the support group through friends and two from family members, but this was not fully explained. Only one heard from the CBR social worker a few years ago. This shows that the disabled children and their families lack the support of the rehabilitation social workers. This was however not surprising because at the time of the interview there was no rehabilitation social worker at all. She had been transferred two years prior to this study and had not been replaced. The physiotherapist was the one who was trying to perform all the duties and responsibilities of the social worker as well as her own duties. This however is impossible because the physiotherapist spends most of the time at the clinic.

This information indicates that physically disabled school going children have their own special needs that have to be attended to and their mothers have the burden of caring for them with their special needs. In order for the mothers to manage this burden, they need assistance from the rehabilitation social worker with their psychosocial needs. But the role of the social worker is not fulfilled in Letlhakeng at all. The disabled child is the only one attended to through the correction of the disability by the physiotherapist, but the other issues surrounding the families of these children are not attended to. There were two cases which were referred to the community welfare office but they did not attend to them. The other mothers had been on a waiting list for a long time and the other mother ended up with her child being admitted to hospital due to malnutrition. If there was a policy in place which ensured the provision of social safety nets for the disabled people and their families or some type of grant or allowance, they would not be suffering like this.

The rehabilitation social workers have their own challenges. These include limited resources that must be shared with the health clinics such as vehicles and facilities. They are also faced with low budgets that have been administered under two ministries namely Local Government and the Ministry of Health, as discussed earlier, which inhibits the proper execution of their duties. If they are on leave or transferred no other officer does their work. There is also only one social worker in each district, having to cover a lot of clients, their families and the community. But it is better to

share resources than for the office to be without an officer at all. The same issues regarding resources, limited budgets, vacant offices and area coverage were discussed in the past few years by Ingstad (1990), Ingstad (1997) and Mompoti (2000), but there has been no progress.

5.16 SUMMARY

Indeed mothers of the physically disabled school going children are faced with challenges in dealing with their psychosocial needs and they really need the support of the social worker in community based rehabilitation. They require support services with regards to meeting their basic needs, social needs, material needs and psychological needs in order to ensure their wellbeing and to be able to care for their physically disabled school going children.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.1 INTRODUCTION

The psychosocial needs of mothers of physically disabled primary school children do exist and there is a need for social workers in Community Based Rehabilitation (CBR) to assist them and their families. Their psychosocial needs are influenced by the many challenges which surround disability, even though these can be different in each country. Some of these challenges are that the statistics are not reliable, the types of disability are complicated, there are a variety of causes, but most of all the fact that people despite having accepted disability, still associate it with something evil. Furthermore, disabled children need special care as they have special needs. The challenges associated with disability can be medical, social or cultural in nature.

The rationale of this chapter is to present the conclusions based on the findings of the study in order to make recommendations based on the conclusions. The recommendations will guide the rehabilitation social workers to provide effective intervention to assist the CBR programme when attending to the psychosocial needs of the mothers of the physically disabled primary school children.

6.2 CONCLUSIONS AND RECOMMENDATIONS

The conclusions and recommendations are based on the findings of the literature review and the empirical study and are as follows:

6.2.1 Identifying details

The respondents who participated in the study were the biological mothers of the different physically disabled primary school children from Letlhakeng. Their ages ranged from 20 to 50 years and they were mainly from the Kagalagadi tribe, with their main official language being Setswana. Letlhakeng is an area of Bakgalagadi in Botswana. Most mothers were single, have limited education and had little or no income. Their main source of income was farming, piece jobs and payment in kind. Their children have different physical disabilities, which vary in severity. Most mothers owned homes which were not conducive and accessible to the lifestyle of a disabled child.

From these findings it can be concluded that the mothers of the different physically disabled primary school children are of different ages and from the same tribe, are mostly single and have limited education and income.

Recommendation

The assessment that is done by social workers when finding a school for the disabled child should be holistic, so as to include the identifying details of the family of the child, so that the needs of the mother and the child are identified.

6.2.2 The special education programme

Most participants indicated that their children were at school but that they were not fully informed about the school programme. Most mothers did not understand special education, their interaction with the school was not good, and they revealed that their children experience barriers at school. Even though most were registered at schools, it showed that these children do not progress to the top levels as most of them are found in lower standards.

It can be concluded that a lot needs to be done with regards to special education. The division is well established and has good policies, but they are not well implemented and utilised by mothers due to a lack of information from the education and rehabilitation departments.

Recommendation

A partnership between social workers and the special education division is needed to sensitise the community about the programme, especially the families of the disabled children.

6.2.3 The impact of the physical disability on the family

Most mothers expressed that the presence of a child with a physical disability at home has its own challenges, because they have special needs which involve more physical care, high medical care and costs. The challenges of caring for a physically disabled school going child can be physical, social and psychological in nature. These challenges do not affect the physically disabled child alone but also the families, relatives and community they belong to. The mother is the most affected primary caregiver. In order for the mothers to fully care for their physically disabled school going children, they need to have resources like homes that are conducive

and accessible to the physically disabled child, as well as an adequate income to cater for the physical, material and medical needs of the child. They also have to be physically and emotionally fit to provide love and care to the child, and to be able to deal with and cope with the challenges they face with their care giving responsibilities.

In conclusion this showed that most mothers are not able to be engaged in economic activities because of the burden of caring for these children, they are not able to provide for their psychosocial needs. Even if they are working or have a husband or a partner who is working, they are not able to provide for their psychosocial needs, nor are they able to meet the high costs involved in caring for these children. In addition the burden of caring for these children makes it difficult for them to cope alone. They need support from their family and the community.

Recommendations

There is a need for the formation of social support networks for disabled children and their families.

CBR social workers should improve their intervention with cases that involve disabled children. The intervention must include the whole family so that they can take note of their needs too.

The CBR social workers should visit disabled children and their families at home and at school for easy identification of their needs and monitoring of the services provided.

The CBR social workers should advocate for SSN for disabled children and their families. Furthermore, policies intended for them should be put into practice.

6.2.4 Social work services

Most mothers indicated that even if they have a low income their children were not assisted by social workers with the provision of the basic school necessities. Even the mothers were not assisted. The disabled children who needed special equipment waited for long periods. The children's checkups and transport to get there were not well coordinated. Most of the mothers complained that they sometimes went for long periods without being attended to by a rehabilitation social worker.

It can be concluded that the CBR programme is not given the priority that it needs in the lives of the disabled children and their families.

Recommendations

The CBR programme should be structured to accommodate its own facilities and resources as it mostly relies on the Health Department/Clinics, which always gives priority to its own programmes.

There is an urgent need to restructure the community education programme by social workers involved in CBR services. Serious consideration should be given to the provision of transport for mothers and their disabled children and decreasing the waiting period for equipment for disabled children is also necessary.

6.2.5 Community Based Rehabilitation

Most participants did not know about CBR programmes. They indicated that they thought it involved finding a school for the disabled child and transporting them to checkups and school. Issues like community and family education, counselling, utilisation of community resources, home visits and follow ups, support groups were not known about.

It can be concluded that the CBR programme is there, but it is not a priority of the Ministry of Health and it is not easy to monitor. Its offices may have no officer employed there for years.

Recommendations

A full restructuring of the rehabilitation division and a well established programme with a full monitoring system from the ministry and a representative at the office of the president, like in South Africa, should be considered.

Policy with regards to provision of services for disabled children and their families like provision of transport, grants, subsidies and other services like water and electricity should be considered by government.

Provision should be made for more resources, for CBR for example, increasing staff, more vehicles and facilities.

The CBR social workers should receive in-service training on CBR services, as a short term plan to assist those who do not have the training.

Lastly, the formation of a registered and functioning social work association to assist social workers in their fight for improved CBR services offered by social workers should be considered.

6.2.6 General conclusion

Most participants were unhappy and felt that their comments were not useful, while only a few felt that they wanted an improvement in the CBR and that the research was the right answer for them.

Recommendation

An assessment of the functioning of CBR should be done and be used to improve the functioning of CBR.

6.3 FURTHER RESEARCH

The researcher has observed that further research is needed on:

How policy can be developed in Botswana to assist families with disabled children.

How a multidisciplinary approach can be used to assess and assist families with physically disabled children.

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APPENDICES

APPENDIX A: Letter of request from Stellenbosch University to the Ministry of Local Government to carry out the research

TELEPHONE:3658400
TELEGRAMS:
REFERENCE:CLG14/14/3/1/XIX (18)
FAX:3952382/3952384



MINISTRY OF LOCAL GOVERNMENT
PRIVATE BAG 006
GABORONE
BOTSWANA

REPUBLIC OF BOTSWANA

June 16, 2009

Ms. Snowball Dithlamallo Office
P. O. Box 81123
Gaborone
Botswana

Dear Madam,

RE: GRANT OF A RESEARCH PERMIT

This serves to acknowledge your application for a research permit in order to do a study entitled "**The Psychosocial Needs of Mothers With Physically Disabled Primary School Children: The Role of a Social Worker in Community Based Rehabilitation**".

The permit is valid for a period of six (6) months – commencing June 16, 2009 up to December 16, 2009 – and it is granted subject to the following conditions;

1. Copies of the final product of the study are to be directly deposited with the Ministry of Local Government, Ministry of Finance and Development Planning, National Archives and Record Services, National Library Service and University of Botswana Library.
2. The permit does not give you authority to enter any premises, private establishment or protected areas. Permission for such entry should be negotiated with those concerned.
3. You conduct your study according to particulars furnished in application you submitted taking into account the above conditions.
4. Failure to comply with any of the above stipulated conditions will result in the immediate cancellation of the permit.

Yours Faithfully,

L. Kebakile


.....
/For Permanent Secretary- MLG

cc: PS, Ministry of Finance and Development Planning
PS, Ministry of Labour and Home Affairs
Director, National Archives and Records Services
Director, National Library Service
Director, Research and Development, University of Botswana.

APPENDIX B: Permission from the Ministry of Local Government to carry out the research

CONSENT FORM / FOROM YA TUMALANO

i) I fully understand the explanation given by the researcher to me on the area of her investigation. I also understand that if I agree to participate in this study, I am free to withdraw from it at any time I so wish.

ii) Ke tshaloganya ka botlalo tshaloso e o e imphileng ka patlisiso ya gago ebile ke tshaloganya sentle gore fa ke dumela go tsaya karolo mo patlisisong e, ke gololesegile go ikgogela morago nako ngwe le ngwe e ke ikutlwang go dira jalo.

I therefore/ ka jalo:

A) Agree to take part in the study/ ke dumelana go tsaya karolo mo patlisisong:

Signature/ Setlanyo----- **Date/ Letsatsi**-----

B) Disagree to take part in the study/ ga ke dumele go tsaya karolo mo patlisisong:

Signature/ Setlanyo----- **Date/ Letsatsi**-----

Witness/ Mosupi----- **Date/ Letsatsi**-----

APPENDIX C: Consent letter from the participants

JULI-2-2008 10E 07:32 TEL: 3057218 NAME: FORENSIC POLICE



10

UNIVERSITEIT-STELLENBOSCH-UNIVERSITY
 Jou kennisvennoot • your knowledge partner

24 November 2008



TO WHOM IT MAY CONCERN

Ms S D OFFICE is currently registered for the Master's Degree in Social Work in the Social Work Department of the University of Stellenbosch, South Africa. She completed the coursework module with success in 2008. She is currently doing research for her thesis: *The psychosocial needs of biological mothers taking care of their disabled children at home.*

In order to execute the abovementioned research she needs to do an empirical investigation involving interviewing biological mothers of disabled children.

Your co-operation and assistance to her to enable her do execute this research project will be appreciated.

Sulina Green
 Sulina Green
 Professor
 Departmental Chair
 Supervisor

PPHO
 Assist as per request
8/11/09

*For submission
 present why it is good
 they know
 Primary Health
 Care Research Unit
 29/1/09*



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APPENDIX D: Questionnaire

UNIVERSITY OF STELLENBOSCH / MMADIKOLO WA STELLENBOSCH

DEPARTMENT OF SOCIAL WORK / LEPHATA LA BOIPELEGO

THE PSYCHOSOCIAL NEEDS OF MOTHERS WITH PHYSICALLY DISABLED SCHOOL GOING CHILDREN: THE ROLE OF SOCIAL WORK IN COMMUNITY BASED REHABILITATION.

A SEMI-STRUCTURED QUESTIONNAIRE / POTSO SEKA PUISANYO

The aim of this research is to investigate the psychosocial needs of biological mothers with primary school children with physical disabilities. Please respond to the questions and statements as fully and objectively as you can. Give your answers by ticking the appropriate box or writing in the spaces provided. The information you give on this questionnaire will remain confidential. The respondent's personal information and perceptions will not be made known.

Maikaelelo a patlisiso e ke go bona matlhoko a bamaago bana ba banang le bogole ba tsena mo dikolong tse dipotlhana. Araba ka go supa mo lebokosong kana go kwala mo ditselaneng tse o di neilweng. Kitso yotlhe ka pampiri e sephiri. Kitso ka yoo arabang dipotso le maikutlo a gagwe e tla nna sephiri.

1. Details of the respondent (mother of disabled child) / kitso ka yoo arabang(mmaago ngwana yoo nang le bogole)

Age / Dingwaga _____

Marital status / Seemo sa lenyalo (tick /supa)

| | |
|--------------------------|--|
| Cohabiting / Nna mmogo | |
| Single / ga wa nyalwa | |
| Married / O nyetswe | |
| Divorced / Le kgaogane | |
| Widowed / tlhokafaletswe | |

Tribe / Morafe _____

Educational qualification / Seemo sa thuto (tick/supa)

| | |
|---|--|
| Never attended school / Ga o ise o tsene sekolo | |
| Primary school / Sekolo se se botlana | |
| Secondary school / Sekolo se se segolwane | |
| Tertiary / Mmadikolo | |
| Other / Tse dingwe | |

Occupation / Seemo sa tiro (tick/ supa)

| | Before the birth of disabled child / pele ga tsholo ya ngwana oo nnan le bogole | After the birth of the disabled child / morago ga tsholo ya ngwana o nang le bogole | When the disabled child started school / fa ngwana yoo nang le bogole a simolola sekolo |
|--------------------------|---|---|---|
| Employed / Wa bereka | | | |
| Unemployed / Ga o bereke | | | |

Type of employment / mohuta wa tiro (tick/supa)

| | Mother / mmaagwe ngwana | Husband or Partner / Monna kana mopati |
|--|-------------------------|--|
| Skilled labour / tiro e o rutetsweng | | |
| Unskilled labour / tiro e o sa rutelwang | | |
| Professional / Moitsenape | | |
| Other / Tse dingwe | | |

Income per month / Itsholelo ka kgwedi (tick/supa)

| Mother / Mmaago ngwana | Income |
|------------------------|-----------|
| | 100-500 |
| | 501-1000 |
| | 1001-1500 |
| | 1501-2000 |
| | 2001-2500 |
| | 2501-3000 |
| | 3001 + |

| Father / Rraago ngwana | Income |
|------------------------|-----------|
| | 100-500 |
| | 501-1000 |
| | 1001-1500 |
| | 1501-2000 |
| | 2001-3000 |
| | 3001 + |

2. The child with the disability/ Ngwana yoo nang le bogole

Age / Dingwaga _____

Gender / Bongwe:

Male / Mosimane _____

Female / Mosetsana _____

Type of physical disability / Mofuta wa bogole

2.1 Education / Sekol

Attending school / O tse na sekolo

Yes/Ee _____ No/Nnyaa _____

Name of school / Leina la sekolo _____

Is it a government school / sa goroment or private / Se eseng sa goramente?

Age of child when started schooling / ngwaga o simolotseng sekolo? _____

If the child is not attending school give reasons / Ga sa tsene sekolo fa mabaka

2.2 School Teacher

Do you know your child's teacher / A o itse morutabana wa ngwana?

Yes/Ee__ No/Nnyaa__

If yes, how did you know him or her / O mo itsile jang? _____

If no, give reasons why / Ga karabo e le nnyaa mabaka ke eng _____

Have you discussed the child's school work with the teacher / O buile le morutabana ka tiro ta sekolo?

Yes/Ee _____ No/Nnyaa _____

What did the teacher say about the child / Morutabana o buile eng ka ngwana?

What are your feelings regarding what has been said / Maikutlo a gago le se se builweng?

Do you think your child relates well to other children, please specify / O akanya gore ngwana o tsalana sentle le bana ba bangwe?

Do you think there are any barriers at school which hamper your child's schooling / O akanya gore go na le dikgoreletsi tse di amang ngwana ko sekolong?

Do you understand anything about special education / O tlhloganya gore special education ke eng? Yes/Ee _____ No/Nnyaa _____

Specify _____

Is special education helpful to your child / A lenaneo la special ducation le thusa ngwana wa gago? Yes/Ee _____ No/Nnyaa _____

Give reasons / Fa mabaka _____

3. Services of a social worker / Dithuso tsa mmaboipelego

What are the types of services provided by social workers to assist with the schooling of the disabled child / Dithuso tsa Boipelego go thusa ngwana mo sekolong (tick/supa)?

| | |
|---|--|
| Find school for disabled child / go batlela ngwana sekolo | |
| Clothing or uniform / Diaporo tsa sekolo | |
| Food / dijo | |
| Transport / sepagamo | |
| Toiletries / melora | |
| Equipment for disabled child / didirisiwa | |
| Counselling / Tshidilo maikutlo | |
| Referrals to other services / O isitswe ko dithuso tse dingwe | |
| Others / tse dingwe | |

What do you think are the most important needs of your disabled school going child / Bolela letlhoko la ngwana wa gago yoo nang le bogole yo tsenang sekolong?

4. Psychosocial needs of mothers with disabled children / Letlhoko la bomabana ba ba nang le bogole

4.1 Physical Needs / Letlhoko la tsa selegae

4.1.1 Shelter

Do you own a home / A o na le legae?

Yes/Ee _____ No/Nnyaa _____

What type of structure is your house / Ntlo ya gago key a mofuta ofe? (tick/supa)

| | |
|---|--|
| Modern / segompieno | |
| Traditional / Setswana | |
| Mix of traditional and modern / E kopantse Setswana le segompieno | |
| Shack / mokhuku | |

No of rooms / dikamore di kae (Tick/supa)

| | |
|----|--|
| 1 | |
| 2 | |
| 3 | |
| 4 | |
| 5 | |
| 6 | |
| 7 | |
| 8+ | |

How many people are living in the house / Le dula le lekae mo ntlung? _____

Does the home have electricity and water / legae le na le metsi le motlhakase?
Electricity / Motlakase _____ Water / Metsi _____

Is your home accessible to the disabled child / A ngwana wa bogole o kgona go nna sentle mo legang? Yes/Ee _____
No/Nnyaa _____

Give reasons / Fa mabaka _____

Do you need help regarding your housing situation / O tlhoka thuso mabapi le bonno
Yes/Ee _____ No/Nnyaa _____

What type of help (tick/supa)

| | |
|---|--|
| Building a house / Go aga ntlo | |
| Renovation and maintenance / go baakanya kana ntshafatsa | |
| Adding necessities for accessibility / Go tsenya didirisiwa tse di thusang bogole | |
| Rent payment / Tuelo ya bonno | |

What action did you take to request help and what was the response / O tsera dikgato dife go kopa thuso. Karabo e nnile eng? _____

4.2 Material needs / didirisiwa

How do you provide for the food, clothes and other necessities the family requires / O tlhokomela jang ba ba lelwapa mabapi le dijo le diaparo? _____

Does your disabled child have any special equipment / a ngwana wag ago o na le special equipment? Yes/Ee _____ No/Nnyaa

If yes, what type of special equipment / Fa karabo e le ee ke sedirisiwa sa mofuta mang?

How did you obtain the equipment / O kgonne go bona sedirisiwa jang?

How long after it was determined that the disabled child needs special equipment did he/she get it / Go tsere sebaka se se kae go bona sedirisiwa morago ga letlhoko? _____

How does lack of material resources affect you / letlhoko la didirisiwa le go ama jang?

Does your child need to go for medical checkups / Ngwana wa o tlhokana le bona ba bo ngaka?

Yes?Ee _____ No?Nnyaa _____

How often / Morago ga lebaka le lekae? (Tick/Supa)

| | |
|----------------------------|--|
| Daily / Tsatsi le tsatsi | |
| Weekly / Beke le beke | |
| Monthly / Kgwedi le kgwedi | |
| Yearly / Ngwaga le ngwaga | |
| Never / Ga nka a bonwa | |
| | |

Where does the disabled child go to for medical checkups?

How far is the place where you go for checkups **from** your home / lefelo la bo bongaka le bokgala bokae?

Do you need transport to get there / O tlhokana le sepagamo go ya teng?

Yes/Ee _____ No/Nnyaa_____

How do you provide for the transport / O tsaya kae sepagamo?

How do you feel about your child's checkups / O ikutiwa jang ka ditlhatlhobo tsa bogole tsa ngwana wa gago? (tick/supa)

| | |
|-------------------------------|--|
| Not affected / Ga wa amega | |
| Excited / ke a itumela | |
| Depressed / Ke utlwa botlhoko | |
| Strained / Ke a imelwa | |
| Helpful / Ke a thusega | |
| Not helpful / Ga ke thusege | |

Do you need help with the physical care of your child such as lifting, transferring and positioning the disabled child throughout the day and night / O tlhoka thuso tlhokomelong ya ngwana jaaka go tsholetsa, go sutisa, go baaya ngwana mo letsatsing le mo bosigong?

Yes/Ee _____ No/Nnyaa_____

Specify/

Supa

Did you get any assistance with your material needs / A o bone thuso bo go bomaitsenape ka didirisiwa?

Yes/Ee _____ No/Nnyaa _____

What type of assistance / Thuso ya mofuta mang? _____

Which programme within the Department of Welfare assisted you / O bone thuso mo lephate lefe?

How does having a disabled child influence your welfare / Go nna le ngwana yo o nang le bogole go amile botshelo jag ago jang?

4.3 Social Needs / Letlhoko la botsalano jwa selegae

How is your relationship with your disabled child / Botsalano jwa gago le ngwana yoo nang le bogole? _____

How is your relationship with your husband or partner regarding the disabled child / Botsalano jwa gago le monna kana mopati ka ngwana yo o nang le bogole?

How is your relationship with your family members, relatives and friends / Botsalano le ba lelwapa, masika le ditsala?

How is your interaction with the community / Tirisanyo ya gago le sechaba e ntse jang?

Do you carry out your daily activities without any obstacles or barriers / A o bereka tsa lelwapa go sena dikgoreletsi?

Yes/Ee _____ No/Nnyaa _____

Specify/supa _____

4.4 Psychological needs / Letlhoko la maikutlo

How do you feel about having a disabled child / Maikutlo a gago ka ngwana yoo nang le bogole? (tick/supa)

| | |
|--|--|
| Guilt / O nna le letswalo | |
| Desperate / Maikutlo a sa iketlang | |
| Fear / Letshogo | |
| Depressed / Kutlo botlhoko | |
| Overprotective / Tshireletso e feteletseng | |
| Rejected /Ga o batlege | |
| Unlucky / O tlhokile lesego | |
| Not affected / Ga wa amega | |

How do you feel about sending your disabled child to school / Maikutlo a gago ka go isa ngwana o nang le bogole sekolong?(tick/supa)

| | |
|--|--|
| Unsettled / Ga wa iketla | |
| Overprotective / Tshireletso e feteletseng | |
| Guilty / Letswalo | |
| Uncertain / Ga o itlhaloganye | |
| Not affected / Ga wa amega | |

How did your husband/partner feel / Monna kana mopati wa gago o ne a ikutlwa jang?

(Tick/Supa)

| | |
|-----------------------------------|--|
| Accepting / O a amogetse | |
| Rejecting / Ga nkgatale | |
| Supportive / O nkeme nokeng | |
| Unsupportive / Ga nkema nokeng | |
| Blaming / O ntshwaya poso | |
| Shameful / O tlhabiwa ke ditlhong | |

How did it affect you / Go ne ga go tsaya jang?

How did your child's siblings feel / Bomonnao le bomogoloo ba ne ba ikutlwa jang?

| | |
|-----------------------------------|--|
| Accepting / a o amogetse | |
| Rejecting / Ga nkgatale | |
| Supportive / O nkeme nokeng | |
| Unsupportive / Ga nkema nokeng | |
| Blaming / O ntshwaya poso | |
| Shameful / O tlhabiwa ke ditlhong | |

What is the reaction of others outside your home / maikutlho a batho ba bangwe ko ntle ga lelwapa?

| | |
|------------------------------------|--|
| Accepting / O tlhabiwa ke ditlhong | |
| Rejecting / Ga nkgatale | |
| Supportive / O nkeme nokeng | |
| Unsupportive / Ga nkema nokeng | |
| Blaming / O ntshwaya poso | |
| Shameful / O tlhabiwa ke ditlhong | |

How do you feel about your role as a mother having to care for a disabled school going aged child / Maikutlo ka ngwana wag gago yo tsenang sekolo a nang le bogole?

| | |
|---------------------------|--|
| Effective / Ke kgona | |
| Ineffective / Ke sa kgone | |
| Adequate / E sa tlhabela | |
| Inadequate / E tlhabela | |

Do you know any other mother with a disabled school going child / A o itse motsadi mongwe o nang le ngwana yo tsenang sekolo mme a na le bogole?

Yes/Ee ____ No/Nnyaa _____

If yes, how do you relate to them / Karabo ga e le ee, o tsalana jang le bone?

Do you feel part of your family and community / A o ikutlwa o amana le ba lelwapa la gago kgotsa sechaba?

Yes/Ee ____ No/Nnyaa _____

Motivate your answer

What do you associate having a disabled child with / O amana go nna le ngwana yo o nang le bogole le eng?

| | |
|---|--|
| Witches / Boloji | |
| Punishment / Kotlhao | |
| Natural cause / Tlholego | |
| Bad luck / Go tlhoka lesego | |
| Family problems / kgotlhang tsa lelwapa | |

Are you concerned about mothering your disabled child / A o tshwenyegile mabapi le ngwana yoo nang le bogole?

Yes/Ee _____ No/Nnyaa _____

Do you think you need help / O a akanya gore o tlhokana le thuso?

Yes/Ee_____ No/Nnyaa _____

Specify/Supa _____

Do you have any physical or emotional conditions that developed after having your disabled child / O na le Bokoja mmele kana maikutlo jo tlileng morago ga ngwana yoo nang le bogole?

Yes/Ee____ No/Nnyaa _____

What kind of conditions / Ke bokoa jwa mofuta mang?

5. Community Based Rehabilitation(CBR) / Tlhokomelo mo Iwapeng

Who is your main supporter / Thuso ya gago e tswa kae botlhalo?

How did they support you / Ba go kgothadise jang?

Do you know anything about CBR / A o itse ka CBR?

Which services were you assisted with through CBR / Ke dithuso di fe tse o di bonyeng?

Do you feel involved in CBR / A o ikuthwa o le botlhabongwe ba CBR?

How often do you see the CBR officer / O bona mmereki wa CBR ga kae? (Tick/Supa)

| | |
|----------------------------|--|
| Daily / Tsatsi le tsatsi | |
| Weekly / Beke le beke | |
| Monthly / Kgwedi le kgwedi | |
| Yearly / Ngwaga le ngwaga | |
| Never / ga nke ke mona | |
| Other / Tse dingwe | |

Did you attend any education activity organised by CBR / A o kile wa tsenelela dithuto dingwe di dirilwe ke ba CBR?

| | |
|--|--|
| Home visit / Ketelo mo lapeng | |
| Seminar / Bokopano | |
| Workshop / Thuto se ka dipuisano | |
| Short course / dithuto tse di potlhana | |
| Demonstration / Thutoka sekai | |

Do you know anything about a support group / A o itse sengwe ka lekotlhana la kgothatso?

Yes/Ee _____ No/Nnyaa_____

Who informed you about it / O le itsile jang?

| | |
|--|--|
| CBR officer / Mmerekwa wa CBR | |
| Other professionals / Baitsanape baba bangwe | |
| Community leader / Moeteledipele wa Morafe | |
| Family member / Mongwe mo lapeng | |
| Friend /Tsala | |
| Advert / Kitsiso | |

Other / Tse dingwe _____

Do you attend any support group / A o tsena lekgotlana la kgothatso lengwe?

Yes/Ee ____ No/Nnyaa ____

What is the profession of the organiser of the support group?

Does the support group benefit you / A lekgotlana le a go thusa?

Yes/Ee ____ No/Nnyaa ____

How / jang?

Do you want to comment or talk about anything that you feel we have left out / A go na le se o batlhang go akgela kana go bua ka sone se re se tlogetseng?

Thank you / Ke a leboga