THE EXPERIENCES OF MOTHERS CARING FOR THEIR SCHOOL-GOING CHILDREN WITH PHYSICAL OR MENTAL DISABILITIES IN LOW-INCOME COMMUNITIES: AN ECOLOGICAL PERSPECTIVE

By

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DECLARATION

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ABSTRACT

The aim of this study was to develop an understanding of the experiences of mothers caring for their school-going children with mental or physical disabilities in low-income communities using the ecological perspective. The rationale for this research was a gap in the existing literature regarding the experiences of mothers caring for their school-going children with mental or physical disabilities in low-income communities in South Africa, which was identified in the preliminary and main literature review. The literature review further indicated that these mothers have to struggle with several challenges, particularly in low-income communities. In order to achieve the aim of this study, four research objectives were formulated for this study. To reach the objectives of the study the researcher employed both qualitative and quantitative research methods to collect the data for the research. The research methodology comprised two main parts: firstly, a literature study of all relevant literature on the subject matter, in order to gain the necessary in-depth understanding of the field; and secondly, qualitative and quantitative data-collection, using a semi-structured questionnaire.

The first part of this study, the extensive literature review, helped firstly to provide the necessary background information on the mental and physical disabilities of school-going children, secondly, it helped to establish a number of challenges that mothers caring for their disabled children face and the needs that result from them, from an ecological perspective. These were categorized into four groups of needs: (1) access needs; (2) economic needs; (3) social and cultural needs; and (4) mental/psychological needs. Consequently, ways of meeting these needs were discussed, from formal support, such as government grants, to informal support, for example, the support of family and friends. Assessing the South African environment it was found that while the country has provided a very positive policy environment, through its constitution, policies and grant system, the practical implementation of this is, in many instances, inadequate.

Using the findings of the first part of this thesis to create a questionnaire, its second part, the empirical study, presented and analysed the answers of nineteen mothers caring for their disabled children who attend the special school selected for the research study in Cloetesville, Stellen-

bosch; a low-income community. The questionnaire explored, among other aspects, the physical, social, emotional, psychological and economic needs of the mothers; the role of the school, family, friends, non-governmental organisations and other coping options in meeting them, as well as the mothers´ awareness of available resources. The findings in the South African low-income community corresponded to a large extent with what was indicated in the literature study. The mothers were found to live under precarious economic and employment situations, having to rely on child support and disability dependence grants. Furthermore, the mothers reported that they experienced stress, emotional and physical, as a result of having to care for disabled children. It was shown that while receiving grants and sending their children to the special school did alleviate some of the challenges, this aid was not perceived as sufficient. On the other hand, the study confirmed and emphasized the importance of understanding and support by family and friends in helping mothers meet their needs. Moreover, it was found that most of the mothers interviewed for this thesis had a positive perception of their role as caregiver for their disabled child: for example, seeing themselves as good mothers, being proud to be self-sufficient, as well as a positive influence on the mothers' relationship with their family.

As a consequence of the results this study, several recommendations were made for government (social development) and service providers (social workers, teachers, doctors): firstly, government should aim to achieve a better congruence between the positive policy environment in South Africa and the implementation of these policies; secondly, among other recommendations for service providers, awareness needs to be raised in communities to decrease the stigma of disability and increase understanding and support.

Finally, while this study was a success, it was only a first step in filling the gap in the literature on the experiences of mothers caring for their mentally and physically disabled children in South African low-income communities, and therefore needs to be complemented and tested by further research on the subject.

OPSOMMING

Die doel van hierdie studie was om 'n begrip te ontwikkel van die ervarings van moeders wat sorg vir hul skoolgaande kinders met verstandelike- of fisiese gestremdhede, in lae-inkomste gemeenskappe, deur gebruik te maak van die ekologiese perspektief. Die rasionaal vir die navorsing was, die gaping in bestaande literatuur ten opsigte van die ervarings van moeders wat sorg vir hul skoolgaande kinders met verstandelike- of fisiese gestremdhede in lae-inkomste gemeenskappe in Suid-Afrika, soos geïdentifiseer is in die voorlopige- en hoof literatuur oorsig. Die literatuur oorsig het verder aangedui dat hierdie moeders, veral in lae-inkomste gemeenskappe, verskeie uitdagings in die gesig staar. Ten einde die doel van hierdie studie te bereik, is vier navorsingsdoelwitte vir die studie geformuleer. Die navorser het beide kwalitatiewe- en kwantitatiewe navorsingsmetodes vir data-insameling gebruik, ten einde die doelwitte van die studie te bereik. Die navorsingsmetodologie het uit twee primêre dele bestaan: eerstens, 'n literatuurstudie van al die relevante literatuur oor die spesifieke onderwerp, ten einde die nodige in-diepte begrip in verband met die onderwerp te ontwikkel; en tweedens, kwalitatiewe- en kwantitatiewe data-insameling, deur gebruik te maak van 'n semi-gestruktureerde vraelys.

Die eerste deel van die studie, naamlik die uitgebreide literatuuroorsig, het eerstens gehelp om die nodige agtergrondinligting oor verstandelike- en fisiese gestremdhede van skoolgaande kinders te voorsien en tweedens, het dit gehelp om 'n aantal uitdagings te identifiseer wat moeders ervaar wat vir hul kinders met gestremdhede sorg, asook om te identifiseer watter behoeftes hierdie uitdagings tot gevolg het, vanuit 'n ekologiese perspektief. Die behoeftes is gekategoriseer in vier kategorieë van behoeftes: (1) behoeftes van toeganklikheid; (2) ekonomiese behoeftes; (3) sosiale- en kulturele behoeftes; en (4) verstandelike/sielkundige behoeftes. Vervolgens, is maniere bespreek waarop hierdie behoeftes bevredig kan word, van formele ondersteuning, soos staatstoelae, tot informele ondersteuning, byvoorbeeld ondersteuning deur familie en vriende. Deur middel van die assessering van die Suid-Afrikaanse konteks, is daar bevind dat, terwyl die land 'n baie positiewe beleidsomgewing voorsien, deur sy

konstitusie, beleide en toelae-sisteem, is daar in baie gevalle agterstande met betrekking tot die praktiese implementering daarvan.

Nadat die bevindinge van die eerste deel van hierdie tesis gebruik is om 'n vraelys saam te stel, het die tweede deel van die studie, naamlik die empiriese studie, bestaan uit die voorstelling en die analisering van die antwoorde van 19 moeders wat sorg vir hul kinders met gestremdhede wat 'n laerskool in Cloetesville, 'n lae-inkomste gemeenskap in Stellenbosch, bywoon. Die vraelys het, onder andere, die fisiese-, sosiale-, emosionele-, sielkundige- en ekonomiese behoeftes van die moeders, die rol van die skool, familie, vriende, nie-regeringsorganisasies en ander hanteringsopsies om die voorafgenoemde behoeftes te bereik, asook die moeders se bewustheid van beskikbare hulpbronne, ondersoek. Die bevindinge in die Suid-Afrikaanse lae-inkomste gemeenskap het grootliks ooreengestem met die bevindinge aangedui in die literatuurstudie. Daar is bevind dat die moeders hulself in baie moeilike ekonomiese- en werksituasies bevind het, wat beteken het dat hul moes staatmaak op kinderondersteunings- en ongeskiktheidstoelae. Verder, het die moeders gerapporteer dat hul emosionele- en fisiese stres ervaar het, as 'n gevolg van hul verantwoordelikheid om vir hul kinders met gestremdhede te sorg. Daar is ook bevind dat, alhoewel die ontvangs van toelae en die feit dat hul kinders spesiale skole bygewoon het, sommige van hul uitdagings verlig het, was dit nie as voldoende beskou nie. Aan die ander kant, het die studie die belangrikheid van die begrip en ondersteuning van familie en vriende om moeders te help om hul behoeftes te bevredig, bevestig en beklemtoon. Daar is ook bevind dat die meeste van die moeders wat aan die studie deelgeneem het, positiewe persepsies van hul rol as versorgers van hul gestremde kinders gehad het: byvoorbeeld, deur hulself as goeie moeders te sien, deur trots te wees daarop om self-onderhoudend te wees, asook deurdat hul rol as versorgers, 'n positiewe invloed op hul verhoudings met hul familie gehad het.

As 'n gevolg van die resultate van die studie, is verskeie aanbevelings aan die regering (Maatskaplike Ontwikkeling) en diensverskaffers (maatskaplike werkers, onderwysers, dokters) gemaak: eerstens, behoort die regering te poog om 'n beter kongruensie tussen die positiewe beleidsomgewing in Suid-Afrika en die implementering van hierdie beleide te bereik; tweedens, onder ander aanbevelings aan diensverskaffers, moet bewustheid in gemeenskappe geskep word, ten einde die stigma gekoppel aan gestremdheid te verminder en om begrip en ondersteuning te verhoog.

Laastens, alhoewel die studie 'n sukses was, is dit slegs 'n eerste stap met betrekking tot die vervulling van die gaping in literatuur in verband met die ervarings van moeders wat sorg vir hul verstandelike- en fisies gestremde kinders in Suid-Afrikaanse lae-inkomste gemeenskappe. Hierdie onderwerp moet egter gekomplimenteer en getoets word deur verdere navorsing.

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1.1 PRELIMINARY STUDY AND MOTIVATION

Caring for a child with a physical or mental disability can be a demanding experience, as the lifelong care required taxes both the physical and emotional capacities of the care-giver, as well as the material resources of the family. For example, having a school-going child with a physical or mental disability has considerable financial implications. According to Read (1991:563) families find that while their expenditure increases, their capacity to earn is reduced. Some of the costs are incurred routinely every day while others, often involving substantial outlays of money, occur less frequently. High costs in terms of the special diets for the special needs child, high fuel bills, transport costs, the need to adapt accommodation or move to a suitable home, all place extra financial strain on the families (Read,1991:563).

Another aspect is that while the environment, consumer goods and services, leisure activities and almost all aspects of public life are designed with the able bodied in mind, school-going children with mental or physical disabilities and their families find themselves consistently requiring the exceptional. The exceptional is, however, more expensive than standard issue and this places even more strain on families that are living in low-income communities. The income of the family is also affected, mainly because the additional care involved in bringing up a disabled child leaves fewer adults available for paid work outside the home (Read, 1991:563).

Moreover, the implications of raising a school-going child with mental or physical disabilities on the relationships between family members and their psychological and social well-being are often also grave. According to Floyd and Gallagher (1997:359) the special care demands placed on the mothers of school-going children with mental or physical disabilities can cause significant disruption to the family relationships. These demands persist throughout childhood and into the adult years, and require continual adaptation by the parents to both on-going stressors and frequent crises (Floyd and Gallagher, 1997:359). This is also supported by the research carried out in Kenya by Gona, Mung'ala, Newton and Hartleys (2010:176) in which they found that families

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with school-going children with mental or physical disabilities experienced a great deal of strain and disruption in their relationships, as a result of the demands placed on them when caring for their disabled child.

Nearly half of the 2,000 parents surveyed in the United Kingdom on caring for school children with mental or physical disabilities, also expressed that having to care for a mentally or physically disabled child had caused problems in their relationships. Around one in ten felt that it had led to separation and one in six was bringing up their disabled child alone. A quarter of the parents had received professional relationship counselling and another 38 per cent said they would have found it helpful (Paediatric Nursing News, 2004:4). Of the 76 per cent who suffered stress or depression, 88 per cent linked this to having a physically or mentally disabled child. Similarly, of the 72 per cent who cited tiredness and lack of sleep, 84 per cent attributed this to their child's physical or mental disability. An additional source of stress was money; a third of the parents had problems at work, because they needed flexible hours to work so that they could have time to provide enough care for their school-going child with physical or mental disability (Paediatric Nursing News, 2004:4).

1.1.1 Support and care for children with disabilities

It is well documented in the researched literature that the parents of children with disabilities require professional support (Lindblad, Holritz-Rasmussen, 2007:238). This support can come in a variety of ways. Informally, for example, through social networks (friends and family), was experienced as being more efficient in reducing stress than formal support. For instance, the ability of mothers to share concerns about their children with other mothers, who had children with similar a disability, was found to be a valuable source of informal support (Wickham-Searl, 1992:14).

Formal support can come from professionals who may provide counselling and training (such as social workers, nurses) for the mothers to help them to deal with their disabled children in terms of how to meet their needs and avoid stressful experiences. Respite care may also act as a means to help reduce stress and fatigue and increase coping ability in mothers raising children with disabilities (Doig, McLennan and Urichuk, 2009:234). It may also provide a brief 'time out' for the care-giver, giving them an opportunity to attend to their own personal care and social needs such

as going out with friends or relaxing. These services may also provide the opportunity for increased social interaction and skills development for the mentally or physically disabled child. Additionally, childcare systems are beginning to address the need of childcare for school-going children with disabilities. Childcare programmes can provide community-based options and meet the increasing need for out-of-home care for school-going children with physical and mental disabilities. The benefits of inclusive programmes for school-going children with disabilities have been enumerated in the literature. Socialisation is regarded as the key factor in the selection of inclusive child care. However, the ability of programmes to provide responsive care to children with physical or mental disabilities depends on the quality of the programme (Buell, et al., 1999: 218).

While the majority of children with mental or physical disabilities are cared for at home, as mentioned before, families of children with disabilities are increasingly relying on non-parental childcare for their children, particularly in wealthier countries. According to Buell, McCormick and Hallam (1999:217), in the United States family child care accounts for approximately 15 per cent of out-of-home childcare. These programmes are typically operated out of providers' homes and states regulate the number of children permitted in these settings. Many families prefer family child care to centre-based care, as it provides a more home-like environment and allows for more individual attention for school-going children with disabilities (Buell et al., 1999:217).

1.1.2 Effects on the care-giver

In all types of families, whether in low-income or middle-class communities, children with mental or physical disabilities are more likely to be cared for by their mothers than other family members (Read, 1991: 562). It is not only the children who require support, but also their care-givers, mostly the mothers, who are strongly affected by caring for a child with physical or mental disabilities, who require support (Wickham-Searl, 1992:13).

Mothers are particularly affected by the problems and challenges related to caring for these children. This is because the mothers have to undertake exacting work and they are restricted, on a daily basis, in the choices that they have to make about their lives (Read, 1991:561). Studies have found that mothers caring for their school children with disabilities exhibit high levels of psychological problems such as anxiety and depression, partly related to the behavioural epi-

sodes and communication difficulties of their children with physical and mental disabilities such as autism (Phelps, Hodgson, McCammon and Lamson, 2009: 27).

Research indicates, for example, that in 90 per cent of families that have children with feeding disabilities, mothers bear the sole responsibility for the child's nutritional intake. An examination of family systems theory suggests that anything happening to a family member has an effect on other family members because they are interconnected and operate as a group; this also applies to the ecological perspective (Johnson and Yanca, 2007:13). Therefore, in a family with a child who experiences feeding disabilities, the additional time, safe-food handling procedures and emotional and physical energy required from the care-giver, affects not only the mother, but also other family members. As a result there is decreased interaction with other family members, because of extra attention given to the disabled child (Adams et al., 1999:962).

The social identity of a care-giver in part gives an explanation for the fact that the majority of parental care is provided by the mothers of children with mental or physical disabilities, as well as their particular vulnerability to the challenges and problems of providing such care. Firstly, care-giving forms part of the social identity of mothers, and probably women in general. Secondly, caring for their physically or mentally disabled children, the stigma of the disability transfers to the care-givers as well. With this in mind Wickham-Searl (1992:6) argues that mothers experience devaluation on different levels. This includes the fact that they are care-givers, then females, and that they are associated with their school children's disability. Furthermore, as part of the social identity of mothers, all mothers are subjected to several demands and therefore a lot of pressure: children demand that their lives are preserved and their development is fostered, and society demands that children are shaped in ways that are consistent with norms and more. Mothers have to try to meet these demands through acts of protection or preservative love, nurturance, and behaviour training (Spalding, McKeever, 1998:234). Mothers of children with physical or mental disabilities, as mentioned before, often face much higher pressures and greater challenges, and this makes both formal and informal forms of support very valuable.

It should be mentioned at this point that despite the many challenges and problems that they face, care-givers of physically and mentally disabled children frequently see a positive side to their experiences. This may be a result of both informal and formal support which may also include

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spiritual guidance. These support systems can help to strengthen the mothers' emotional health and serve as useful coping tools through life transitions. Additionally, spirituality may provide a valuable means of guidance and purpose throughout the challenging experience of having a child diagnosed with autism (Phelps, Hodgson, McCammon and Lamson, 2009: 27). Having a child with a disability may also help to build stronger connections among family members. Some mothers caring for a disabled child viewed their experiences as life-enriching with one relational benefit being that care-givers have a greater sense of value regarding progress and achievements of all their children (Phelps, Hodgson, McCammon and Lamson, 2009: 30).

1.1.3 Implications of economic and cultural circumstances

So far the effect of a child's physical or mental disability on its family surroundings and the re-lief that different support systems can give to the care-givers, particularly mothers, from some of the challenges, has been discussed. However, both the way in which a disabled child is raised and how care-givers are supported are affected by external conditions too.

In countries such as South Africa, which have a high number of low-income communities, very little social support for children with physical or mental disabilities is available. This places fur-ther strain on the mothers, as they cannot gain access to the resources that may be needed for their disabled school-going child. Wickham-Searl (1992:9) explains that while some limited re-sources may be available in low-income communities, these might be insufficient to cater for the needs of the child. Additionally, even if resources are available, parents might be unaware of their availability or unsure about how to access them. Therefore school-going children with dis-abilities living in low-income communities are very likely to receive full-time care from their mothers, due to limited or no support at all from either family members or the outside (Wick-ham-Searl, 1992:6). While many challenges are the same for each economic background, low income can have a magnifying and protracting effect on problems and dilemmas typically faced by mothers with physically and mentally disabled children (Read, 1991: 562).

Mothers in low-income communities caring for their disabled school-going children experience psychological problems such as high levels of stress as they constantly have to chase, challenge and struggle with services to ensure that their child receives an adequate level of care. These mothers sometimes also hesitate to send their children to a special school as they are not sure of

the school´s quality, the training of the providers, or whether there are enough teachers to meet the demands of all the children in their care (Koshti-Richman, 2009:19).

Another common problem in low-income communities is the lack of support for mothers who are caring for school-going children with physical or mental disability in dealing with the difficult experiences with which they are faced. Additionally, the number of single mothers in low-income communities is higher than average and it is therefore more likely that the mother is the sole care-giver of a disabled child. Being a mother, a sole care-giver and sole provider, and living under poor circumstances is already hard for these mothers and their situation is exacerbated by having to care for a mentally challenged or disabled child (Hanson and Sporakowski, 1986:4).

Another prevalent issue in low-income communities is under-diagnosis of physically or mentally disabled children and insufficient information regarding the disorder/disability's biological etiology, due to a lack of resources and inexperienced specialists (Phelps, 2009:29). This researcher's own experience indicates that under-diagnosis of children with disabilities makes it difficult for the mother to seek appropriate medication or resources for her disabled child and also increases stigmatisation of the child and the mother (Kayama, 2011:118).

Not only is the economic background of the family relevant in this regard, but also the cultural settings in which a physically or mentally disabled child is being raised, as these factors might either create further challenges, add to existing challenges, or, on the other hand, help to relieve some of the strains experienced. While no literature on the relationship between disability and culture in South Africa could be found during the preliminary research, the case of Japan helps to illustrate this point. In Japan, disability has a strong social stigma, as it is often seen as abnormal or disturbing, and as something that does not belong in the public domain, but is a private matter. Additionally, this stigma extends to those caring for disabled children and their families, as problems of individual family members are considered to be family problems, and Japanese people frequently prefer to avoid situations in which they may feel shame. For example, they may go as far as hiding the disabled family member from neighbours, or not applying for support services available to them, in order to avoid their problem becoming public knowledge (Kayama, 2010:118). A similar situation was experienced by this researcher in the township of Kayamandi, where she was unaware that a client with whom she was working actually had a six-year-old

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disabled child locked in a bedroom at home. Neighbours were also unaware of the child's existence.

From an ecological perspective, which emphasises the role of the environment in a comprehensive manner and in relation to the individual, the needs of mothers caring for their disabled children are understood as a consequence of the condition of the relationship between the mother and her environment (Johnson and Yanca, 2007:13). Therefore, these mothers have so many needs and problems as the environment in which they live, lacks resources. For example, because the mothers live in a low-income community environment, where there is no formal or informal support to help them with caring for their disabled children, it is very likely that they may become stressed and depressed, as they are unable to provide appropriate care for their disabled child. However, if they are provided with the support they need it is very likely that they will respond in a way that satisfies the environment. This means that if enough formal and informal support (family support and social networks) is available to them, it will help them to cope better. As a result they will be able to support their children and themselves and thereby improve the environment for their children. Therefore, there has to be a mutually beneficial interaction between the mothers caring for their physically or mentally disabled child and environment. When needs are met, then a state of congruity exists. There is agreement or harmony, a 'fit', between the person and the environment (Johnson and Yanca, 2007:13). If the interaction between the mothers caring for their physically or disabled child and their environment is not well balanced in a way that can sustain the needs of either one or both over time, a state of incongruity – that is, a lack of agreement or harmony between the person and the environment develops. As a result, a mother who is the sole care-giver for her disabled child is thrown into the deep end of her problems (Johnson and Yanca, 2007:13).

This preliminary study has shown that caring for children with physical and mental disabilities is a challenging task with which many care-givers, the majority of whom are mothers, struggle. It furthermore was argued that the specific circumstances – economic, cultural and other – affect the way a child with disability is raised. In this regard, it emerged that, particularly in low-income communities, a lack of support, services, medical care and information, adds to the challenges mentioned before. Moreover, in the course of this preliminary study only very little data and literature (on academic search engines such as the *ProQuest and Nexus)* on the experiences

of mothers caring for their school-going children with mental or physical disabilities was found. For example a total of thirteen studies were found on the Nexus data base regarding the experiences of mothers caring for their disabled children with mental or physical disabilities. The highest number of the studies were done in Psychology (7 or 54 percent), followed by three (23 percent) on studies in Social Work. Topics included experiences of parents with children being treated for attention deficit/hyperactivity and effects of caring on mothers of intellectually disabled children. Only two (15 percent) studies were done in Medical sciences, followed by one (eight percent) study from sociology studies and another one (eight percent) from the disability studies. Within these studies emphasis was placed on the support for mothers with children with learning disabilities in main stream school and the support they need.

In ProQuest data base a total of twenty-six studies were found regarding the experiences of mothers caring for their disabled children. Most of these studies were done in Psychology (10 or 38 percent) and Medical Sciences (8 or 31percent). Topics included costs of caring for disabled children and the changes in mothers' experiences for receiving diagnosis of the child's disability. Only six (23 percent) studies were done in sociology and only two (eight percent) were done in social work. The topic in these studies focused on realities of parents caring for disabled child and their concerns. It can therefore be seen that there is a big gap in literature on the experiences of mothers caring for their school-going children with mental or physical disabilities. In other words the lack of data in combination with the generally precarious situation of school-going children with physical or mental disabilities and their mothers in low-income communities in South Africa provided the rationale for this research. Consequently, the following section will specify the focus of this study and the underlying problem statement as the basis for the research question.

1.2 PROBLEM STATEMENT AND FOCUS

The literature reviewed showed that mothers caring for their school-going children with mental or physical disabilities experience psycho-social and socio-economic problems. It was stated that mothers from low-income communities often lack support, services, medical care and information, to help them to care for their school children with mental or physical disabilities. Further-

more, it was pointed out that these mothers experience feelings of discrimination, stigma and exclusions from their communities on a daily basis (Gona et al., 2010) In addition, these mothers often experience the problem of their child being under-diagnosed, as a result of a lack of re-sources/specialist-experience, as well as psychological challenges due to a lack of answers re-garding the disorder's biological etiology (Phelps, 2009:29). This places even more stress and pressure on these mothers, as they may lack strategies on how to cope with or respond to the needs of their disabled child. Moreover, poverty, unemployment and low levels of education in the low-income communities in which these mothers live further exacerbate the situation (Hanson and Sporakowski, 1986:4), as they may not be able to support themselves and their disabled child. Consequently, this can lead to a vicious circle, in which there is no special needs school for the child in the community and the mother cannot afford to send the child to a suitable school elsewhere, resulting in the child being left at home and not having a chance to socialise with peers, increasing the stigmatisation of the child and the mother (Kayama, 2011:118).

Most importantly, in the context of this thesis, the preliminary research (*Nexus, ProQuest* academic search engines) for this study revealed that very little research addressing the experiences of mothers caring for their school-going children with mental or physical disabilities in low-income communities in South Africa has been carried out.

In summary, although there has been a great deal of research pertaining to the adverse situation of mothers caring for school children with disabilities and their experiences around the world, the gap in the literature regarding South Africa necessitates a closer analysis of the experiences of mothers caring for their school-going children with physical or mental disabilities in South African low-income communities, from an ecological perspective.

The focus of this research is therefore to explore and analyse these experiences. This is done firstly by compiling an extensive literature review and secondly, by conducting an empirical study in order to gain a better understanding of the experiences and needs of mothers caring for a child with disability, within an ecological perspective as briefly discussed earlier.

1.3 AIM OF THE RESEARCH

The aim of this study is to develop an understanding of the experiences of mothers caring for their school-going children with physical or mental disabilities in low-income communities using the ecological perspective.

In order to achieve this aim the following objectives were formulated:

- To give an overview of the nature of physical and mental disabilities of school-going children and the care they need.

- To explain the challenges and resulting needs of mothers caring for their school-going children with physical and mental disabilities.

- To describe how the needs of mothers caring for primary school-going children with physical or mental disabilities are and can be met in South Africa within an ecological perspective.

- To conduct an empirical study in order to investigate the experiences of mothers caring for their physically or mentally disabled school-going children in low-income communities and to evaluate the impact these experiences have on their psycho-social well-being, as well as investigating the actual support that these mothers need in order to make their caring work more effective.

1.4 RESEARCH METHODOLOGY

1.4.1 Research approach

The researcher used both qualitative and quantitative research methods to collect the data for the research. De Vos, Strydom, Fouché and Delport (2011:308) postulate that a qualitative research approach requires the design of the research study to be more than a set of 'worked-out formulas' compared to a quantitative research approach that provides a step by step formula or plan or a fixed recipe for the researcher to follow. In other words, using a qualitative approach is more focused on understanding than explanation, with natural observation rather than controlled measurement, with the subjective exploration of reality from the perspective of an insider as opposed to that of an outsider predominant in the quantitative paradigm. These points regarding qualitative research are also similar and agree with the literature of Babbie, Mouton, Vorster and

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Prozesky (2007:646), who explain that qualitative research is unique in the sense that the research takes as its departure point the insider perspective on social action. This is also regarded as the 'émic perspective'. With these explanations in mind the researcher chose to use the qualitative approach to understand the participants' perspectives on their experiences for caring for their school-going children with physical or mental disabilities and understand how these experiences impact on their lives as individuals (Babbie, Mouton, Vorster and Prozesky, 2007:646).

According to De Vos, Strydom, Fouché and Delport (2011:308) a researcher using a qualitative approach needs to make sure that she/he believes that the research question can be answered truthfully. With this in mind, the researcher approached the research question objectively as an external entity, with a detached attitude, while conducting the study. In other words qualitative research is primarily focused on the meaning that subjects give to their life.

In terms of the quantitative research approach the researcher focused on the actual quantification of constructs. In the opinion of the researcher this approach was the most viable way of measuring the properties of the phenomena. Another aspect with regard to a quantitative approach is that emphasis is placed on variables describing and analysing human behaviour (Babbie, Mouton, Vorster and Prozesky, 2007:646). With this information on the quantitative research approach the researcher gathered numerical data which was used to better understand the experiences of mothers caring for their school-going children with physical and mental disabilities. By using both qualitative and quantitative research approaches, the researcher hopes to have gathered representative, valid and reliable data.

1.4.2 Research Design

Babbie et al. (2007: 646) defines a research design as a plan or structured framework of how the researcher intends to conduct the research process, in order to solve the research problem. In other words it is a plan outlining how information is to be gathered for an assessment or evaluation that includes identifying the data gathering methods, the instruments to be used/created, how the instruments will be administered, and how the information will be organised and analysed (Academic glossary, 2011).

De Vos et al. (2011:171) also regard a research design as a plan, recipe, or blueprint for the investigation, and they provide a guideline according to which a selection can be made of which

data collection methods are most appropriate for the researcher's goals and the selected design. Research designs can be classified according to whether they are empirical or non-empirical studies. This research mainly focuses on the empirical study, which uses both secondary and primary data; both numerical and textual data is collected, as both qualitative and quantitative data is used in the research.

The research design followed in this research is a combination of exploratory and descriptive research designs.

1.4.2.1 Exploratory research and descriptive research design

According to Babbie, Mouton, Vorster and Prozesky (2007:646), using exploratory research design the researcher examines a new interest, thereby satisfying the researcher's curiosity to test feasibility of further research and to develop methods to use in a more careful study. In line with the statement above, Bless, Smith and Kagee (2006: 182) explain that exploratory research explores a certain phenomenon with the primary aim of formulating more specific research questions or hypotheses relating to that phenomenon. De Vos et al. (2005:134) go on to explain that this type of design is more of a qualitative nature and the data collection usually involves observations and unstructured or semi-structured interviews. The researcher therefore uses this research design to better understand the experiences of mothers caring for their school-going children with physical or mental disabilities in low-income communities.

In terms of the descriptive research design, this thesis mainly focuses on giving descriptions of what has been observed in the results (Babbie, 2004:88). According to Reaves (1992:8), the only focus of a descriptive research design is to describe and not to explain or predict the future developments of a particular subject or phenomenon. This research design is used in this instance to provide in-depth descriptions of the experiences of the mothers caring for their mentally or physically disabled children and to provide descriptions of their psycho-socio economic needs regarding social and economic support.

1.4.3 Research method

1.4.3.1 Literature Study

A literature review is an integrated summary of all available literature relevant to the research topic (Bless et al., 2006:183). De Vos et al. (2002:127) emphasize that it is important to conduct a literature study in order to gain a clearer understanding of the nature and meaning of the research field. The researcher therefore conducted a literature review in order to understand what has already been written regarding the experiences of mothers in low-income communities caring for their school-going children with mental and physical disabilities and the support they need, within an ecological perspective.

1.4.3.2 Data collection method

According to De Vos et al. (2011:171) quantitative data collection methods often employ measuring instruments. These instruments may be structured observation schedules, structured interviewing schedules, questionnaires, checklists, indexes, and scales. The researcher uses questionnaires when collecting both qualitative and quantitative data.

The questionnaire included semi-structured questions (both open-ended and closed questions), as the researcher focuses on both qualitative and quantitative data. All the quantitative data is then presented in tables and figures and necessary calculations are made (De Vos et al., 2005:166).

In order to obtain valid and reliable data the researcher ensured that, before implementing the study, all the measurement procedures and the measurement instruments used had acceptable levels of reliability and validity.

In this case **validity** refers to the extent to which an empirical measure adequately reflects the meaning of the concept under consideration. It incorporates the terms truthfulness, accuracy, authenticity, genuineness and soundness and stresses the fact that these terms describe validity.

1.4.3.3 Questionnaires

Semi-structured questionnaires with open and closed questions were completed with the respondents during the semi-structured interviews. As this research study is a combination of quantitative and qualitative study, the semi-structured questionnaires provided the researcher with greater

depth than possible with a totally structured questionnaire on the experiences of mothers for caring for their school-going children with mental or physical disability (De Vos et al.,2005:170).

1.4.3.4 Pilot study

Before conducting the empirical study, the researcher took precautions in order to ensure that she was confident that the research procedures and all the requirements were suitable, valid, reliable, effective and free from problems and errors that may have arisen when conducting the empirical study (De Vos et al.*,* 2011:236). This was done by conducting an initial pilot study. According to De Vos et al. (2005:206-211), a pilot study is a small study that is conducted prior to the main research to determine whether the methodology, sampling instruments and analysis are adequate. Bless et al. (2006:184) explain that a pilot study is done in order to highlight the feasibility of the project and bring possible deficiencies to the attention of the researcher. By doing this the researcher is given the opportunity to make adjustments to the research instrument in order to make it more effective in gathering the required data.

For this research study a pilot study was conducted with two participants. This allowed for the researcher to ensure that the semi-structured questionnaire that was designed for collecting data was appropriate and that the terminology within the questions was clear and understandable for the participants, and at the same time provided appropriate data.

1.4.3.5 Methods of data analysis

De Vos et al. (2005:333) have defined data analysis as the process of bringing meaning and structure to the data that is collected. Macintosh (1996:1) has also defined data analysis as a body of methods that help to describe facts, detect patterns, develop explanations, and test hypotheses. Data analysis is used in all of the sciences, in business, in administration, and in policy.

Analysing data enables the researcher to detect consistent patterns within the data (Bless et al., 2006:163). In this research study data was collected by means of the semi-structured questionnaire and then coded and represented in graphs and figures. This allowed for the data to be interpreted and for trends to be identified in the findings (Bless et al., 2006:163; De Vos et al., 2005:337). The data that was collected was then summarised and interpreted in the research report and compared to the existing data in the literature study. In other words, a literature control process was used.

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1.5 POPULATION AND SAMPLING

According to De Vos et al. (2005:193), a sample is seen as an indication of the simultaneous 'existence of a population or universe of which the sample is a smaller section or a set of individuals selected from a population'. Universe is defined as '…all potential subjects who possess the attributes in which the researcher is interested. Population is then defined as individuals in the universe who possess specific characteristics.

The research was conducted at a special school of children with disabilities in Cloetesville, Stellenbosch.

The population of this study consisted of biological mothers between the ages of twenty and forty years whose children with physical or mental disabilities attend the special school selected for this research study in Cloetesville, Stellenbosch, a low-income community.

The researcher used a non-probability sampling method. The type of non-probability sampling used in this study was purposive or judgmental sampling. According to Babbie, Mouton, Vorster and Prozesky (2007:202), in this type of sampling method the researcher uses his/her own judgment in selecting sample members. This is because the researcher aims to gather both qualitative and quantitative data. Therefore, when the researcher uses non-probability sampling for the qualitative data, she focuses on the purposive sampling techniques rather than random sampling as qualitative researchers seek out individuals, groups and settings where the specific processes being studied are most likely to occur (De Vos et al., 2002:334). Consequently, twenty mothers who are full-time carers of their school-going children with mental or physical disabilities at the special school for children with disabilities selected for this study were interviewed using a semi-structured questionnaire.

1.6 ETHICAL CONSIDERATIONS

Before conducting any research it is important for the researcher to consider all the ethical issues. According to Babbie et al. (2007:522) social research should never injure the people being studied, regardless of whether they volunteer to be part of the study or not. This means that the participant should volunteer to take part in the study. These two concepts: 'no harm to the participants and voluntary participation' can be formalised in the concept of informed consent. This means that the participant should be informed about the risks and the research purpose should be explained. It should be a participant's own will to give consent to take part in the research (Babbie et al., 2007:522). Therefore, in this research the researcher made sure that all participants in the study were not forced to take part, but did so voluntarily. The researcher also made sure that the research did not harm any of the participants in any way (psychologically, emotionally or physically).

Anonymity and confidentiality were also maintained throughout the research. Maintaining confidentiality is important and obliges the social worker to guard the information supplied by the client. Confidentiality was also maintained as the researcher will not reveal the participant's private details to the public. Anonymity is guaranteed by protecting the participants' identity, such as not referring to the participants' actual name in a given response (Babbie et al., 2007:523).

Furthermore, a debriefing session was conducted, allowing the interviewees to share and to work through their experiences, reducing any possible negative effects caused by the research (Babbie et al., 2007:523).

1.7 LIMITATIONS OF THE RESEARCH STUDY

The participants for this research study were those who lived near the school where the research study was taking place. Other potential participants who had children attending the school but lived very far from the school and out of the mentioned communities were not contacted. This is because there would not have been enough time to complete the study had it been necessary to transport these mothers to the school. It would also have been difficult for these mothers to organize child minders to stay at home with the other children. So all the logistics involved meant

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that only the mothers not far from the school were contacted, which, of course, is a limitation of the study.

Another limitation was that the sample was supposed to have twenty participants (n=20), however, because some potential participants failed to indicate whether they would come to take part in the study or returned incomplete forms, a sample of only nineteen participants (n=19) was used.

1.8 TIMEFRAME FOR INVESTIGATION

The research was conducted throughout the academic year of 2011. The work was done in the following way: the final proposal was concluded by 15 April. The literature study chapters were completed once a month, and were finalised by 26 August. The data for the research was gathered by means of a questionnaire. This was done over the period from 1 to 22 September. This information was presented by means of an empirical study, which was completed by 5 October, after which the conclusions and recommendations were submitted. The final research report was submitted on 1 November.

1.9 CLARIFICATION OF KEY CONCEPTS

1.9.1 Experiences

The term 'experiences' as a general concept comprises knowledge of or skill in or observation of something or some event gained through involvement in an event or life experience or being part of an action. In other words it is the accumulation of knowledge or skill that results from direct participation in events or activities (*Randcompare*, 2010:1).

1.9.2 Mothers

A mother is a biological and/or social female parent of an offspring. Because of the complexity and differences of a mother's social, cultural, and religious definitions and roles, it is challenging to define a mother (*Randcompare*, 2010:1).

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1.9.3 Caring

Caring may be defined as providing for the physical, emotional and social needs of another person, often one who is dependent and cannot provide his or her own needs as a result of disability or illness. This may involve physical care, emotional care or psychological care (Barker, 1987:19).

1.9.4 School-going children

These are children aged from six to eighteen years of age who attend a special school (*Randcompare,* 2010:1).

1.9.5 Disability

According to Barker (1987:42) disability is defined as the inability to perform activities, as a result of physical or mental unfitness or infirmity that lasts or is expected to last continuously for life, indefinitely, or for a specific time. It may also be regarded as a condition or function judged to be significantly impaired relative to the usual standard of an individual or group. The term is used to refer to individual functioning; including physical impairment, sensory impairment, cognitive impairment, intellectual impairment, mental illness, and various types of chronic disease (*Disabled World*, 2011:1) The World Health Organisation defines disability as a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives.

The US Census defines disability as a long-lasting physical, mental, or emotional condition. This condition can make it difficult for a person to do activities such as walking, climbing stairs, getting dressed, bathing, learning or remembering (Census Data Organisation, 2011:1).

1.9.5.1 Mental disability

This is a condition characterised by impairment of an individual's normal cognitive, emotional, or behavioural functioning, and it is caused by social, psychological, biochemical, genetic, or other factors, such as infection or head trauma. It is also called emotional illness, mental disease and mental disorder (*American Heritage Dictionary*, 2000:1).

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1.9.5.2 Physical disability

This is a physical impairment, which has a substantial and long-term effect on the individual's ability to carry out day-to-day activities.

People with physical disabilities, also known as disabled people or physically disabled people, have a physical impairment which has a substantial and long-term effect on their ability to carry out day-to-day activities (*American Heritage Dictionary*, 2000:1).

<u>*1.9.6 Low-income community*</u>

These are communities where people tend to have an extremely low income and little financial security. It is also where there are the poorest job prospects, minimal education attainments, and orientation that often includes apathy and hopelessness (Barker, 1987: 91).

<u>*1.9.7 Ecological perspective*</u>

Barker (1987: 46) defines the ecological perspective as theory that emphasises the environmental context in which people function. The important aspects involved in this concept include the principle of <u>adaptation</u>, <u>transaction</u> and <u>goodness of fit</u> between people and their environment, and <u>reciprocity</u> and <u>mutuality.</u>

1.10 OUTLINE OF THE REMAINDER OF THE THESIS

The research report includes six chapters. Chapter I serves as an introduction to the study and presents a plan for how the research will be undertaken. Chapter II focuses on giving an overview of the nature of physical and mental disabilities of primary school-going children and the care they need. Chapter III of this research study explains the challenges and resulting needs of mothers caring for their school-going children with physical or mental disabilities in low-income communities. Chapter IV gives a description of the ways in which these needs can be and are being met in South Africa. Chapter V of this research study discusses the empirical study investigating the experiences of mothers and the impact that these experiences have on their well-being, as well as investigating the actual support that these mothers need in order to make their caring work more effective. Chapter VI, the last chapter of this research study, includes conclusions and recommendations based on the findings of the study.

CHAPTER II: AN OVERVIEW OF THE PHYSICAL AND MENTAL DIS-ABILITIES OF SCHOOL-GOING CHILDREN AND THE CARE THEY NEED

2.1 INTRODUCTION

This chapter presents an overview of the physical and mental disabilities of school-going children and the care that they need on the regular basis. This chapter also corresponds with the first chapter of this research study. The chapter will firstly provide a background on disabilities in children in general. The first section of this background will include the definition of disabilities followed by the identification of common physical and mental disabilities in school-going children. Further, the chapter will discuss the specific disabilities that the participants' children have such as *epilepsy* and *autism*. This section will include the definitions of these disabilities, their causes, how they are assessed and diagnosed, their symptoms as well as the treatment that can be provided. The last section will give an explanation of the care that the children need, based on their identified physical and mental disabilities.

In summary, this chapter will focus on explaining the nature of the disabilities in children by defining the different types of disabilities, their causes and characteristics and how they are diagnosed. Further, the chapter will explain the care that these children need on a regular basis.

2.2 BACKGROUND ON DISABILITIES

This section will provide a description of how the concept of disability has been defined by different authors and will identify the different types of physical and mental disabilities in children and their prevalence. In terms of the physical disabilities, this research will focus on specific disabilities, namely, epilepsy and cerebral palsy. In terms of mental disabilities this research will focus on: autism spectrum disorder, learning disabilities, Down syndrome and fetal alcohol syndrome.

2.2.1 Definition of disability

As explained in the first chapter, the concept of disability is defined differently by different organisations and government agencies. In the first chapter it was shown that Barker (1987:42) defines disability as the inability to perform activities, as a result of mental unfitness or infirmity that lasts continuously for life, indefinitely, or for a specific time. On the other hand, *Disabled World* (2011:1) uses the term disability to refer to individual functioning, including physical impairment, intellectual impairment, mental illness and various types of chronic disease. However, these different definitions have one aspect in common: they both state that disability means either a permanent physical or mental impairment, or chronic health or mental health condition, which may be visible or invisible to others (*Disabled World*, 2011:1).

2.3 COMMON PHYSICAL DISABILITIES AMONG SCHOOL-GOING CHILDREN

As shown in Table 1 below, physical disabilities can be categorised in four groups, each of which has one or more subcategories, for example, blindness as a form of visual impairment.

Table 2.1: Different types of physical disabilities

Type of physical disability	Different types
Visual impairment	- Blindness - Blurred vision - Cataract - Colour blindness
Hearing impairment	- Hearing loss - Minere's disease - Tinnitus
Mobility impairment	- Arthritis - Cerebral palsy - Epilepsy - Multiple sclerosis (MS) - Muscular dystrophy (MD)
Head injury	- Traumatic head injury

Source: *Disabilities World* (2011:3)

Epilepsy, a form of mobility impairment, will be described in more detail in the following section.

2.3.1 Epilepsy

Epilepsy is defined as a convulsive disorder, in which seizures occur when there is an abnormal electrical discharge in the brain. This is usually triggered by a chemical imbalance or structural abnormality (*Epilepsy South Africa*, 2010). Schneider (1990:618) also defines epilepsy as a convulsive disorder, where there is a sudden, excessive and disorderly discharge of neurons in a normal or diseased cortex. Helfer (2006: 34) explains that the discharge that occurs leads to a disturbance sensation, a loss in consciousness and convulsive movements.

The South African Epilepsy Organisation data (2010:1) illustrates that epilepsy affects at least one in 200 of the global population, and one in 100 in South Africa. It can affect anyone, at any age, but most commonly develops before the age of twenty. It is also stated that an isolated seizure is not necessarily an indication of epilepsy. Many people have their epilepsy controlled by medication. Many children with epilepsy outgrow it. Epilepsy is not a mental illness or psychiatric disorder and it is also not infectious or contagious (*Epilepsy South Africa*, 2010). This disability may affect children in different ways; it is therefore important to try to identify accurately the individual child's type of epilepsy in order to meet the child's needs and therefore provide the most appropriate help.

2.3.1.1 Common childhood epilepsies

There are two main types of epilepsy in children: some children have more than one type, but the majority have only one. Firstly, there is Type A epilepsy, characterised by 'generalised' seizures, which involve the whole brain, usually with some loss of consciousness, however brief. The second type, Type B epilepsy, leads to 'partial' seizures, which originate in a particular part of the brain and may or may not involve a loss of consciousness (*Epilepsy South Africa*, 2010). These two main types of epilepsy in children are presented in the figures below, with brief descriptions of the particular symptoms and their duration.

Figure 2.1 on Type A epilepsy, 'generalised seizures', indicates that school children with this type of epilepsy may go through different phases, namely the tonic phase and the cloning phase, seizures lasting up to a few seconds and several different symptoms. Figure 2.2 on Type B epilepsy, 'partial seizures', indicates that these children may experience complex or simple seizures.

For example 'complex type' seizures may last up to two minutes whereas in the simple seizures the child may only experience a funny feeling of jerking in just one limb.

Figure 2.1: Type A of epilepsy

TYPE A: GENERALISED SEIZURE

1. Tonic / clonic

Lasts few minutes

Tonic phase
- The body will stiffen and the child may cry (this is not pain)
- The child then will fall, jerking movements

Clonic phase
- The child may go blue due to lack of oxygen. Incontinence may occur.

2. Absence

Lasts few seconds
- The child may look blank, stare and have slight twitching or blinking.

3. Myoclonic

- Single or multiple occurrences in a variable period of time.
- A limb, limbs or the trunk may jerk possibly leading to a fall.

Source: *Epilepsy South Africa* (2010).

Figure 2.2: Type B of epilepsy

TYPE B: PARTIAL SEIZURES

1. Complex

- Seizure lasts for up to two minutes
- May start with an 'aura' or warning –visual, auditory, taste.
- Child may appear conscious but may not respond.
- Abnormal movement like plucking at clothing or smacking of lips may occur.
- Child may want to wander.

2. Simple
- Funny feeling of jerking in just one limb or down one side of the body
- Consciousness is not lost
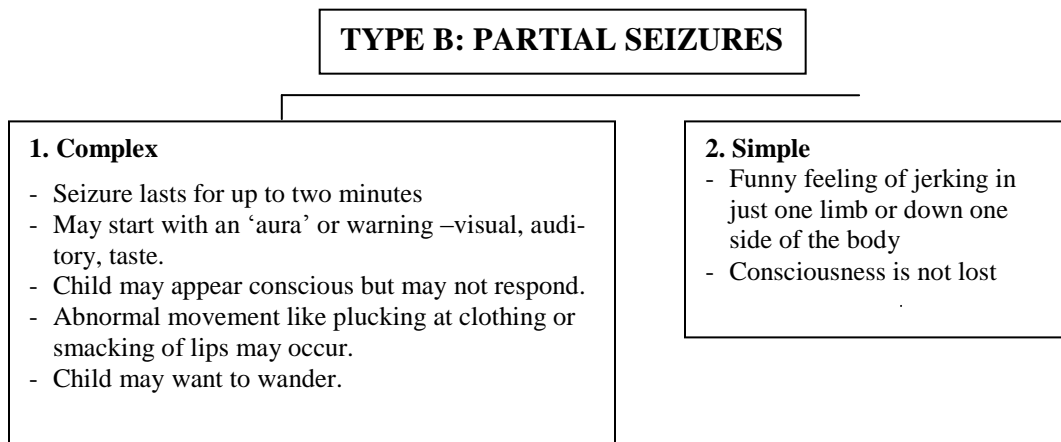
Source: *Epilepsy South Africa* (2010).

2.3.1.2 How epilepsy is diagnosed

According to the South African Epilepsy Organisation (2011), diagnosing epilepsy can be difficult, however it is important that non-epileptic seizures are not misdiagnosed as epilepsy, seizures are not misdiagnosed as non-epileptic and that the precise type of seizure is identified.

Mistakes can happen if the episodes and the circumstances in which they occur are not described exactly. A precise account of the exact sequence of events from the first changes in the child to complete recovery and the circumstances in which the seizure occurs should be obtained. In difficult cases, EEG monitoring over longer periods can be helpful to discover if there is epileptic activity in the brain at the time of the suspected attacks, or to identify the nature of non-epileptic attacks, for example, sleep disorders (*Epilepsy South Africa*, 2010).

There are numerous possible causes of epilepsy and these should be carefully considered by a doctor. Often the cause cannot be determined, even when a careful assessment has been carried out. This may be difficult for parents to accept, but it is important that a search for the cause is not pursued indefinitely and that the parents themselves do not feel somehow responsible in such circumstances (*Epilepsy South Africa*, 2010).

2.3.1.3 How to treat epilepsy

There are three major treatment options that can be used to treat epilepsy. Firstly, *prescribed drugs* may be used without causing harmful side effects. However, it is recommended that one drug should be used in as few doses each day as possible to ensure adequate blood levels by day and by night (*Epilepsy South Africa*, 2010).

The second treatment option is *psychological intervention*. It is argued that some children's seizures are made worse by such things as stress, emotional upset and boredom. In these cases it is essential to identify the problem and deal with it. This may require help from a counsellor in addition to medication (*Epilepsy South Africa*, 2010).

The third treatment option is *surgery*. The South African Epilepsy Organisation (2010) explains that only a small percentage of children with epilepsy are suitable for surgery. However, improved investigations and new surgical techniques mean that surgery can now be very successful

for some children. Unfortunately, not all epilepsies have a good prognosis and some children will have seizures for many years, sometimes for all their lives. In general, the prognosis for good seizure control is poor where epilepsy is associated with intellectual disability, especially if severe. Rarely, seizures cannot be controlled because of progressive underlying brain disease.

2.3.1.4 The needs of children with epilepsy

Children who have epilepsy and seizures as a result of brain damage or malformation may need special placement, where both their medical and educational needs can be met. This is very difficult, especially for mothers/families who are already living in poverty as they may not be able afford the special placement that their child needs in order to receive appropriate care (Read, 1991:563). The children may also need full-time care from parents, especially if they have other disabilities, meaning that they may need to be watched/monitored at all times by their caregivers. However, children with less severe epilepsy may attend mainstream schools, where many of them do well. In fact, epilepsy is compatible with the full range of intelligence and achievements. However, there is evidence that some children with epilepsy may underachieve at school. If underachievement is suspected, careful psychometric assessment is required and the child may need special learning support at school *(Epilepsy South Africa*, 2010).

School children with epilepsy need to be diagnosed properly so that they receive appropriate care. As explained in the first chapter of this research study, children who have disabilities are often incorrectly diagnosed in the low-income communities (Phelps, 2009:29). This is due to the fact that they do not have access to services that can help them to be diagnosed or they may live far from the organisation. This can lead to a situation where the child´s needs are not being met and this can cause emotional pain for the child as well as for the parents (Wickham-Searl, 1992).

In summary, epilepsy is a serious physical disability in children, with several different symptoms. It is not always easy to diagnose and has different treatment options. It is therefore necessary to make sure that the mothers who care for children with this type of disability are well informed by the professionals on what epilepsy is, how they can spot the signs and symptoms of epilepsy in their children, and how they can seek appropriate treatment to meet their child's needs and at the same time provide effective care for their child.

2.3.2 Cerebral palsy

Cerebral palsy is the most commonly occurring physical disability in childhood. Literature from Dormans and Pellegrino (1998:5) illustrates that there are three important elements in defining cerebral palsy. Firstly, they state that it is associated with significant problems with motor function. Secondly, the motor impairment is a result of something that went wrong in the early development of the brain. Thirdly, cerebral palsy is said to be non-progressive.

Cerebral palsy occurs when there is a disturbance in the early development of the brain. This means that any insults to the brain before the age of three may result in neurological impairments such as cerebral palsy (Helfer, 2006:29). Current evidence suggests that cerebral palsy is largely a developmental event, not significantly influenced by current obstetric technologies available in developed countries. In developed countries it has been suggested that most cases of cerebral palsy occur ante-natally, before the onset of labour. Although cerebral palsy rates are thought to be similar in developed and developing countries, the etiology does seem to differ as the contribution of severe birth asphyxia, kernicterus and central nervous system infections (tuberculosis, bacterial meningitis, cerebral malaria) continue to be significant problems in many developing countries. The range varies from 5 per cent in the most developed countries to 60 per cent in the least developed countries (Laughton, Van Toorn and Van Zyl, 2007:74).

2.3.2.1 Types of cerebral palsy

According to Dormans and Pellegrino (1998:8), children suffering from cerebral palsy usually experience different abnormalities that include: *movement,* where there may be involuntary movements or disturbance; *muscle tone,* either hypertonia (increased muscle tone) or hypotonia (decreased muscle tone); and *posture,* referring to the motion of positioning parts of the body in relation to one another.

According to Helfer (2006: 30) the three types of cerebral palsy that have been identified above are classified according to their physiological type and their geographic distribution in the body. This means that each child with cerebral palsy may be affected differently by this disability, resulting in different needs. Some of the impairments affecting the nervous system associated with cerebral palsy are shown in Table 2.2 below. These impairments can affect vision, hearing, sen-

sory and cognitive functions; can be neurological, orthopaedic and other physiological impairments, and can include epilepsy.

Table 2.2: Impairments affecting the nervous system associated with cerebral palsy

Impairment	Explanation
Vision	Children experience near-sightedness, loss of vision due to 'lazy eye' or loss of vision in segments of the visual field
Hearing	Children may have difficulties processing the sounds they hear
Sensory impairments	Children may struggle with awareness of the position of their limbs in space
Cognitive impairments	Children may experience difficulties regarding memory learning, language processing, problem solving and attention
Neurological, orthopaedic and other physiological impairments	Children may experience seizure disorders, muscular contractures, hip dislocation, scoliosis, respiratory and gastrointestinal problems and urinary tract dysfunction
Epilepsy	About half of children with cerebral palsy also suffer from epilepsy

Source: Dormans and Pellegrino (1998:24)

2.3.2.2 *The needs of children with cerebral palsy*

Children with cerebral palsy often need much more attention than other children do. Special needs for movement, interaction and communication are sometimes taxing and frustrating for mothers caring for these children, and without special help this can place a great deal of strain on the mother. The first and most important thing to realise is that most children with cerebral palsy have the capacity for intellectual and emotional development. Even though life may be more challenging and stressful for the sole care-givers, they still need to encourage and enable their child to grow and explore. This may be difficult in communities where there is stigmatisation of families that have children with disabilities (*Resources for Cerebral Palsy,* 2011:1)

Literature from the *Resources for Cerebral Palsy* (2011:2) states that in families where there is a child with cerebral palsy it is important that the siblings of a child with cerebral palsy receive the appropriate amount of attention as well. With so much focus on the child with special needs, these siblings can often feel excluded from the family, and studies show that these children are statistically more likely to develop behavioural and emotional problems later in life.

Children with cerebral palsy also need special schooling. In South Africa, even though the South African School Act of 1996 and the White Paper 6 on special needs education as well as the Child Care Act 0f 2003 provide for the inclusion of learners with special needs, and state that every child has a right to attend school, children with cerebral palsy have special needs that some schools are unable to address. Special inclusion programmes mix disabled and healthy children into a single learning environment in order to teach them about differences at an early age (*Resources for Cerebral Pals*y, 2011:2).

2.3.2.3 Caring for children with cerebral palsy

All children are inherently their parents' responsibility. Food, clothes, toys, medical appointments, education – virtually everything that a child needs is incredibly expensive. For children with special needs such as cerebral palsy, these basic necessities can cost three or four times more than for children who do not have disabilities (*Resources for Cerebral Palsy*, 2011:2).

Children with cerebral palsy need structured and focused long-term treatment in order to fully reach their maximum potential. Some of the more common ways to care for children with cerebral palsy include:

- **Physical therapy.** Training the child's body, muscles, and coordination at an early age can eventually lead to less dependence on mobility aids later on. Early therapy can also prevent contractures, a difficult condition in which the child's muscles become fixed, rigid, and immobile.
- **Speech therapy.** Some children with cerebral palsy have challenges in their speech patterns, so it is important to concentrate on building the child's ability to speak early on. This therapy can also improve the child's ability to eat.
- **Daily living therapy**. This type of therapy concentrates on improving the skills the child needs to use on a daily basis; things such as feeding, dressing, and general hygiene.
- **Hearing and vision therapy**. Cerebral palsy can affect the muscles that coordinate eye movement, so some children need corrective surgery or eye patches to remedy their situation. Hearing aids can also help the child to interact better with the world.
- **Medication.** Some muscle relaxants can reduce the rigidity of underused muscles and anticonvulsants like Botox can help control muscles spasms.

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- **Surgery.** By far the most invasive and complicated way to care for children with cerebral palsy is through surgery. Depending on the severity of a child's cerebral palsy, he or she may need surgery to correct problems on muscles, joints, tendons, or nerves. These procedures can help the child to move more efficiently or make better use of walking aids. One effective operation that can help to relieve medication-resistant muscle spasms is an intrathecal-baclofen procedure. A large amount of the anti-spastic medication baclofen is placed into a reservoir under the skin around the spinal cord and it is continuously pumped through the body to prevent spasms. This complicated procedure requires careful planning by a team of neurosurgeons, orthopaedic surgeons, neurologists, and physical therapists (*Resource for Cerebral Palsy* 2011:3).

The points above have identified different ways that children with cerebral palsy can be cared for and the treatment that can be provided for them. Many of the mothers caring for their school-going children with such disabilities in low-income communities may not be aware of such ways to care for the child with cerebral palsy. It is therefore recommended that the all the service providers, as well as community organisations, should have this information available for the mothers so that they are aware of ways of providing care for their disabled child.

The following section will discuss and identify the common mental disabilities in children. The discussion will include a description of the symptoms and characteristics of these mental disabilities, followed by a discussion of the causes mental disability, as well as the treatment that can be provided. Most importantly, the section will cover the specific needs of school-going children with mental disabilities.

2.4 COMMON MENTAL DISABILITIES AMONG SCHOOL-GOING CHILDREN

Mental disorders result from the interaction of a child with his or her environment. Thus, mental illness often does not lie within the child alone. Within the conceptual framework and language of integrative neuroscience, mental disorder is an emergent property of the transaction with the environment. This means that proper assessment of a child's mood, thought and behaviour demands a simultaneous consideration of nature and nurture, genes and environment biology and

psychosocial influences. These relationships are reciprocal. The brain shapes behaviour and learning shapes the brain (*National Institute of Mental Health*, 2010)**.** Mental disabilities must be considered within the family and peers, school, home, and community. Taking the socio-cultural environment into consideration is essential to understand mental disorders in children and adolescents, as well as in adults. However, the changing nature of these environments, coupled with the progressively unfolding process of brain development, puts the emphasis on context, as well as development, more complex and more central in child's mental growth.

There are a number of mental disorders in children as indicated in *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV, 2000 :), namely:

- Anxiety disorders
- Attention-deficit and disruptive behaviour disorders
- Autism and other pervasive developmental disorders
- Eating disorders
- Elimination disorders
- Learning and communication disorders
- Mood disorders (for example, depressive disorders)

All the mental disabilities identified above affect school-going children in different ways. Some children may require intensive and special care in order for their needs to be fully met. Some children with a specific kind of disability, such as autism, may not be able to attend mainstream education while others, who may only have learning disabilities, may be able to. This basically means that each of the disabilities identified is unique in its own way and children are required to receive care based on their specific type of mental disability

2.4.1 Assessment and diagnosis of mental disorder

Assessment of the mental function of children has several important goals. These include learning the unique functional characteristics of each individual (formulation) and diagnosing signs and symptoms that suggest the presence of mental disorder. Case formulation helps the clinician understand the child in the context of family and community. Diagnosis helps identify children who may have a mental disorder with an expected pattern of distress, limitation, course, and re-

covery. Both processes are useful in planning for treatment and supportive care, helpful in developing a treatment plan (*National Institute of Mental Health*, 2010)**.**

Literature from the National Institute of Mental Health (2010) indicates that most disorders are diagnosed by their manifestations, that is, by symptoms and signs, as well as functional impairment. A diagnosis is made when the combination and intensity of symptoms and signs meet the criteria for disorder listed in DSM-IV. However, diagnosis of childhood mental disorders is not an easy task. Clinicians with less experience may either over-diagnose normal behaviour as a disorder or miss a diagnosis by failing to recognise abnormal behaviour. Inaccurate diagnoses are more likely in children with mild forms of a disorder (*National Institute of Mental Health*, 2010)**.**

2.4.2. Mental retardation /intellectual disability

Mental retardation (MR)/Intellectual disability (ID) is the significantly sub-average intellectual functioning present from birth or early infancy, causing limitations in the ability to conduct normal activities of daily living. This disability can be genetic or the result of a disorder that interferes with brain development. Most children with MR/ID do not develop noticeable symptoms until they are in pre-school. Support from many specialists, therapy, and special education help children to achieve the highest level of functioning possible (*National Institute of Mental Health,* 2010).

Both physical and mental disabilities that a school-going child has, may affect how the child plays and the child's ability to use play as an avenue of learning and generalising new skills or concepts. Personality, environment and gender also affect how play skills develop, as well how children approach play and the lessons that the child takes from the play activity. Children with disabilities show distinct differences in their play. They may need to be taught specific play skills before they can begin to learn through play. The child may need to be taught such adaptations, for example, how to get materials or how to ask another child to play (*National Institute of Mental Health,* 2010)**.**

Physical disabilities may affect the child's play in a variety of ways, depending on how the disability restricts movement. The child may have difficulty moving to the materials or areas available for play. She/he may also have difficulty manipulating materials in a constructive or meaningful way. Cerebral palsy may also restrict the use of speech.

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Cognitive disabilities, that is delays or impairments in cognitive functioning, may also delay the development of play skills. Children may need opportunities to imitate and learn specific play skills before they are ready to put skills to work in the more generalised nature of play. They may also find it difficult to engage in high levels of socio-dramatic play, because of difficulty to think abstractly. Children with cognitive delays may also engage in more exploratory behaviours than direct play behaviours.

2.4.3 Learning disabilities

The other mental disorder on which this research focuses is learning disability. This refers to neurological differences in processing information that severely limits the child's ability to learn in a specific skill area. Learning disability may persist throughout the individual's life, and may also impact independent living and social relationships (Logsdon, 2011:1).

Learning disabilities can be identified when children struggle with learning in their school years. Children with learning disabilities may have difficulty learning basic skills in reading or under-standing reading. Difficulty with writing, maths, or language may also signal learning disabilities. Furthermore, some students with learning disabilities may easily learn basic skills, but have difficulty applying skills to problem solving or higher-level school work (Logsdon, 2011:1).

In the following paragraphs different types of learning disabilities will be discussed, followed by a discussion on their causes. The specific needs of school-going children with this disability will also be addressed.

2.4.3.1 Different types of learning disabilities

Learning disability is a broad term used by educators to describe many different types of learning problems that affect various skills and abilities. In public schools in the United States, the Individuals with Education Disability Act of 1997 (IDEA) includes the following guidelines on specific types of learning disabilities (Logsdon, 2011:4).

- Basic reading and reading comprehension are the two broad categories of reading disabilities. Dyslexia is another term by which reading disabilities are known.

- Language comprehension and speaking and expressive language are the two main types of language disorders.

- Basic writing and expressive writing are the two types of writing disorders. Some diagnostic systems refer to writing disorders as dysgraphia.

From the points above one can see examples of the learning disabilities that professionals can use to categorise and define specific learning disabilities.

2.4.3.2 Causes of learning disabilities

Learning disabilities are caused by neurological differences in the way the brain processes information. People with learning disabilities usually have average or higher intelligence. The United States current learning disability regulations under the Individuals with Learning Disabilities Education Act of 1997, indicate that learning disabilities exist when the child's ability to learn is average or higher, but his skills in one or more academic areas are significantly weaker. This way of diagnosing a learning disability is typically referred to as the 'aptitude achievement discrepancy' method (Logsdon, 2011:2).

2.4.3.3 The needs of children with learning disabilities

Living with a learning disability can be a painful struggle for both the parents and the child with the learning disability. In many cases, parents are relieved to find an answer when children are diagnosed with learning disabilities, as it is reassuring and leads to additional support at school through specially trained teachers and special education programmes. Additionally, students with learning disabilities can benefit from individual education programmes developed to address their specific learning disability needs, as well as specially designed instruction based on each child's unique strengths, weaknesses, learning styles (Logsdon, 2011:6).

2.4.4 Autism spectrum disorder

The autism spectrum disorders (ASD) are more common in the paediatric population than some better-known disorders such as diabetes, spinal bifida, or Down syndrome. The earlier the disorder is diagnosed, the sooner the child can be helped through treatment interventions. Paediatricians, family physicians, day-care providers, teachers, and parents may initially dismiss signs of

ASD, optimistically thinking that the child is just a little slow and will catch up (*National Institute of Mental Health*, 2011: 5).

All children with ASD demonstrate deficits in social interaction, verbal and nonverbal communication, and repetitive behaviours or interests. In addition, they often show unusual responses to sensory experiences, such as certain sounds or the way objects look. Each of these symptoms can range on a scale from mild to severe and can present in each child differently. For instance, a child may have little trouble learning to read, but may exhibit extremely poor social interaction. Each child will display communication, social, and behavioural patterns that are individual, but that fit into the overall diagnosis of ASD (*National Institute of Mental Health*, 2011: 5).

Children with ASD do not follow the typical patterns of child development. In some children, hints of future problems may be apparent from birth. However, in most cases, problems with communication and social skills become more noticeable as the child lags behind children of the same age. The differences in the way in which they react to people and other unusual behaviours become apparent often between the age of twelve to eighteen months. On the other hand, some children start off well enough and later display signs of ASD (*National Institute of Mental Health*, 2011: 6).

2.4.4.1 Prevalence

In 2007, in the most recent government survey carried out in the United States on the rate of autism, the Centres for Disease Control (CDC) found that the rate is currently higher than the rates found in studies conducted in the United States during the 1980s and early 1990s (*National Institute of Mental Health, 2011:3).*

Data from an earlier report of the CDC's Atlanta-based programme found the rate of ASD was 3.4 per 1,000 for children of three to ten years of age. Summarising this and several other major studies on autism prevalence, CDC estimates that 2 to 6 per 1,000 (from 1 in 500 to 1 in 150) children have an ASD. The risk is three to four times higher in males than females. Compared to the prevalence of other childhood conditions, this rate is lower than the rate of mental retardation (9.7 per 1,000 children), but higher than the rates for cerebral palsy (2.8 per 1,000 children), hearing loss (1.1 per 1,000 children), and vision impairment (0.9 per 1,000 children). The CDC

notes that these studies do not provide a national estimate (*National Institute of Mental Health*, 2011: 3).

2.4.4.2 Social symptoms

From the start, typically developing infants are social beings. Early in life, they gaze at people, turn toward voices, grasp a finger, and even smile. In contrast, most children with ASD seem to have tremendous difficulty learning to engage in the give-and-take of everyday human interaction. Even in the first few months of life, many do not interact and they avoid eye contact. They seem indifferent to other people, and often seem to prefer being alone. They may resist attention or passively accept hugs and cuddling. Later, they seldom seek comfort or respond to parents' displays of anger or affection in a typical way. Research has suggested that although children with ASD are attached to their parents, their expression of this attachment is unusual and difficult to read (*National Institute of Mental Health*, 2011: 7).

Children with ASD are also slower in learning to interpret what others are thinking and feeling. Subtle social cues – whether a smile, a wink, or a grimace – may have little meaning. To a child who misses these cues, 'Come here' always means the same thing, whether the speaker is smiling and extending her arms for a hug or frowning and planting her fists on her hips. Without the ability to interpret gestures and facial expressions, the social world may seem bewildering (*National Institute of Mental Health*, 2011: 7).

To compound the problem, people with ASD have difficulty seeing things from another person's perspective. Most five-year-olds understand that other people have different information, feelings, and goals than they have. A person with ASD may lack such understanding. This inability leaves them unable to predict or understand other people's actions (*National Institute of Mental Health*, 2011: 7).

Although not universal, it is common for people with ASD also to have difficulty regulating their emotions. This can take the form of 'immature' behaviour, such as crying in class or verbal outbursts that seem inappropriate to those around them. The individual with ASD might also be disruptive and physically aggressive at times, making social relationships even more difficult. They have a tendency to 'lose control,' particularly when they're in a strange or overwhelming envi-

ronment, or when angry and frustrated. They may at times break things, attack others, or hurt themselves. In their frustration, some bang their heads, pull their hair, or bite their arms (*National Institute of Mental Health*, 2011: 8).

(a) Communication difficulties:

By age three, most children have passed predictable milestones on the path to learning language; one of the earliest is babbling. By the first birthday, a typical toddler says words, turns when he hears his name, points when he wants a toy, and when offered something distasteful, makes it clear that the answer is 'no' (*National Institute of Mental Health*, 2011: 8).

Some children diagnosed with ASD remain mute throughout their lives. Some infants who later show signs of ASD coo and babble during the first few months of life, but they soon stop. Others may be delayed, developing language as late as age five to nine. Some children may learn to use communication systems such as pictures or sign language (*National Institute of Mental Health, 2011: 8).*

(b) Repetitive behaviours

Although children with ASD usually appear physically normal and have good muscle control, odd repetitive motions may set them apart from other children. These behaviours might be extreme and highly apparent. Repetitive behaviour sometimes takes the form of a persistent, intense preoccupation. For example, the child might be obsessed with learning all about vacuum cleaners, train schedules, or lighthouses. Often there is great interest in numbers, symbols, or science topics (*National Institute of Mental Health*, 2011: 9).

As children, they might spend hours lining up their cars and trains in a certain way, rather than using them for pretend play. If someone accidentally moves one of the toys, the child may be tremendously upset. ASD children need, and demand, absolute consistency in their environment. A slight change in any routine – in mealtimes, dressing, taking a bath, going to school at a certain time and by the same route – can be extremely disturbing. Perhaps order and sameness lend some stability in a world of confusion (*National Institute of Mental Health*, 2011: 9).

2.4.4.3 How autism can be diagnosed

In evaluating a child, clinicians rely on behavioural characteristics to make a diagnosis. Some of the characteristic behaviours of ASD may be apparent in the first few months of a child's life, or they may appear at any time during the early years. For the diagnosis, problems in at least one of the areas of communication, socialisation, or restricted behaviour must be present before the age of three. The diagnosis requires a two-stage process. The first stage involves developmental screening during 'well child' check-ups; the second stage entails a comprehensive evaluation by a multidisciplinary team (*National Institute of Mental Health*, 2011: 13).

2.4.4.4. Treatment options

There is no single best treatment package for all children with ASD. One point that most professionals agree on is that early intervention is important; another is that most individuals with ASD respond well to highly structured, specialised programmes.

Among the many methods available for treatment and education of people with autism, applied behaviour analysis (ABA) has become widely accepted as an effective treatment. The goal of behavioural management is to reinforce desirable behaviours and reduce undesirable ones (*National Institute of Mental Health*, 2011: 17).

In elementary school, the child should receive help in any skill area that is delayed and, at the same time, be encouraged to grow in his or her areas of strength. Ideally, the curriculum should be adapted to the individual child's needs. Many schools today have an inclusion programme in which the child is in a regular classroom for most of the day, with special instruction for a part of the day. This instruction should include such skills as learning how to act in social situations and in making friends. Although higher-functioning children may be able to handle academic work, they too need help to organise tasks and avoid distractions (*National Institute of Mental Health,* 2011: 27).

Dietary interventions are based on the idea that food allergies can cause symptoms of autism, and an insufficiency of a specific vitamin or mineral may cause some autistic symptoms. If parents decide to try a special diet for a given period of time, they should be sure that the child's nutritional status is measured carefully.

2.4.4.5 Research into causes and treatment of autism spectrum disorders

Research into the causes, the diagnosis, and the treatment of autism spectrum disorders has advanced. With new well-researched standardised diagnostic tools, ASD can be diagnosed at an early age. And with early diagnosis, the treatments found to be beneficial in recent years can be used to help the child with ASD develop to his or her greatest potential. For example, the Institute of Medicine (IOM) conducted a thorough review on the issue of a link between thimerosal and autism. The final report from IOM, 'Immunization Safety Review: Vaccines and Autism', released in May 2004, stated that the committee did not find a link (*National Institute of Mental Health*, 2011:31).

(a) Research on the biological basis of ASD

Post-mortem and MRI studies have also shown that many major brain structures are implicated in autism. These include the cerebellum, cerebral cortex, limbic system, corpus callosum, basal ganglia, and brain stem (*National Institute of Mental Health*, 2011: 31).

Research into the causes of ASD is being fuelled by other recent developments. Evidence points to genetic factors playing a prominent role in the causes of ASD. Twin and family studies have suggested an underlying genetic vulnerability to ASD. Further research in this field is, for example, being conducted at the Autism Genetic Resource Exchange, a project initiated by the Cure Autism Now Foundation, and aided by NIMH (*National Institute of Mental Health*, 2011: 31).

The figure below (2.3) helps to illustrate which major brain structures affected are implicated in ASD. As can be seen, seven main brain structures are implicated in autism: the cerebral cortex, amygdala, hippocampus, basal ganglia, brain stem, cerebellum, and corpus callosum. It indicates how widespread and diverse the effects of ASD on brain function can be, from basic and automatic motor functions like breathing to memory, behaviour and perception.

Major Brain Structures Implicated in Autism

Corpus callosum - consists primarily of closely packed bundles of fibers that connect the right and left hemisphere and allows for communication between the hemispheres.

Brain stem - located in front of the cerebellum, it serves as a relay station, passing messages between various parts of the body and the cerebral cortex. Primitive functions essential to survival (breathing and heart rate control) are located here.

Cerebellum - located at the back of the brain, it fine tunes our motor activity, regulates balance, body movements, coordination, and the muscles used in speaking.

Cerebral cortex - a thin layer of gray matter on the surface of the cerebral hemispheres. Two-thirds of its area is deep in the fissures or folds. Responsible for the higher mental functions, general movement, perception, and behavioral reactions.

Amygdala - responsible for emotional responses, including aggressive behavior.

Hippocampus - makes it possible to remember new information and recent events.

Basal ganglia - gray masses deep in the cerebral hemisphere that serves as a connection between the cerebrum and cerebellum. Helps to regulate automatic movement.

Figure 2.3: Major brain structures implicated in autism

Source: *National Institute of Mental Health*, 2011: 31.

2.4.5 Down syndrome

This is another type of mental disability that school-going children may have. Firstly, a definition of this disability will be provided, followed by the identification of the characteristics and symptoms of this disability. The fourth part will give an explanation of how this disability can be diagnosed as well as the treatment that can be provided once it has been diagnosed. Lastly, the needs of the school-going child with Down syndrome will be explained, followed by a summary of the material covered in this section.

2.4.5.1 Definition

Down syndrome is a genetic disorder that occurs in approximately 1 of 800 live births. It is the leading cause of cognitive impairment and is also known as Trisomy 21. Down syndrome is associated with mild to moderate learning disabilities, developmental delays, characteristic facial features, and low muscle tone from early infancy. Many individuals with Down syndrome also have heart defects, leukaemia, early-onset Alzheimer's disease, gastro-intestinal problems and other health issues (*Medicine Net*, 2011:1).

Down syndrome is named after Doctor Langdon Down, who in 1866 first described the syndrome as a disorder. Although Doctor Down made some important observations about Down

syndrome, he did not correctly identify what causes the disorder. It was not until 1959 that scientists discovered the genetic origin of Down syndrome (*Medicine Net*, 2011:1).

2.4.5.2 Characteristic features and symptoms of Down syndrome

Although the severity of Down syndrome ranges from mild to severe, most individuals with Down syndrome have widely recognisable physical characteristics. These include:

- A flattened face and nose, a short neck, a small mouth sometimes with a large, protruding tongue, small ears, upward slanting eyes that may have small skin folds at the inner corner (epicanthal fold)

- White spots may be present on the coloured part of the eye (iris)

- The hands are short and broad with short fingers, and there is a single crease in the palm

- Poor muscle tone and loose ligaments are also common

- Development and growth is usually delayed and often average height and developmental milestones are not reached.

The most common condition associated with Down syndrome is cognitive impairment. Cognitive development is often delayed, and all individuals with Down syndrome have mild to severe learning difficulties that last throughout their lives. How the extra chromosome 21 leads to cognitive impairment is not entirely clear. The average brain size of a person with Down syndrome is small and scientists have found alterations in the structure and function of certain brain areas such as the hippocampus and cerebellum. Particularly affected is the hippocampus, which is responsible for learning and memory. Scientists are using human studies and animal models of Down syndrome to find out which specific genes on the extra chromosome 21 lead to different aspects of cognitive impairment (*Medicine Net*, 2011:2).

2.4.5.3 Diagnosis of Down syndrome

The diagnosis of Down syndrome can be made before birth using one of several diagnostic tests. These tests carry a small risk of miscarriage.

If Down syndrome is suspected after a child is born, a diagnosis can be made via chromosome analysis.

Amniocentesis performed between sixteen and twenty weeks of pregnancy. During this procedure, a thin needle is inserted through the abdominal wall and a small sample of amniotic fluid is taken. The sample is analysed for chromosome anomalies.

Chorionic Villus Sampling (CVS) is done between eleven and twelve weeks of pregnancy. It involves the collection of a chorionic villus cell sample from the placenta either through insertion of a needle in the abdominal wall or through a catheter in the vagina. The chromosomes in CVS are analysed for deviations (*Medicine Net*, 2011:2).

2.4.5.4 Treatment of Down syndrome

Although the genetic cause of Down syndrome is known, there is currently no cure. Owing to advances in technology, scientists are slowly beginning to understand which genes when present in three copies are responsible for which Down syndrome characteristics.

Corrective surgery for heart defects, gastrointestinal irregularities, and other health issues is necessary for some individuals. Regular health check-ups should be scheduled to screen for other conditions such as visual impairment, ear infection, hearing loss, hypothyroidism, obesity, and other medical conditions. Additionally, individuals with Down syndrome should be fully included in family and community life (*Medicine Net*, 2011:3).

Early intervention, for example, stimulating, encouraging, and educating children with Down syndrome from infancy, is very important. Programmes for young children with special needs are offered in many communities. Early intervention programmes, including physical therapy, occupational therapy, and speech therapy can be very helpful.

2.4.5.6 The needs of infants and pre-school children with Down syndrome

Like all children, children with Down syndrome greatly benefit from being able to learn and explore in a safe and supportive environment. Being included in family, community, and pre-school life will help a child with Down syndrome develop to his or her full potential.

While social development and social learning are often quite good, development in other areas such as motor skills, speech, and language are usually delayed. Many children with Down syndrome eventually reach most developmental milestones, but mild to severe learning difficulties will persist throughout life. In general, children with Down syndrome are more prone to illness, and vision and hearing impairments, which can contribute to the child's learning difficulties. Regular health check-ups are very important. Some children may have more severe developmental delays. This could be due to coexisting medical or psychiatric conditions such as seizures, autism, or ADHD (*Medicine Net*, 2011:3).

2.4.6 Fetal alcohol syndrome

This is the last mental disability that will be covered in this chapter. Firstly, a definition of this disability will be provided, followed by explanation of its causes. Further, the prevalence of the number of children affected by this disability will be discussed. Symptoms as well as treatment of FAS will be discussed as well as the care that children with FAS need on a regular basis.

2.4.6.1 Definition

Fetal Alcohol Syndrome (FAS) is a pattern of mental and physical defects that can develop in a foetus when a woman drinks alcohol during pregnancy. Prenatal alcohol exposure is thought to be the most common cause of mental retardation (Nutrition Information Centre, 2011:1)

2.4.6.2 Causes of FAS

The ultimate cause is alcohol intake by the pregnant mother. However, alcohol itself may not be directly responsible for all (or any) of the features of FAS. What may be responsible are by-products generated when the body metabolises ('burns') alcohol. The end result is a decrease in the number of brain cells (neurons), abnormal location of neurons (due to disturbance of their normal migration during fetal development), and gross malformation of the brain (Nutrition Information Centre, 2011:1).

2.4.6.3 Prevalence of FAS in children

In South Africa, FAS-related research has been limited to a few at-risk areas. The experience of paediatricians and medical practitioners in the Western Cape is that FAS is a common diagnosis

and a known cause of mental retardation in the population with mixed ancestry. In the last decade, 1 in 10 referrals to genetics clinics in the Western Cape yielded a FAS diagnosis. The Foundation for Alcohol Related Research (FARR) has reported a steady increase in the prevalence of FAS in school-entry children in the Wellington area of the Western Cape. Prevalence rates in 1997 of 4,8 per cent increased to 7,6 per cent in 1999 and most recent reports from 2001 indicate an alarming prevalence of FAS at 8,8 per cent in this population group. Other studies in Gauteng have reported a prevalence of 2.2 per cent in Soweto, 1.2 per cent in Lenasia and 3.7 per cent in Westbury. Recent research by FARR in De Aar in the Northern Cape revealed a prevalence of 10.2 per cent in this area. The estimates of FAS prevalence elsewhere in the world range from 0.1 to 0.2 per cent in developed countries, to 1 per cent in some Native American Indian populations. Thus, the prevalence of FAS in certain areas of South Africa is the highest reported anywhere in the world. Current data indicates that nearly 1 million adults and children in South Africa are affected by the advanced mental or physical FAS defects. Studies indicate that in high-risk areas, children living in rural areas are at higher risk than urban children (Nutrition Information Centre, 2011:3).

2.4.6.4 Symptoms and signs of FAS

The symptoms and signs of FAS are outlined in the table below. It should be noted that even though the children may have the symptoms and signs stated below, their needs are usually different from other children more severely affected. The table below shows that the impairments resulting from FAS can be of a physical and mental nature, from characteristic facial and bodily features to mental retardation.

Table 2.3: Symptoms and signs of FAS

Symptom	Explanation
Growth is diminished	Birth weight is lessened. Retardation of longitudinal growth is evident on the measurements of length in infancy and of standing height later in childhood. The growth lag is permanent.
Performance is impaired.	The FAS infant is irritable. The older FAS child is hyperactive. Fine motor skills are impaired with weak grasp, poor hand-eye coordination, and tremors
Intelligence is diminished	The average IQ is in the 60s. (This level is considered mild mental retardation and qualifies a child in the U.S. as educable mentally retarded.)
The head is small (microcephalic)	This decrease may not even be apparent to family and friends. It is evident upon comparison of the child's head circumference to that of a normal child on a growth chart. The usual degree of microcephaly in FAS is classified as mild to moderate. It is primarily due to failure of brain growth. The consequences are neither mild nor moderate.
The face is characteristic	The face is characteristic with short eye openings (palpebral fissures), sunken nasal bridge, short nose, flattening of the cheekbones and midface, smoothing and elongation of the ridged area (the philtrum) between the nose and lips, and smooth, thin upper lip.
The skeleton shows characteristic changes	The skeleton shows characteristic changes; abnormal position and function of joints, shortening of the metacarpal bones leading to the fourth and fifth fingers, and shortening of the last bone (the distal phalanx) in the fingers. There is also a small fifth fingernail and a single transverse across the palm.

Source: Nutrition Information Centre (2011:3).

2.4.6.5 Problems particular to children with FAS

With time, FAS children tend to have eye, ear, and dental problems. Myopia (nearsightedness) may develop. Problems with the eustachian tube leading to the middle ear set the stage for ear infections. There is frequent malalignment and malocclusion of the teeth. Children with FAS have enough difficulty in life without the additional burden of not being able to see, hear, and eat normally (Nutrition Information Centre, 2011:4).

Behaviour problems in FAS school-going children include unpredictable extreme mood swings, impulsiveness, diminished judgment, and attention-deficit, lack of normal self-discipline, irresponsibility and difficulty in taking social cues.

2.4.6.6 Fetal Alcohol Syndrome Treatment for Children

(a) Behaviour and education therapy

Behaviour and education therapy can be an important part of treatment for children with FASDs. Although there are many different types of therapy for children with developmental disabilities, only a few have been scientifically tested specifically for children with FASDs. The following are behaviour and education therapies that have been shown to be effective on children with FASDs (Nutrition Information Centre, 2011:6).

- *Friendship training:* Many children with FASDs have a hard time making friends, keeping friends, and socialising with others. Friendship training teaches children with FASDs how to interact with friends, how to enter a group of children already playing, how to arrange and handle in-home play dates, and how to avoid and work out conflicts. A research study found that this type of training could significantly improve children's social skills and reduce problem behaviours (Nutrition Information Centre, 2011:6).
- *Specialised maths tutoring:* A research study found that special teaching methods and tools can help improve maths knowledge and skills in children with FASDs, (Nutrition Information Centre, 2011:7).
- *Parent-child interaction play therapy*: This type of therapy aims to improve parent-child relationships, creates a positive discipline programme, and reduces behaviour problems in children with FASDs. Parents learn new skills from a coach. A research study found significant decrease in parent distress and child behaviour problems (Nutrition Information Centre, 2011:7).Parenting and behaviour management training: The behaviour and learning problems that affect children with FASDs can lead to high levels of stress for the children's parents. This training can improve care-giver comfort, meet family needs, and reduce child problem behaviours (Nutrition Information Centre, 2011:8).

2.5. CONCLUSION

The aim of this chapter was to provide an overview of the physical and mental disabilities of school-going children and the care required. The symptoms, diagnosis, causes, treatment and resulting needs of epilepsy, cerebral palsy, learning disabilities, autism, Down syndrome, and

fetal alcohol syndrome were covered in this chapter. In conclusion, not only did this chapter provide an overview of these disabilities, it also illustrated how complicated and diverse a single disability can be and, consequently, how complicated and diverse the needs of the affected child can be. The following chapter will examine those caring for children with disabilities, particularly mothers, the challenges they face and the needs they have as a consequence.

CHAPTER III: THE CHALLENGES AND RESULTING NEEDS OF MOTHERS CARING FOR THEIR SCHOOL-GOING CHILDREN WITH PHYSICAL OR MENTAL DISABILITIES FROM AN ECOLOGICAL PERSPECTIVE

3.1 INTRODUCTION

Caring for school-going children with mental or physical disabilities can be a challenging experience for the care-givers as a result of the demanding needs of the disabled child. This chapter will identify and explain the needs of mothers caring for their school-going children with physical or mental disabilities. The purpose of this chapter corresponds with the second objective of this research study. The specific problems and challenges experienced by these mothers, as briefly discussed in Chapter I, will be used to identify the specific needs. However, before identifying the challenges, the first section of this chapter will introduce the ecological perspective, which will help to conduct a structured analysis of the experiences of mothers caring for disabled school children in low-income communities. The chapter will then identify the challenges of the mothers caring for these children and their resultant needs. Aspects such as access to medical expertise and care, required knowledge and skills, as well as economic challenges for caring for a school-going child with physical or mental disabilities will be discussed.

3.2 ECOLOGICAL PERSPECTIVE

The ecological perspective is a framework that is used to examine the multiple effects and inter-relatedness of social elements in an environment in which an individual exists (Gregson, 2001: 21), in the context of this thesis – low-income communities. In other words, the function or societal side is made more relevant to people's everyday lives by including the environment in a comprehensive manner. This is related to Johnson and Yanca's (2007:13) explanation that the ecological perspective includes the environment in the change process and encompasses human development, human diversity and social systems theory. According to Klein et al., (1999); Rousseau and House, (1994); an Stokols, (1996), this perspective allows for an examination of

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multiple levels and contexts to establish the big picture in conflict, communication, health or physical activity contexts. Research that focuses on any one level underestimates the effects of other contexts.

Johnson and Yanca (2007:13) add that from an ecological perspective the 'need' is a condition of the relationship between a person or people and the environment. In the context of this research it can be stated that the mothers caring for their school-going children with disabilities and their 'environment', that is, the community, have needs. These mothers' needs – emotional, economic, physical and psychological – are met when the environment responds to the mothers in an appropriate way and the person responds to the environment in a way that satisfies needs in the environment. For example, if the mother is well informed about resources available in her community, these are easily accessible and meet her level of need, it means that the mother's environment, part of which is her child, will be better, because she will be able to support and care for her physically and mentally disabled child better. This is because her needs and those of her child are being met better, the result being that both the need for her support and that of the environment is at peace, resulting in the state of **congruity.** This means that there is agreement or harmony between the mother and the environment (Johnson and Yanca, 2007:13).

Johnson and Yanca (2007:13) continue to explain that unmet needs reflect an imbalance between the responses of the person and the environment to each other. For example, some of the emotional or psychosocial needs of mothers caring for their children with mental or physical disabilities in South African low-income communities are not met because there are insufficient resources available in their communities. This means that the interaction between the mothers and their environment is not balanced in a way that can sustain the needs of either one or both over time. This results in the state of **incongruity**, which represents a lack of agreement or harmony between the person and the environment.

In order to structure an analysis from an ecological perspective the Social Ecological Model (SEM), an approach to understanding development that occurs in various spheres due to actions in different systems, can be a useful tool. SEM describes the relationship between individuals and their environment on several different, but interrelated levels, or systems (Gregson,

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2001:22). These include: micro-systems, meso-systems, exo-systems and macro-systems. These will be briefly discussed below.

3.2.1 Micro-systems

Microsystems consist of individual or interpersonal features and those aspects of groups that comprise individuals' social identity, include roles that an individual plays (for example, mother, father, sister, brother, child) or characteristics they have in common (Gregson, 2001:22). These interpersonal attributes strongly influence the way in which an individual perceives him/herself. These qualities and factors can be learned, as in membership to a group, but many are ingrained (for example, ethnicity, gender). In the interpersonal sphere, there are also many components of the individual, including psychological and cognitive factors such as personality, knowledge and beliefs (Gregson, 2001:22). The individual in his or her own micro-system is constantly shaped, not only by the environment, but by any encounter with another individual. Examples of micro-systems outside the self also include groups of friends, family, unorganised athletics, or social clubs.

3.2.2 Meso-systems

These are the organisational or institutional factors that shape or structure the environment within which the individual and interpersonal relations occur (Gregson, 2001:23). These aspects can be rules, policies, and acceptable business etiquette within a more formal organisation - examples include schools, companies, churches, and sports teams. Meso-systems are essentially the norm-forming component of a group or organisation, and the individual is an active participant in this group or organisation.

3.2.3 Exo-systems

This refers to the community-level influence, including fairly established norms, standards, and social networks (Gregson, 2001:24). There are likely to be many organisations and interpersonal relationships that compose the community, and this web of organisations and relationships creates the community. The community is larger than the meso-system; however, it is considerably smaller than the respective nation or culture it composes. However, it does not have to be associated with any physical or spatial relationships. Another example could be membership of special

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interest groups or political affiliations. Exo-systems are essentially any settings that affect the individual, although the individual is not required to be an active participant (Bronfenbrenner, 1979:3). The mothers under discussion need to be supported in their communities and by their social networks. This can be done by educating people in the communities about different dis-abilities that children in their community have so that they are knowledgeable and are therefore able to help the mothers with such children and also reduce the communities' stigmatisation and discrimination of the children with disabilities in their communities.

3.2.4 Macro-systems

These are cultural contexts (Bronfenbrenner, 1979:3), not solely geographically or physically, but emotionally and ideologically. Cultural influences are more easily visible than the other in-fluences, mainly due to the magnitude of their impact. Within the macro-system,mothers caring for their physically and mentally disabled school-going children need to receive more economic and practical support from the government and emotional support from the religious group to which they belong.

Consequently it can be stated that applying an ecological perspective during the analysis can add valuable aspects to this research, firstly by emphasising the complexity and interdependence of the relationship between individual and environment, and secondly by allowing for a structured analysis using the different systems in which this relationship must function.

3.3 CHALLENGES FOR MOTHERS AND RESULTING NEEDS

Parenting a child with a disability can involve a range of unusual or atypical care-giving re-quirements distinguishing it from 'normal' care-giving by level of intensity and complexity, as well as the amount and duration of time devoted to care, depending on the kind and severity of the disability (Leiter, Krauss, Anderson, Wells, 2004:382). Considering the ecological perspec-tive, this highlights the mutually reinforcing relationship between the needs of the environment, i.e. the child, and the needs of the mother.

It has been briefly discussed in previous chapters that mothers are more likely to be the main care-givers of their school-going children with mental or physical disabilities. While all mothers,

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parents, and care-givers in general experience certain challenges and difficulties, it was argued in Chapter I and indicated in Chapter II that the mothers in the target group of this study experience different and additional challenges and have to deal with them under different circumstances. These challenges result in certain specific needs for the mothers. Therefore, the purpose of this section is to elaborate upon and discuss these challenges in order to identify specific needs, which will allow for an assessment of the target group's situation in South African low-income communities.

Before going into more detail on the challenges and needs of mothers caring for their mentally or physically disabled children, it has to be pointed out that these challenges and needs differ depending on the specific disability of the child. For example Smith, Hong, Seltzer, Greenberg, Almeida and Bishop (2009:167), explain that parents of children with Autism Spectrum Disorder (ASD) report greater negative impact of having a child with a disability and poor well-being in comparison to mothers of children with other developmental disorders such as cerebral palsy. Another aspect is that these mothers have less time for personal care in comparison with mothers of children without disabilities. Another example can be seen in Foster, Kozachek, Stern and Elsea's (2009:187-188) study, which explains that the psychological, physical and emotional well-being of care-givers of children with Smith-Magenis Syndrome (SMS) is more likely to be negatively affected. This is because it is a complex disorder characterised by numerous challenges such as intellectual disability, speech delay, decreased pain sensitivity, sleep disturbances, hyperactivity, mood disability and self-injury. With these characteristics it is important for the care-giver to be able to readily adapt to these physical and behavioural features as they fit into the typical developmental experiences of all individuals. The characteristics of children with SMS, make the role of the care-giver even more challenging on a daily basis. In their study in the USA Smith, Hong, Seltzer, Greenberg, Almeida and Bishop (2009:167) found that 50 per cent of the mothers who had children with ASD reported significantly more days when they felt fatigued by work intrusions. It was also reported that these mothers spent more of their time caring for their children and doing chores than the mothers who had children with other disabilities or with no disabilities at all (Smith et al., 2009:167). This is also illustrative of the relationship between the environment, (the child), and the individual, (the care-giving mother), and how this relationship, and the needs involved, is affected by changes in the environment's characteristics, that is, the kind and severity of disability.

However, it should be noted that the mothers do not only have negative experiences, but may also have positive experiences, feeling that they benefit from their tasks. In one of the studies by Phelps (2009:29), approximately twenty care-givers reported that their experience with their child's disability (autism) resulted in benefits. They found that their care-giving role allowed them to gain psychological strength, including higher levels of selflessness, greater compassion for others, and a stronger sense of peace during times of uncertainty.

The challenges and resulting needs of mothers discussed in the following section will be grouped into several categories in order to create a clear and concise structure. However, the interdependence of these categories of challenges and needs has to be strongly emphasised. For example, as will be shown below, accessing medical treatment or diagnosis can create or have an aggravating effect on psychological problems of the mothers.

3.3.1 Access to medical expertise and care

Access to medical expertise and care plays a crucial role in the development of children with mental or physical disabilities and consequently the experiences and needs of their mothers. This is true right from the 'beginning', the diagnosis of the disability. Realising that a new-born child is severely disabled, with potentially life-threatening problems, for example, seizures, is often extremely stressful and can instil strong feelings of being overwhelmed and powerless regarding the future in the parents. Here, the 'initial experiences with health professionals have a major, lasting influence on the parents' ability to cope with their child's condition' (Graungaard and Skov, 2006:296). According to Graungaard and Skov (2006) there are several factors which affect parents' satisfaction with the diagnostic process. First is the 'the time lapse between the suspicion of disability and the diagnosis' (Graungaard and Skov, 2006:297). In interviews conducted by these authors the father of a child with an unknown diagnosis said:

'. . . and then a couple of weeks passed where we were in the paediatric ward and nothing happened really. Tests were done, and the situation was put on hold. He was having daily seizures and we did not feel that anything was happening at all' (Graungaard and Skov, 2006:300).

Another father of a child with a late diagnosis said:

'We hoped that if they managed to find out what it is, then it would be possible to do something for him, I believe, we wanted to do something for him – what could we do?' (Graungaard and Skov, 2006:301).

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Girard (2010:3) argues that mental disabilities that are difficult to diagnose also contribute to the mothers' stress levels. This can be due to unanswered questions, trial and error treatment and testing medications for months while the doctors try to reach a diagnosis.

A period of uncertainty between the realisation that something is not 'right' with the child and knowing what is wrong, is often filled with stress, and mixed emotions of hope and despair. The longer this period lasts, possibly after a variety of tests and seeing different experts, the more these feelings intensify and lead to frustration and a mistrust of the doctors.

The second factor identified by the authors, which is closely related to the first, is the certainty of the diagnosis. Graungaard and Skov (2006) found that a certain diagnosis, while it makes parents realise that there is a possibly life-long disability, also makes them aware of the potential of the child, treatment options, hope for and predictability of the future (Graungaard and Skov, 2006:302).

The third factor is rooted in the doctor-parent relationship: the way the doctor conducts tests, treats the child and communicates with and informs the parents. Here, a personal emphatic approach, an individual treatment of the child, open communication of the diagnosis, options and possibility, were identified as needs of the parents (Graungaard and Skov, 2006:305).

Shearn and Todd (2000:116) explain that finding suitable care for disabled children is a struggle. The preferred substitute care arrangement for mothers in the general population is their informal network comprising family, friends, and neighbours. A problem occurs when mothers have lost relatives or have relations who live very far away. In addition, Shearn and Todd (2000:116) found that some felt that other mothers would not want to help because they had their own disabled children to look after or were working themselves.

Some mothers also reported that their husbands were not as involved in caring for their disabled children (Shearn and Todd, 2000:116). The mother's comments revealed both a belief that their husbands lacked the skills and ability to cope with their child's needs and behaviours, and an observation that their husbands were not as willing as other fathers to spend sufficient time with their disabled children. Shearn and Todd (2000:117) conclude that these families may be built around an idealised version of the gendered division of family labour.

Mothers also perceived that their children were more vulnerable to accidents or events which might cause emotional upset or physical injury. In turn they saw themselves as special mothers, owning exclusive competencies to care for their children. These were not seen as typical or natural competencies (Shearn and Todd, 2000:117). Mothers felt that it was difficult to find others in the informal networks who possessed similar competencies to care for their children. In particular, this excluded an important source of support, that of slightly older siblings and older relatives. However, the responsibilities were viewed as too great for older siblings and too demanding for older relatives. While mothers viewed the work they did as having a special 'maternal identity' it was seen as uncoveted work (that is, they believed that others in the informal network, as well as private child care agencies, were unlikely to want to look after their children (Shearn and Todd, 2000:118). This demonstrates powerfully the effect of interactions between the environment and the individual in the micro-system.

If mothers felt that their informal networks might not offer adequate resources, it meant there was little adequate support available from services or other organisations, that is, within the meso- and exo-systems. The mothers tended to value the support services they received and the occasional break this provided from having to balance all their child's demands simultaneously. However, despite the support they received, only one mother stated that she was receiving enough support to noticeably reduce the demands of caring for her disabled child (Shearn and Todd, 2000:118). This means that the support that was provided was inadequate for encouraging participation in non-parental activities, in this instance maternal employment. For example, flexicare and respite care were not provided at times, which would support the mother's involvement in employment, such as at the beginning and end of the school day and/or over school holidays (Shearn and Todd, 2000:118).

During interviews in Shearn and Todd's (2000:19) study the mothers were asked whether they felt that service providers were aware that they wished to work. Most said that they did not discuss this at all. They felt it would be pointless since resources were limited and were currently not even managing to successfully achieve their current goal of lessening the load of caring. Some had already engaged in battles with social services to obtain respite services. The difficulties they had encountered strengthened their perceptions that requesting any additional support

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would be futile. Importantly, some respondents also felt that service providers would disapprove if they were to request support that could be interpreted as 'selfish'.

Cichon (2004:39) found that in the USA parents seeking treatment for a mentally disabled child are also faced with a nation-wide shortage of accessible community-based mental health services. Private services are available, but are often cost prohibitive. While third-party health insurance generally provides coverage for limited periods of inpatient mental health, community-based care is often not covered or is discouraged by high deductibles and maximum dollar limits (Cichon, 2004: 40). In the public sector, limited community services are provided by child-serving agencies in a haphazard and fragmented fashion. Parents are often transferred from agency to agency and find this uncoordinated system virtually impossible to navigate (Cichon, 2004:41). In a desperate attempt to obtain services, parents often take drastic measures. Insured parents may resort to private psychiatric hospitalisation or residential treatment even though their child does not suffer from the type of serious mental illness that traditionally has justified such care. Tragically, other parents relinquish legal custody of their children to the state to obtain public-funded services (Cichon, 2004: 41).

In his study Cichon (2004:43) also found that some mothers had negative experiences of using existing service support and did not feel that they would be able to rely on it to provide an acceptable standard of care so that they could work. Some claimed that services could be unreliable since domiciliary workers sometimes did not turn up as arranged and could not cope at other times. Many women also felt that such workers lacked the skills to care for their child because they were changed so frequently that they did not develop expert knowledge about the child's specific needs. Finally, the mothers also pointed out that there was a lack of private child care agencies that had staff trained to deal with their child and that the cost of specialist care for children with special needs was prohibitive, reflecting the special and extensive care these children required.

Several needs of mothers, and parents in general, can be deduced from this section: (1) access to qualified doctors (2) a short time lapse between the realisation of a problem and diagnosis; (3) certainty of diagnosis; (4) personal, emphatic approach by the doctor; (5) individual treatment of

the child; and (6) open communication of the diagnosis, options and possibilities. These needs, to achieve some level of congruity lie in the micro-, meso- and exo-systems.

3.3.2 Required knowledge and skills

Caring for a child with disability often requires specialised knowledge, extensive collaboration with health professionals, and the acquisition of skills by parents that are usually associated with professional health care work (Leiter et al., 2004:382). Most mothers feel that they have to perform complicated tasks, such as administering complex medical treatments and attending numerous medical appointments with their child. Mothers' involvement with a range of social, educational and health service professionals and agencies as a consequence of their child's disability itself creates the need for specific knowledge (Shearn and Todd, 2000:115). For example, the primary care-givers of children who are technology-dependent may be required to learn a great deal of medical information and technology.

The needs deduced from this section are a continuation of and overlap with the previously identified needs: (1) access to sound and understandable information; (2) access to advice, support and training by medical practitioners and agencies; and (3) access to necessary equipment. These needs can be seen to reside within the meso-system level, referring to the services available directly in the community, but also in the macro-system, the national environment, which, of course, are interdependent.

3.3.3 Economic challenges

Chronic mental or physical disabilities in children can impose substantial private costs on families. The costs of special medical care, therapeutic and educational services, transportation, and other special needs services can constitute a particularly heavy burden (Lukemeyer, Meyers, Smeeding, 2000:399; Vecchio, Cybinski, Stevens, 2008:784). For example, a research study carried out in the US reported that 40 per cent of families of children with special health care needs experience a financial burden due to their child's condition (Anderson, Dumont, Jacobs and Azzaria, 2007:4). Regardless of the nature of the disability, a severely disabled child will cost parents at least three times as much as a child who is not disabled and these costs are often long-term, even life-long costs (Kagan, Lewis, Heaton and Cranshaw, 199:370-371).

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Lukemeyer et al. (2000:400) use what they call the Human Capital Approach to describe and analyse the economic impact of caring for children with chronic disabilities and illnesses. This model assumes that the care imposes both direct and indirect costs on families.

3.3.3.1 Direct costs

Direct costs include medical and rehabilitative or restorative services, the cost of hospitalisation, home health care and special equipment. These direct costs can strongly increase the risk of families sliding into poverty. In their study, Lukemeyer et al. (2000:405) found that 12.5 per cent of families reported at least one major expenditure, of over $100, in the months between the two waves of the study. Medical care such as tests, hospital stays or therapies, as well as special equipment, such as wheelchairs or braces, were the most common reason for major expenditure (Lukemeyer et al., 2000:405). The effect these costs have on families with disabled children is also strongly dependent on the availability of health insurance and similar state measures, for example, social grants. Lukemeyer et al. (2000:407) indicate that at least 10 per cent of families of children with disabilities in the United States have no form of health insurance coverage. Thus, out-of-pocket expenditure is likely to be higher. It is also indicated that higher income families make larger out-of-pocket expenditures on behalf of their children with disabilities. This suggests that lower income families are not able to meet all the needs of their children with disabilities.

3.3.3.2 Indirect costs

Indirect costs can result from the loss of productive output by the care-giver, such as loss of earning (leaving work), related to increases in the extent and intensity of care-giving responsibilities. Approximately 32 per cent of the mothers in one study reported that special care responsibilities limited their ability to work, and 19 per cent reported that special care responsibilities prevented them from working at all (Lukemeyer et al., 2000:406-407).

The growth in the number of single parent households, as well as the economic need for two incomes in two-parent families, aggravates the impact of these costs. The employment situation can further exacerbate the risk of sliding into poverty. For example, one third of the mothers in a study reported that they quit employment to take care of a child at home, with only 37.1 per cent remaining employed outside the home, compared with 69 per cent of comparison group mothers.

Single care-takers were fifteen times more likely to quit employment compared with mothers in two-parent families (Thyen, Kuhlthau and Perrin, 1999:1235). For most mothers in a study by Yantzi et al. (2008:302), involvement in employment was restricted to a few hours a day, often in low-paid, low-skilled jobs, such as being a supervisor of school-going children during dinner hours.

Most mothers selected these jobs because it allowed them to be with their children outside school hours. They also reported that their employers were sympathetic to their extra child-care responsibilities, and allowed them time off to collect their children in the case of illness, injury or when they had a medical appointment. In other words, mothers selected jobs that suited their demands at home and their caring role (Shearn and Todd, 2000:121).

According to Ceglowski et al. (2009: 498), the existence and severity of a child's mental or physical disability plays an important role in making work-related decisions for about one-third of the families, especially the mothers.

Another aspect that Ceglowski et al. (2009: 498) highlight is that mothers with school-going children with disabilities, when working with professionals providing services for their children, are hesitant to bring up their own desires to work or their feelings of isolation. Fearing the professionals' judgement of their mothering or questioning their motivation for advocating for their children, they remain quiet. According to Glendinning (1992: 19), mothers of children with disabilities are confined throughout their working lives to the unsatisfactory employment conditions experienced by mothers of very young children. For the overwhelming majority of mothers with disabled children, this situation is undesirable and incompatible with their personal aspirations.

All these issues, including the inability to work in order to provide full-time care for their disabled child, as well as resulting issues, are strongly exacerbated by an already precarious economic situation of the family, or mother, in, for example, low-income communities. These issues, which are of particular interest in the context of this study, will be discussed in a separate section in this chapter.

The primary need of mothers caring for their mentally or physically disabled school-going children that can be deduced from this section, is the need for economic, or material, resources. Depending on the existing economic circumstance of the parents, these might not be sufficient, re-

sulting in the need for material support, for example, in the form of health insurance and government grants. Consequently, the nature of these economic needs and hence their congruity, or incongruity, with the environment is affected by the conditions in all system levels of which the individual mother is a part.

3.3.4 Social and cultural challenges

This section aims to group challenges that arise from the social and/or cultural environment.

The social and cultural challenges for mothers in this study can be wide-ranging. Firstly, due to their culture and/or social environment, from micro- to macro-system, they may define disability differently to the professionals, and this may create problems in accessing suitable support services. For example, a mother might prefer her child to be regarded as learning disabled, as the term generally reflects the notion of an impairment that is specific, rather than global in nature, and is therefore less stigmatising to the image of the child as a whole person (Harry, 1992:27).

Moreover, mothers may deny or fail to accept the actual definition of the disability of the child as they may feel that they are being labelled or may blame themselves for their child's disability. However, clinging to unrealistic definitions of the child's disability may result in negative effects.

Mothers may also be influenced by the terminology they perceive to be negative. For example, as Harry (1992:28) further explains, mothers of children labelled learning disabled estimated their child's status to be lower than the ratings actually given by the children themselves. This may be because of the mother's perceptions of social judgements. Using the work of Kaufman (1982), Harry (1992:28) explains that mothers were offended when professionals labelled their children as mentally retarded rather than developmentally delayed. Harry (1992:29) further explains in one study by Mercer (1972) that in a report of interviews, Black and Hispanic parents explicitly rejected the label given to their children. For example, the term handicap may mean many things. One of the mothers in the study rejected the label 'handicapped' given to her child as in her Puerto Rican culture and low-income community this word is understood as 'crazy'. The mother explained that the label retarded or handicapped would only be applied to someone whose competence is severely impaired or who is considered mentally deranged.

These difficulties with perceptions of disabilities are often closely related to cultural stigma. Literature shows that parents who have children with disabilities experience different levels of rejection by family, friends and the community. Some feel discriminated against. A study by Schall (2000:417) found that mothers experienced subtle and sometimes overt judgement by family members, friends and strangers about their competence as parents. This may also add to the reason for mothers´ refusal to accept the actual definition of their child's disability (Schall, 2000:417). As discussed in the first chapter of this research, children with disabilities are often viewed as crazy in African communities, especially in low-income communities. This can be due to a lack of education or lack of knowledge with regard to the disabilities. As a result, families that have children with disabilities are more likely to be isolated and excluded in these communities. This argument is supported by Office (2011:4), who uses the work of Silwimba (1992) to explain that in African communities, disability is often perceived as a punishment from God. Consequently, a family member (usually the mother) may hide the disabled child from the public in order to avoid being judged, or discriminated against by people in the community. The author of this thesis has personally experienced this scenario, where she observed a mother hiding her child in the house at all times because he had a physical and mental disability. Furthermore, she did not send the child to school, as she thought people would not understand her child's disability and feared that he would be rejected by the people in the community and by his peers. In some cases, families are also accused of being the cause of the child's disability and they may be accused of witchcraft.

Furthermore, literature from Cichon (2004: 40) suggests that mothers of children with disabilities face many obstacles when seeking mental health services for their children. They are usually discouraged by the stigma and prejudice, and discrimination associated with mental health problems. A study (Cichon 2004:40) of parents whose children had mental disabilities revealed that approximately 50 per cent of respondents felt they were blamed by mental health professionals, school personnel and other care providers for their child's emotional problems, lack of treatment progress and academic difficulties. These parents often feel shunned by and isolated from their communities and the family is blamed (Cichon, 2004:40). This is supported by a study by Simeonsson (2008:21) in which he reports that most mothers are not pleased with their neighbours' and communities' reactions towards them for having a disabled child.

Additionally, these mothers often find that they have deprived themselves of their own basic personal needs, such as an adequate night's sleep or making the time for proper nutrition. Their social activities are also limited as they have to dedicate all their time and energy to caring for their disabled child. This may also result in difficulties in maintaining friendships or careers (Koshti-Richman, 2009:19).

The parents' challenges explained above are similar in other cultures, for example, the Japanese culture, in the context of family-professional relationships. By challenging teachers concerning, for example, the proper treatment of the child, parents go against Japanese hierarchism. As a result, mothers are left with the anxiety that teachers may not properly care for their children once the parents become critical of them. Therefore, mothers need someone who can provide support to speak up for them without consequences, a school social worker, for example, may be an appropriate person to act as a liaison between parents and educational personnel (Kayama, 2010:117).

The challenges described here suggest several needs of the mothers: (1) proper information about the disability, including cause, treatment and progress; (2) medical, social work and teaching personnel aware of the cultural and social environment of the patient and family; (3) awareness-raising in communities to reduce stigma and discrimination.

3.3.5 Mental and physical well-being of the care-giver

During the course of this chapter it has become clear that caring for a disabled child can be an extremely stressful and time-consuming job. Sleep deprivation and stress are common experiences for the care-giver (Girard, 2010:1). Studies, for example, by Byrne et al. (2009:69), have found that the mental health of mothers caring for disabled children was found to be much poorer than those of mothers of children without disabilities. Many parents caring for mentally and physically disabled children experience more stress than those without children with disabilities. This stress can be both physical and psychological (Girard, 2010:1).

As discussed before, parents of children with disabilities are often subjected to economic challenges, medical challenges, social and cultural challenges and care-taking demands, resulting in stress or other psychological symptoms, and these stressors can affect all family members. These challenges can persist throughout the child's life span (Floyd and Gallagher, 1997) and may also

increase over time (Dyson, 1993), due to the continued persistence of the stressors (Saunders, 2003), as the care demands of children with mental or physical disabilities also require continuous adaptation by the mothers to ongoing stressors of frequent crises.

The stress can stem from the discrepancy between the child's physical size and developmental capacity and that of other children, the visibility of the disability, an educational placement, difficulty in maintaining babysitters and respite care providers and stigmatisation from the people in the community (Girard, 2010:12). While these children develop, parents are often confronted with an increase in child management that leads to further psychological and emotional draining (Girard, 2010:2).

In addition to psychological problems resulting from these challenges, there are several other challenges associated with caring for a disabled child. Amongst others, parents of children with mental disabilities may also experience grief, self-blame, isolation, helplessness and hopelessness. Psychological distress (anxiety, depression and insomnia) has been reported to be twice as high for parental care-givers of children with disabilities (Girard, 2010:4). The mental burden is related to care-giving responsibilities and is the result of dealing with disruptive behaviours and providing emotional assistance (Girard, 2010:12). Mothers of children with physical or mental disabilities are at risk of emotional difficulties, especially those who believe that they are somehow responsible for their child's disability (Ferguson, 2002). According to Akerlof and Kranton (2000) the 'identity' is central to how people feel they should behave, leading in some cases to behaviour that might be viewed as self-destructive. In a Canadian study it was found that 63.6 per cent of Canadian women believed that it was a parents' responsibility to sacrifice their own well-being for their disabled children, in other words, to put their child's needs ahead of their own (Burton, Lethbridge and Phipps, 2008:360). This may include sacrificing leisure time, or resting and socialising, which may negatively impact their health, especially over a long period of time.

The well-being of the mothers is also directly negatively affected if they feel guilt about not living up to idealised norms about being a 'good mother' who provides her child with a happy, normal childhood. It is argued that mothers may blame themselves for their child's problems and have their identities threatened by the illness and disability of the child. This may also lead to

anxiety about the child's current condition and future prospects (Burton, Lethbridge and Phipps, 2008:361).

Furthermore, caring for a child with mental or physical disabilities may result in compassion fatigue in the mothers. According to Figley (1995:10) compassion fatigue is defined as a state of exhaustion and dysfunction within biological, psychological and social domains as a result of a deep feeling of sympathy and sorrow for another who is suffering, which is accompanied by a strong desire to alleviate their pain and remove its cause. Compassion fatigue can result from prolonged exposure to compassion stress due to lack of relief from responsibility burdens and inability to decrease the compassion stress, which creates a disruption or change in a person's functioning or lifestyle (Figley,1995:11). There are three content domains of symptoms associ-ated with compassion fatigue and these include: re-experiencing another's traumatic event, avoiding/numbing of reminders of stressors; and persisting arousal (Figley, 1995:13). In his 2002 report Figley (2000:13) points out that compassion fatigue is associated with a sense of helpless-ness, confusion, isolation from family and friends; and is often triggered by others' adverse ex-periences. Additional symptoms associated with compassion fatigue are: hyper-arousal, sleep disturbances, concentration difficulties, agitation, irritability, hyper-vigilance, distress and physiological reactions to reminders of another's adverse experience, a decrease in pleasurable activities and contagion. These emotions may result in one distancing oneself from others or emotional withdrawal, leading to increased stress levels (Figley, 2000:17).

The term moral proscription describes a situation where a mother with a disabled child feels that she has to sacrifice her own needs and desires to that of her family in order to fulfil her role of the 'good mother'. Many mothers reported that they experience guilt and anxiety about leaving their children in the care of others. However, the mothers' judgements about vulnerability of their children, the nature of their impairments and lack of suitable support, heightened the sense that only their care was adequate. As described previously, their special identity as a 'good mother' brought them special responsibilities. These responsibilities, as well as limiting the depth of their support networks, brought deeply rooted anxiety (Shearn and Todd, 2000:119).

According Foster, Kozachek, Stern and Elsea (2009:187), the psychological, physical and emo-tional well-being of these mothers can be positively improved by seeking support from profes-

sionals or relatives/friends (informal support). For example, the 87.8 per cent of mothers who were sole care-givers reported moderate to high levels of anxiety. Therefore formal or informal support may help in improving these mothers' well-being. The study by Foster et al. (2009:187) found that mothers who received counselling and support in their caring role reported improvement in their well-being. Therefore, support needs to be provided to these mothers on different levels, formal and informal, as one of the most important aspects of care-giving is for the care-giver to take care of her- or himself (Foster et al., 2009:188). All the challenges mentioned above can not only affect the psychological well-being of the mother, but also negatively affect the physical well-being of the mother.

In addition to other psychological problems incurred through stress, these mothers have specific emotional needs, as can be seen from this section. The primary need is the need for emotional support, as these mothers provide extensive emotional support for their disabled children and this results in the mothers being drained emotionally (Smith, Hong, et al., 2009:167). Emotional support has to be both formal and informal in order to assure the emotional well-being of the mother, the child and the family. Consequently, a number of secondary needs can be identified: (1) 'someone to turn to', (2) support groups; (3) counselling; (4) inclusion in social support networks. While these needs are most apparent in the micro-system, they are still affected by the other system-levels and reflect back on them.

3.3.6 Resulting needs of mothers

In the course of this chapter, seventeen needs of mothers caring for their disabled children have been identified: these can be categorised using the table below, in four broader categories.

Table 3.1 Needs of mothers with disabled school-going children

Access needs
- access to qualified doctors - a short time lapse between the realisation of a problem and diagnosis - certainty of the diagnosis - personal, emphatic approach by the doctor - an individual treatment of the child - open communication of the diagnosis, options and possibility - access to sound and understandable information - access to advice, support and training by medical practitioners and agencies - access to necessary equipment.
Economic needs
- economic, or material resources (Depending on the existing economic circumstance of the parents, these might not be sufficient, resulting in the need for material support, e.g. in the form of health insurance, government grants, etc.)
Social and cultural needs
- proper information about the disability, including cause, treatment and progress - medical, social work and teaching personnel aware of cultural and social environment of patient and family - awareness-raising in communities to lessen stigma and discrimination.
Mental/psychological needs
- 'someone to turn to' - support groups - counselling - inclusion in social support networks.

3.3.7 Socio-economic circumstances in low-income communities as an aggravating factor

As this thesis aims to investigate the experiences of mothers of school-going children with mental or physical disabilities from an ecological perspective, emphasizing the environmental context of the care-giver, this section will briefly discuss how these challenges and needs are influenced by the socio-economic environment of a low-income community, which corresponds with the meso-system and, in part, the exo-system.

Firstly, it is quite obvious that a low-income environment can make it harder to cover the direct economic costs described earlier, from transport to medical costs (Koshti-Richman, 2009:21). Additionally, literature indicates an association between low income and children with special needs, associations that might go both ways (Anderson, Dumont, Jacobs and Azzaria, 2007:4). In other words, not only can having to care for a disabled child lead to a lower income, but children with disabilities are often born into low-income families. Many families of children with disabilities in the United Kingdom live in poverty or in its margins. Recent government reports place

around 55 per cent of families with children with disabilities in a low-income category (Blackburn and Read, 2005:508).

Lukemeyer et al. (2000:400) extrapolate that children in low-income communities are more likely to suffer chronic illness and disabilities than those in middle class or higher class communities. It is estimated that children in low-income communities face a 40 per cent higher risk of being disabled. Lukemeyer et al.'s (2000) literature shows that poverty can be a cause of disability due to malnutrition, lack of safe shelter, lack of access to basic health services, and crime. Many of the causes of disability among children are linked to the manifestations of poverty.

According to Guthrie (2001:24) the majority of single mothers with disabled children lack the income to provide for their children, and live in underdeveloped areas with little infrastructure. The disability is further compounded due to lack of services and necessary intervention – many children become disabled through diseases that are preventable.

Guthrie (2001:24) further explains that in a recent survey with regard to children and disabilities, it was found that most children suffering from malnutrition and ill health live in rural areas, and that 75.2 per cent of all children living below the poverty line are based in rural areas. It is therefore clear that the relationship between poverty and disability is not only caused by the lack of sustainable and sufficient financial income, but also by the educational, social, political and economic exclusion of people with disabilities.

Disability causes and deepens poverty within families and communities due to high unemployment, lack of appropriate education provisioning, the additional costs attached to disability, disempowerment and negative attitudes (Guthrie, 2001:21). It is also argued that poverty is closely linked to disempowerment, and it is when looking at the causes of the high levels of disempowerment found among people with disabilities, that one starts to understand the relationship between poverty, disability and exclusion better (Guthrie, 2001: 22). Moreover, families who care for a child with a disability are more likely to be single-income families with lower quality jobs yielding lower incomes, more likely to live in poor housing and in poverty (Anderson, Dumont, Jacobs and Azzaria, 2007:4). Additionally, the number of single mothers is often higher in low-income communities. Furthermore, according to Leiter et al. (2004:383), associations between

having a child with special needs and the mother's employment situation are particularly high in low-income families, further exacerbating the economic situation of the care-giver.

As shown at the beginning of this chapter, the needs of mothers start with the diagnostic process of the disability, depending on access to and availability of qualified doctors, which is often more difficult in low-income communities. Consequently, under-diagnosis of physically or mentally disabled children as a result of a lack of resources/specialists creates psychological challenges due to a lack of answers regarding the disorder's biological etiology, is not an uncommon problem in low-income communities (Phelps, 2009:29). This researcher's own experience indicates that under-diagnosis of children with disabilities makes it difficult for the mother to seek appropriate medication or resources for her disabled child and also increases stigmatisation of the child and the mother (Kayama, 2011:118). Subsequently, it is safe to say that poor availability of qualified doctors within the community can add to existing challenges and create additional challenges throughout the life of the child (Koshti-Richman, 2009:21). Many mothers who have children with mental or physical disabilities living in low-income communities are not successful in finding safe and affordable child care programmes to address the child's and family's needs (Ceglowski et al., 2009: 497-498).

Not only is the need for access to medical expertise and care more difficult to fulfil in low-income communities, but, in countries such as South Africa, with a high number of low-income communities, very few social (formal and informal) support services for children with physical or mental disabilities are available. This places further strain on the mothers, as they cannot gain access to the resources that may be needed for their disabled school-going child. Wickman-Seal (1992:9) explains that while some limited resources may be available in low-income communities, these might be insufficient to cater for the needs of the child and the mother. Additionally, even if resources are available, parents might be unaware of their availability or of how to access them. Therefore, school-going children with disabilities living in low-income communities are very likely to receive full-time care from their mothers, due to limited or no support at all from either family members or the outside (Wickham-Seal, 1992:6).

In the same way as the challenges of access to medical expertise, treatment, care, formal and informal support are exacerbated by a low-income environment, the risk of psychological prob-

lems, such as high levels of stress, increases, as the mothers constantly have to chase, challenge and struggle with services to ensure that their child receives a manageable and safe level of care, in addition to ensuring daily survival in poverty (Koshti-Richman, 2009:19).

Concluding this section, it is fair to say that while many challenges are the same for all economic backgrounds, low income can have a magnifying and protracting effect on problems and dilemmas typically faced by mothers with physically and mentally disabled children (Read, 1991: 562). Hence, mothers caring for their school-going disabled children living under such precarious circumstances are much more vulnerable to the resulting challenges.

3.4 CONCLUSION

The aim of this chapter was to analyse the challenges faced by mothers caring for their disabled children in order to identify their needs from an ecological perspective. The ecological perspective taken here highlighted how the environment, on different system-levels, influences these challenges and resulting needs of the mothers and how these in turn can affect the environment, emphasizing the importance for congruity between the environment and the individual. The way in which the socio-economic environment in low-income communities can aggravate the challenges faced by these mothers was also clarified. The identified seventeen needs will be used for the empirical study to develop a questionnaire to explore and analyse the experiences of the target group of this study.

The next chapter provides the necessary background to the situation in South Africa with regard to the socio-economic circumstances, as well as the legal situation and available formal support, for example, grants.

CHAPTER IV: MEETING THE NEEDS OF MOTHERS CARING FOR THEIR SCHOOL-GOING CHILDREN WITH PHYSICAL OR MENTAL DISABILITIES: AN ECOLOGICAL PERSPECTIVE

4.1 INTRODUCTION

This chapter focuses on describing how the needs of mothers caring for their school-going children with physical or mental disabilities identified in the previous chapters can be met in general, as well as within the South African context. The chapter corresponds with the third objective of this study.

It was shown in the previous chapter that mothers caring for their school-going children with disabilities face a number of challenges, particularly in low-income communities, and that these challenges result in specific needs, as identified in Chapter III. This chapter will therefore take the previously discussed needs of mothers caring for their disabled children, discuss how these needs can be met and place them in the South African context. Firstly, the socio-economic circumstances in South Africa, the macro-system, particularly the prevalence of poverty, will be briefly described, before looking at the prevalence of disability in South Africa. Secondly, the formal support available in South Africa, corresponding to the meso-system of the ecological perspective, will be assessed by, among other aspects, looking at the existing legislation and its implementation. Thirdly, the importance of certain coping strategies and moderating factors, as well as informal support opportunities (micro- and exo-system) within communities and families will be discussed. Lastly, the needs identified in Chapter III will be used to assess whether these are being met by the formal support available in South Africa.

4.2 POVERTY IN SOUTH AFRICA

South Africa is characterised by extremes of wealth and inequality. Classified as a middle-income developing country, it is home to 'two nations': a small number of very wealthy people and a large number of very poor people (Dube, 2005:16). Despite this wealth, the experience of most South African households is of outright poverty or of continuing vulnerability to being

poor. In addition, the distribution of income and wealth in South Africa is among the most un-equal in the world, meaning that the rich are getting richer and the poor are getting even poorer. Many households still have unsatisfactory access to education, health care, energy and clean water. Approximately one third of all South African households (35.2 per cent, amounting to 18 million people) are living in poverty. Of these, African households and households in rural areas, particularly rural households headed by women and those with children with disabilities are the worst affected. Over half (54 per cent) of all South African children live in poverty (Dube, 2005:17-18). Extreme inequality in the distribution of income exists among racial groups and households. The poorest 40 per cent of households in South Africa earn less than 6 per cent of the total national income, while the richest 10 per cent earn more than half of the national income. It can therefore be stated that although South Africa has undergone a dramatic economic, social, and political transition in the past decade, many of the distortions and dynamics introduced by apartheid continue to reproduce poverty and perpetuate inequality (Dube, 2005:18) in the macro-system.

In March 1995, South Africa joined the nations of the world in pledging to work towards the eradication of poverty at the World Summit for Social Development in Copenhagen (Dube, 2005:19, 15). According to Lombard (2008:156) the Bill of Rights of the South African new Constitution, Act 108 of (1996) was especially important because it extended basic human rights to all citizens for the first time in the history of South Africa. It gave all people the right to vote, and outlawed unfair discrimination against any person on a number of grounds. The Constitution, Act 108 of (1996) also provided for the creation of equity among all people in the country, by recognising the need to implement specific measures that would address the disadvantages that particular groups of people had experienced in the past. These provisions have since provided the basis for important legislative and policy changes (Lombard, 2008: 156). Referring to the South African Constitution, Act 108 of (1996), Dube (2005:15) explains that one of the grounds on which unfair discrimination may take place is on the basis of disability. In this way, it acknowledges that disabled people have in the past, and may continue to be, discriminated against because of their disability. The inclusion of disability in the South African Constitution, Act 108 of (1996) in this way means that disability has become an important consideration in the new legislation, and in policy documents that make up South Africa's legal and policy framework. The inclusion of disability in the Constitution, Act 108 of (1996) has impacted, either di-

rectly or indirectly, on the lives of disabled people in South Africa, and has created opportunities to address inequalities experienced in the past (Lombard, 2008:160). The new constitutional framework also marked an important milestone in the struggle of disabled people to overcome their previous exclusion from mainstream society. As an 'historical moment' in the history of the disability rights movement in South Africa, the Constitution's (1996) recognition of disability reflects the struggle of disabled people to be treated equally to all other people (Dube, 2005: 15-16).

Consequently, it can be stated that South Africa, the macro-system in which the target group of this study lives, is a middle-income developing country, but one of the most unequal societies in the world, with a large population living under precarious economic circumstances and many low-income communities.

4.3 PREVALENCE OF DISABILITY IN SOUTH AFRICA

Very few reliable statistics exist on the prevalence and nature of disability in South Africa, largely due to a historical failure to integrate disability into mainstream government statistical processes (Guthrie, 2001:14). Dube (1992:2) holds similar views on the prevalence of disability in South Africa, as he provides evidence that indicates that the available statistical data on the prevalence of disability in South Africa is not comprehensive or accurate. It is estimated that the number of persons with disabilities in South Africa varies from 5.9 per cent to 12 per cent. The 2001 census found that the total number of disabled people had decreased between 1996 and 2001. Stats SA recorded 2,657,714 disabled people in 1996 compared to 2,255,973 in 2001. This decrease might reflect the sampling methods used, or the fact that there is widespread confusion on the definition of disability, or other factors. This is supported in literature by Harry (1992:27).

As indicated in Chapter III, a number of support options are necessary in order to meet the needs of mothers caring for their disabled children. The first to be discussed here are formal support options, starting with the legislation.

4.4 FORMAL SUPPORT

Formal support refers to support that is provided by professionals and organisations. This support may either be free of charge or clients may have to pay. Formal support corresponds with the two first categories of needs identified in the previous chapter: access needs and economic needs. This section will look at the formal support available for the disabled as well as their care-givers, by looking at the rights that have been put in place to influence the support that should be or is provided within the South African context.

4.4.1 International conventions

This section will discuss some of the important international conventions that have an influence on South African legislation and policy. Conventions such as the Universal declaration of Human Rights (1948) and the Convention on the Rights for Children (2005) will be discussed in the following section.

4.4.1.1 The Universal Declaration of Human Rights

The Universal Declaration of Human Rights (UDHR) was adopted by the General Assembly on 10 December 1948. It recognises that the inherent dignity and the equal and inalienable rights of all members of the human family form the foundation of freedom, justice and peace in the world (Trindade, 1948:1).

The rights upheld in the UDHR (1948) state that every individual has the right to life, liberty and security of person. Every person has equality before the law and is entitled without any discrimination to equal protection by the law. The UDHR (1948) also emphasizes that every individual has the right to privacy, freedom of movement and residence. In addition, every individual also has the right to a nationality, to freedom of thought, conscience and religion, as well as the right to take part in the governance of the country. With these rights it can therefore be stated that mothers who care for their school-going children with physical or mental disabilities should also have a right to receive support from professional people. Whether it is formal or informal support, it should be provided to meet their needs. At the same time this support should alleviate them from poverty and unemployment and, most importantly, enhance their well-being and as a result help them to provide effective care for their disabled children (Trindade, 1948:1).

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Within the Human Rights Act, 54 of (1994) as well as in the Constitution of South Africa, Act of 108 of (1996), everyone has the right to work, and to protection against unemployment (Republic of South Africa). According to the White Paper for Social Welfare of 1997 every individual has the right to a standard of living adequate for health and well-being of himself and his family, including food, housing, medical care, social services, and to security in the event of unemployment, sickness, disability, widowhood, old age, or other lack of livelihood in circumstances beyond his control (Republic of South Africa 1997). Here social security and social insurance are viewed as necessary for smoothing the income cycle and as safety nets for the loss of income due to social risks (Pillay, Proudlock, 2000:26).

4.4.1.2 The Convention on the Rights of the Child

The Convention on the Rights of the Child in the Children's Amendment Bill (2006) and the Children's Act 38 of (2005) is the key international legal instrument on children's rights which was signed and ratified by the South African government in 1995 (Lombard, 2008: 158). It incorporates civil and political rights as well as a wide range of social, economic and cultural rights. These include the right to health care, education, and protection from abuse and neglect, equality and non-discrimination, survival and development, privacy, social security and an adequate standard of living. In recognition of the fact that certain groups of children are more vulnerable than others and often find themselves in need of extra protection, the Convention lists a number of vulnerable categories of children, including children with disabilities, and expressly prohibits discrimination against such children (Pillay and Proudlock, 2000:37).

The Convention on the Rights of the Child (2005) encourages the State's role in providing assistance to parents and legal guardians. It recognises that although parents and legal guardians have the primary responsibility for the upbringing of their children, State parties must render appropriate assistance to parents and legal guardians in the performance of these responsibilities. This provision has special significance for children with disabilities, as it obliges the State to assist the parents and care-givers of children with disabilities (Pillay and Proudlock, 2000:37).

The Convention on the Rights of the Child (2005) accords special attention to children with disabilities. It recognises the right of the disabled child to special care and encourages, subject to available resources, assistance appropriate to the child's condition and to the circumstances of the

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parents or others caring for the child. It further recognises that such assistance should be provided free of charge, taking into account the financial resources of the parents or others caring for the child. The Convention on the Rights of the Child (2005) also emphasizes that assistance shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development (Pillay and Proudlock, 2000:38).

For many people with disabilities, their reduced opportunities for education, training and employment contribute to their increased exposure to poverty and poor living conditions. Therefore many adults and children with disabilities require income maintenance mechanisms that compensate for their loss of income and for the extra costs as a result of the disability. Such schemes should also improve their standards of living, while increasing their opportunities for education, training, and health services. Indeed, the United Nations Committee on Economic and Social Rights notes that social security should also promote their full development, equality and participation in society (Guthrie and Sait, 2001: 10).

There is no universal definition of social security. Because social security has to do with protecting the individual against social risks by providing welfare and services to an individual and his/her dependants if they are unable to provide for their own basic needs, it is clear that there is an ideological and political component to the concept. This means that social security systems differ from country to country (Guthrie and Sait, 2001:10-12).

The concept of social security is interpreted differently in different countries, some focusing on coverage for social risks or contingencies, others including the preventative aspects, and thus the definition would depend on the aim of the schemes. According to Moore et al. (1999:7) social security refers to a set of policy instruments that are set up to compensate for the financial consequences of a number of social contingencies or risks. Broader preventative measures would include preventative health care, safety in the workplace, trading and development programmes and so on.

Another aspect of social security is its contribution to solidarity, to stability within communities and countries, where the negative effects of social risk are seen to affect not only the individual but also the whole nation and economy. Thus a society takes measures to protect itself and its individual members from these contingencies. Social security may also be defined as the body of arrangements expressing a society´s solidarity with people who face (the threat of) a lack of earnings (that is, from paid labour) or other extraordinary costs (Guthrie and Sait, 2001: 11-12).

4.4.2 Policy and Legislation in South Africa

This section focuses on explaining the policies and legislation in the South African context, what they entail and their contribution to the support and rights of children with disabilities, as well as their carers.

According to Dube (2005:1) South Africa is one of the countries with the most comprehensive legislation and policy protecting and promoting the rights of disabled people in the world, and disabled people are involved at all levels of government.

The economic cost associated with caring for children with disabilities is thus a policy concern in South Africa, both because the costs are high and because this is an issue for a growing number of families (Burton and Phipps, 2009:270). According to Anderson, Dumont, Jacobs and Azzaria (2007:4), policy can play a key role in supporting families in their care-giving role.

Firstly, the South African Constitution, Act 108 of (1996) prohibits discrimination based on dis-ability and grants the right of access to social security. Section 27(1)(c) of the South African Constitution, Act 108 of (1996) provides that everyone has the right to access to social security, including if they are unable to support themselves and their dependants, and appropriate social assistance. Section 27(2) obliges the State to take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of the right of access to so-cial security (Lombard, 2008: 157).

During the period 1994 to 2004, South African legislation, policies, interventions, and pro-grammes were formulated with the aim of influencing the environment for addressing equity goals over the medium to long term, and also for addressing immediate goals in ensuring that more people with disabilities could access government services (Dube, 2005: 2).

4.4.2.1 Convention on the Rights of the Child (2005)

This section will now discuss the policies and legislations that have been put in place to support children's rights.

The Convention on the Rights of the Child (CRC) (2005) was ratified by the South African Government in 1995, and pertains to all children, including children with disabilities. The CRC (2005) introduced and underlined the concept of children as people with rights, which in turn begun the transformation of public policy from one based on needs to one based on rights. However, its effect on children, particularly children with disabilities has been limited (Guthrie and Sait, 2001:35).

The Disabled Children's Action Group (DICAG) ensures that disabled children are also involved in the National and Provincial Action (NPA). The government has drawn up national and provincial plans of action, using the world goals as guidelines. The NPA has been launched under the Department of Health, involving other departments. Section 28(1) of the South African Constitution, Act 108 of (1996) describes the right of children to basic nutrition, shelter, basic health care services, and social services. Section 28 (2) of the South African Constitution, Act 108 of (1996) goes further and explains that the child's best interests are of paramount importance in every matter concerning the child: this view is also emphasized in the Children's Act 38 of 2005, in which it states that every decision made during intervention should be done in the child's best interest. Section 28 of the South African Constitution, Act 108 of (1996) requires the state to take steps to ensure that children's rights are observed. All of the legislation and the common law in South Africa impose obligations on parents to care for their children in their communities (Guthrie and Sait, 2001: 35).

4.4.2.2 Implementation of policies

Dube (2005:3) explains that the South African national government has been successful in creating an enabling environment for policy development work in the field of disability. He gives examples of some of the achievements linked to the development of new legislation and policy. These include developing and adopting the White Paper on an Integrated National Disability Strategy (1997)*,* known as INDS. It is premised on the social model of disability. The White Paper for Social Welfare (1997) represents a paradigm shift in the conceptualisation of disability

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from the medical or welfare model of disability, which views persons with disabilities as ill, different from their non-disabled peers, unable to be productive and in need of care (Lombard, 2008:168).

The INDS (1997) provides government and society as a whole with guidelines that will promote non-discriminatory development planning, programme implementation, and service delivery (Dube, 2005:17). A recent development at provincial level has been the formulation of a provincial version of the INDS, termed, in some provinces, the Integrated Provincial Disability Strategies (IPDS) (1997). Secondly, it determines employment-equity quotas that apply to the private and public sector regarding the employment of disabled people through the Employment Equity Act (EEA) of 1998. Thirdly, it increases the basic disability grant and the extension of its provisions to a wider sector of people through the Social Assistance Amendment Act 45 of (1994) (Lombard, 2008: 157). The fourth aspect is the introduction of policy on inclusive education through the White Paper on Special Needs Education (1997) *(*Dube, 2005:4). The fifth point is active participation in continental and international initiatives on improving the lives of disabled people, such as the Africa Decade of People with Disabilities, and participating in the development of the United Nations Convention on the Rights of Disabled People (2006) as well as providing free primary health care to disabled people affected by poverty.

Dube (2005:5) continues to argue that while support for the formulation and adoption of policy has been excellent, policy implementation remains a challenge. Of particular note is the fact that there are capacity constraints that limit the effective implementation of policy. Policy implementation issues are not addressed consistently, for various reasons, at different levels of government. These reasons include limited conceptual understanding, poor championing, inadequate or inappropriate institutional arrangements, and a general lack of capacity.

Two other factors that have contributed to the poor implementation of legislation and policies are that the definition and nature of disabled people's participation has not been adequately reviewed and articulated, and that the policy requirements for disability mainstreaming are not adequately linked to performance management, thereby undermining commitment to implementation (Dube, 2005:5). It is also indicated that legislation and policies are not implemented because of a lack of allocated fiscal resources and commitment. A pertinent example is the Policy on Inclusive Edu-

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cation of the White Paper for Social Welfare (1997) that was released in 2001, yet implementation remains fragmented. It can therefore be stated that in areas where successful implementation of legislation has occurred, it has largely been due to political support by the ministers and senior civil servants in charge of departments, or the sustained commitment and ongoing advocacy by the disability sector, led by Disabled People South Africa (DPSA) (Dube, 2005:6).

Literature illustrates that the Government of South Africa has enacted other pieces of legislation relating to disability. These include the following.

4.4.2.3 South African Schools Act 1996

The South African Schools Act of 1996 provides for the inclusion of learners with special educational needs. Public schools are required by law to admit all learners and provide the necessary educational requirements without discrimination. In 1999, the Department of Education published a White Paper entitled 'Special Education: Building an inclusive education and training system'. The White Paper (1997) defines inclusive education and training as:

- acknowledging that all children and young people can learn, and that all children and youth need support
- enabling education structures, systems and learning methodologies to meet the needs of all learners
- acknowledging and respecting differences in learners, whether due to age, gender, ethnicity, language, class, disability, HIV/AIDS or other infectious diseases
- changing attitudes, behaviour, teaching methods, curricula and environment to meet the needs of all learners
- maximising the participation of all learners in the culture and curriculum of educational institutions, and uncovering and minimising barriers to learning (Dube, 1992: 10).

It can therefore be stated that the South African Constitution, Act 108 of (1996), has done well in creating the legislation to allow all children access to education, without being discriminated against. However, even though the South African School Act of 1996 indicates that every child should have equal access to education and inclusive education, many children in low-income communities are still marginalised, as, due to their disabilities, they cannot attend mainstream education because these schools lack resources and teachers who are specially trained to work

with children who have physical or mental disabilities. It is therefore necessary that the Acts that are in place implement programmes that can reach low-income communities to train educators in schools to work with children with disabilities.

4.4.2.4 Library for the Blind Act 91 of 1998

The South African Library for the Blind, founded under Section 1 of the State-Aided Institutions Act, 1931 (Act 23 of 1931), continues to exist as a juristic body, notwithstanding the withdrawal of the notice by this Act. The objective of the Library for the Blind is to provide a national library and information service to serve blind readers and other people whose disability does not enable them to read printed materials in South Africa. The functions of the Library for the Blind are to:

- build a balanced and appropriate collection of South African and other documents for the use of blind and print-handicapped readers
- record its collections appropriately
- provide a bibliographic service to those readers
- provide access to documents nationally and internationally to those readers
- provide library and information services on a national basis to those readers
- co-ordinate and preserve the national audio and Braille literary heritage
- produce documents in special media, such as Braille and audio, as required by users.

The functions must be performed solely in respect of documents for the use of or relating to blind and print-handicapped readers.

Information on the use of the library was not readily available within the time frame of this research. However, the library provides an excellent service to visually-impaired students, including an extensive inter-library loan facility, through which students can obtain material from a wide range of academic disciplines from audio and Braille libraries all over the world (Dube, 1992: 10).

4.4.2.5 The Promotion of Equality and Prevention of Unfair Discrimination Act 2000

This Act deals with the prevention, prohibition and elimination of unfair discrimination, hate speech and harassment. The Act states that neither the state nor any person may unfairly discriminate against any person on the grounds of disability, including:

- denying or removing from any person who has a disability, any supporting or enabling facility necessary for their functioning in society
- contravening the code of practice or regulations of the South African Bureau of Standards that govern environmental accessibility
- failure to eliminate obstacles that unfairly limit or restrict people with disabilities from enjoying equal opportunities or failing to take steps to reasonably accommodate the needs of such people.

It can therefore be stated that the positive policy environment in South Africa presents unique opportunities for disabled people to address issues such as poverty, high levels of unemployment, education of children and young people with disabilities, access to social security and assistive devices, access to housing, public health services and transport (Dube, 2005:12).

The current legislation, in the form of the Employment Equity Act, 55 (1998), Social Assistance Act 13 of (2004), Skills Development Act, 97 of (1998) and Skills Development Levy Act, 9 of (1999) and others, has helped create a new sense of awareness of the needs of disabled people. However, with the exception of a few policies such as the Social Assistance Act, 59 of (1992), the implementation of these policies has had only a marginal impact on the lives of a majority of disabled people in South Africa (Republic of South Africa, 2004).

4.4.2.6 White Paper 6 on Special Needs Education (2001)

According to Guthrie (2001: 30) special needs education is a sector where the ravages of apartheid remain most evident. Here, the segregation of learners on the basis of race was extended to incorporate segregation on the basis of disability. During the Apartheid era, the South African special schools were thus organised according to two segregating criteria: race and disability.

In accordance with apartheid policy, schools that accommodated white disabled learners were extremely well resourced, while the few schools for black disabled learners were under-resourced and disabled learners experienced great difficulty in gaining access to education. Very

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few special schools existed, and they were limited to admitting learners according to rigidly applied categories. This is still the case in today's South African special schools. The special schools in the low-income communities are still under-resourced and lack specialised teachers, which means that the children are not receiving the education and special care they need even though they have the right to health care and to education (Guthrie, 2011:31).

The World Health Organisation has calculated that between 2.2 per cent and 2.6 per cent of learners in any school system could be identified as disabled or impaired. An application of these percentages to the South African school population would project an upper limit of about 400,000 disabled or impaired learners. Current statistics show that, in fact, only about 64,200 learners with disabilities or impairments are accommodated in about 380 special schools. This indicates that, potentially, 280,000 learners with disabilities or impairments are unaccounted for (Guthrie, 2011:31).

The result of decades of segregation and systematic under-resourcing is apparent in the imbalance between special schools that catered exclusively for white disabled learners and those that catered exclusively for black disabled learners. It is, therefore, imperative that the continuing inequalities in the special-schools sector are eradicated, and that the process through which the learner, educator and professional support services populations become representative of the South African population is accelerated (Guthrie, 2001: 31).

The White Paper 6 on Special Needs Education (2001) arose from the need for changes to be made to the provision of education and training to make it responsive and sensitive to the diverse range of learning needs. Education White Paper 1 on Education and Training (1996) acknowledged the importance of providing an effective response to the unsatisfactory educational experiences of learners with special educational needs, including those in mainstream schools whose educational needs were inadequately accommodated (Guthrie, 2001, 33).

Finally, Sipho Gcaza, of the South African Federal Council on Disability (SAFCD), points out that the existing South African legislative framework appears to be progressive and committed to providing social security for all, including persons with disabilities (Guthrie, 2001, 33).

4.4.3 Grants

Grants may be regarded as a form of public assistance or benefits that individuals may receive from the government as they are unable to support themselves. In countries where grants are provided, such as in South Africa, there is a specific criterion used to determine the individual's eligibility to receive the grant and this criterion is known as a *means test* (Kirst-Ashman, 2007:217).

In first world countries such as Canada, provinces offer support benefits for children with disabilities. This support includes services such as speech therapy and educational support such as sign language interpreters or educational assistants. Extra funds for childcare for special needs children, and help with the cost of aids or medication are also provided by the government. The exact amount and form of support available depends on a discretionary assessment of the needs of the particular child and family. This is also referred to as a means test (Burton and Phipps, 2009:271).

In South Africa there are also policies in place in the form of *social security*, in order to reduce poverty through accelerated economic growth and the strengthening of the social security safety net. There are also policies to help those who are unable to provide for themselves (South African Social Security Agency [SASSA], Presentation: 2011:1).

Social security refers to a wide range of public and private measures that provide cash or in-kind benefits, or both (The White Paper for Social Welfare, 1997:48). Social security includes both social insurance and social assistance. Social insurance usually entails private and contributory schemes, such as occupation retirement insurance, while social assistance is state provided and non-contributory (though usually means-tested). Benefits can include cash transfers, vouchers, and subsidies. These will be discussed fully in later sections.

4.4.3.1 Social Assistance Act No 13 (2004)

The Social Assistance Act, 13 (2004) provides for the rendering of social assistance to individuals, national councils and welfare organisations. This Act was amended in 1994 to further regulate the making of grants and financial awards to certain people and bodies. The Welfare Laws Amendment Act (1997) amended the Social Assistance Act (1992) in order to provide for uni-

formity of, equality of access to, and effective regulation of, social assistance throughout South Africa. Secondly, it was amended to introduce the child-support grant (Guthrie, 2001: 32).

The Social Assistance Act, 13 (2004) is probably one of the most talked-about pieces of legislation in South Africa. The Act is administered by the Department of Social Development's social assistance programme and it provides the legislative framework for awarding the disability grant, dependency grant, and grant-in-aid. The disability grant is for adults from the age of eighteen years who are unlikely to find employment because of their disability and have no, or limited, sources of income. The care dependency grant is for disabled children, and the grant-in-aid is for disabled adults who might or might not be receiving a disability grant (SASA Presentation, 2011:33). In addition, the Department of Social Development gives a grant for social relief distress (Guthrie, 2001: 32).

4.4.3.2 Disabled people benefit through disability grants

Lombard (2008:155) extrapolates that social grants have had a positive impact on those who receive them, by reducing their poverty to some extent, and he notes that these grants are developmental in nature.

The number of social grants given by the South African government has increased significantly. While 2,408,742 grants were received in 1996/1997, this number has increased to 13,026,140 grants in 2008/2009, of which 8,765,354 are Child Support Grants. In 2008/2009 the South African Social Security Agency (SASSA) spent R69 billion on social grant disbursement (SASSA, 2009: 4, 5). According to the National Treasury, since 2000/01, spending on disability grants has increased from R4.0 billion (US$0.6 billion) to an estimated R10.3 billion (US$1.5 billion) in 2003/04 – an overall increase of more than R6.3 billion (US$ 0.9 billion) over the period. In all provinces except Northern Cape, where coverage was already exceptionally high at the beginning of the period, disability spending more than or nearly doubled between 2000/01 and 2003/04. Spending grew particularly rapidly in Free State and KwaZulu-Natal (Guthrie, 2001: 33). The SASSA Western Cape statistics (see table below) indicate that the total number of people receiving social grants in this province has increased from 879,371 in 2009 to 1,027,370 in 2010 and to 1,155,772 in 2011, a 37.4 per cent increase over this period.

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Table 4.1: Western Cape Social Grants (2009-2011)

Grant type	April 2009	April 2010	April 2011
Old Age Grant	196,445	211,394	233,680
War Veterans' Grant	377	321	263
Disability Grants	145,118	157,764	159,054
Foster Care	28,180	27,350	28,307
Care Dependency	8,415	9,428	9,966
Child Support Grant	500,782	615,113	724,502
Total	**879,317**	**1,021,370**	**1,155,772**
Grant-in-Aid	7,307	7,347	8,391

Source: SASSA Western Cape Presentation, 2011: 23

The table also shows that the number of disability grants in the Western Cape has grown by 9.6 per cent between 2009 and 2011 and care-dependency grants have increased by 18.4 per cent in the same period.

4.4.3.3 The Care Dependency Grant for Children

In South Africa any parent providing full-time care for any child between the ages of one year and eighteen years who need full-time care because of mental or physical disability, are eligible for a monthly payment from the government called a Care Dependency Grant. The child must need and have permanent home care (Guthrie, 2001: 33). Only carers whose financial situation is below a certain level can get the grant. The test to decide this is called a means test. The means test for the Care Dependency Grant depends on the income of the entire family. The parent may not earn more than R136 800 per year if single. Combined income should not be above R273 600 per year if you are married (SASSA, 2011).

Another criterion for receiving the Care Dependency Grant for the child is that the child must remain in the parent's care, and accommodation, food and clothing, and necessary medical and dental care must be provided by the parent(s). When the child is six years old, the parent has to take the child to be evaluated to determine his or her educability and trainability for attendance at

a school for specialised education. For eligibility of the grant, the child may not be permanently cared for in a state-run psychiatric hospital or care and rehabilitation centre (Guthrie, 2001: 51).

The application process involves two forms. Firstly, the application form is a general form for all people applying for a variety of social assistance grants. Secondly, the medical assessment form is specific to the Care Dependency Grant and must be filled in by a medical officer. In the medical form, the medical officer is asked to state his or her opinion as to whether the child is severely, mildly or not at all disabled. The officer is also asked to state his or her opinion as to whether the child requires permanent home care due to his or her disability. Finally, the medical officer is asked to give a recommendation as to whether the child needs full-time care, part-time care or is able to care for him- or herself (Guthrie, 2001: 52).

4.4.3.4 Benefit

According to Kirst-Ashman (2007:216) a benefit is anything that individuals may receive through a social welfare programme, based on their specific need/problem. These benefits may be provided in two separate categories, namely, cash benefits and in-kind benefits. Cash benefits are those where recipients are given money in cash, whereas for in-kind benefits individuals are not given cash but may be given food products, food stamps or rent subsidies. Parents caring for their physically or mentally disabled child may receive the amount of R1140 per month from April 2011 (South African Government Services, 2011).

4.4.4 Access to medical expertise and care

To improve the level of effective care-giving by mothers of children with mental or physical disabilities, health authorities need to develop awareness, understanding, and education relating to the experiences of the care-givers in the work or home setting, so that these mothers can gain access to the resources and maintain good health while caring for their children (Hu, Lin, Yen, Loh, Hsu and Wu (2010:32-33).

In the South African context treatment services should be child-centred and family–oriented. Services should be provided in accordance with the needs of the individual child and family rather than expecting the child and family to conform to the service system. Services tailored to children may also address underlying family dysfunction contributing to the child's emotional

problems. With appropriate counselling and training, parents and other family members can provide an important source of support and strength for the child (Hu, et al., 2010:32-33).

4.4.5 Access to information and knowledge

According to Blackburn and Read (2005:507) the provision of crucial information to parents of disabled children, at a time when they need it and in a form that they can use it, is an intractable problem. This makes it important to develop new and effective approaches to information presentation, distribution and delivery.

The internet has been suggested as a medium through which families´ needs for information and services can be met. In their study to find out how the parents of disabled children experienced using the internet in the United Kingdom, Blackburn and Read (2005:507) found that 75 per cent had previously used the internet. Of these, 63 per cent were frequent users and 91 per cent were using it at home. Popular users were emailing, obtaining information about caring, ordering equipment and shopping online.

Despite positive benefits, users experienced problems relating to technical issues and equipment and system design. Lack of time due to caring and other circumstances was an issue for half of all the users. Non-users were more likely to be living in rented accommodation, be unemployed or not have a computer at home. Reasons for not using the internet included lack of access to equipment, cost and lack of skill. Therefore information needs to be made available in other forms to ensure that those who cannot or do not have or wish to use the internet are not socially excluded (Blackburn and Read, 2005:507-508).

First world countries such as the United Kingdom have committed themselves to introducing a range of new measures to support carers, including parents of disabled children, and emphasized the importance of making improved information available to them in a variety of forms, including online (Blackburn and Read, 2005:507-508).

In South African low-income communities it is difficult for mothers caring for their disabled children to access information about their child's disability. This is because most of these mothers are living in poverty and may have low-level education and it may be difficult for them to

read the information or use the internet to search for information on the disabilities and the care that they can receive (Stellenbosch Child Welfare Community Profile for Kayamandi:2009:5).

4.4.6 Schools

According to the South African laws stated in the White Paper for Social Welfare (1997), as well as the Child Care Act, 38 (2005), every child, whether disabled or normal, has the right to access education and to be treated equally without being discriminated against (*Capegateway*, 2009:2).

Even though these laws emphasize the right of the disabled children to receive education, schools do not usually provide support to the mothers who care for these children at home. It is often NGOs that provide and organise support groups for these mothers. However, this support is often inadequate, as the mothers are faced with a number of challenges and schools in low-income communities have limited resources for the disabled child. This can lead to mothers not sending their child to school, which of course leads to isolation, as well as not receiving support from the schools, from the teachers or from other mothers who may also have disabled children in the school (Dyson, 1993).

Another aspect is that the South African Schools Act of 1996 provides for the inclusion of learners with special educational needs. Public schools are required by law to admit all learners and provide the necessary educational requirements without discrimination (Dube, 2005:12). This inclusion of all learners in public schools is not realistic in the low-income communities of South Africa. This is because schools in low-income communities do not have trained therapists or teachers who are trained to educate disabled children and they are under-resourced, and this makes it difficult to meet the needs of mothers with disabled children in these communities (Guthrie, 2001:13).

4.4.7 Evaluation of formal support available in South Africa

The Acts and policies discussed in previous sections show that the positive policy environment in South Africa presents unique opportunities for disabled people to address issues such as poverty alleviation, high levels of unemployment, education of children and youth with disabilities, improved access to social security and assistive devices, access to housing, public health services and transport.

Pillay and Proudlock (2000:72) note that in reviewing the social security system and ensuring its compatibility with the South African Constitution (1996) and relevant international law, it is crucial that the key principles noted above underpin the principles, policies and implementation of the system. In particular, it should be noted that although the South African Constitution(1996) provides for the right of access to social security which is subject to the availability of resources and progressive realisation, this right engenders a minimum core obligation on the State to ensure that *at least* minimum essential levels of the right are fulfilled.

Furthermore, international law has reiterated that the needs and rights of *disadvantaged and vulnerable groups such as people with disabilities should be prioritised* in the implementation of this right. It has further stressed that *specially tailored measures* should be taken to meet the needs of people with disabilities and that *additional resources* invariably need to be made available for such purposes. There is also substantial support in international law that there should be an emphasis on persons with disabilities living with their families (Pillay and Proudlock, 2000:72).

The *maintenance of the family unit* is particularly important, in respect of children in general, and specifically children with disabilities for the reasons noted below. This would require that principles of equity, special regard for adults and children with disabilities, emphasis on the family unit, participation by the beneficiaries of the grant, an adequate amount of the grant as well as the proper administration thereof inform the review of the social security system (Pillay and Proudlock, 2000:72).

Yet the South African Constitution(1996) and the White Paper on Welfare (1997) do not complement each other, and thus the implementation of these two pieces of legislation remains the root cause of the problem for people with disabilities. Thus the provision of social security for people with disabilities is always hindered by cost implications for the State, but it remains the prerogative of the government to provide social security, at the end of the day (Pillay and Proudlock, 2000:73).

As can be seen from the description of South African policies and legislation, government policy clearly recognises the need for comprehensive social security, social assistance and social services for persons with disabilities, and it commits the government to provide for this need. The

legislation and regulations on the other hand take a minimalist and uncoordinated approach which does not reflect the policy plans or commitments (Pillay and Proudlock, 2000:73).

At the level of implementation, the laws and policies such as the White Paper 6 on Special Education (2001) and the South African Schools Act of 1996 discussed in the previous sections have experienced many difficulties. The most apparent are the lack of financial and human resources particularly in the form of trained educators. This has meant that children with disabilities are still not fully integrated into the public school system, and this has resulted in their educational needs being left unmet (Pillay and Proudlock, 2000:74).

4.5 COPING STRATEGIES AND MODERATING FACTORS AS SUPPORT

In the previous chapters it has been discussed that mothers caring for their school-going children with mental or physical disabilities may experience stress and challenges as they have to adjust to new roles, different expectations about their child, and cope with significant emotional, social, physical and financial pressures because of their child's disability. It is therefore necessary that these mothers are informed and educated on the *coping strategies* they can utilise in order to manage the challenges that arise from their caring role and therefore provide effective care for their disabled child.

According to Lazars and Folkman (1984:141) coping is defined as constantly changing cognitive and behavioural efforts to manage specific external or internal demands that are appraised as taxing or exceeding the resources of the person. It includes any attempt to manage stress, regardless of how well it works. Coping strategies also involve efforts to alter the cause of the stress (problem-focused coping) and efforts to regulate emotional responses to the stressors (emotional-focused coping). Turnbull and Turnbull (1993:11) define coping strategies as things that people do to increase the sense of well-being in their lives and to avoid being harmed by stressful demands. Literature confirms that mothers with mentally or physically disabled children use a broad range of coping strategies, some of which are more successful in some situations than in others. Another important aspect is that a mother's ability to cope with the stress of caring for a disabled child changes over time (Lundh, 1999:735).

Judge (1998, 263) extrapolates that parents with children with disabilities can use different coping strategies to meet their needs. Parents who use problem-focused coping strategies that emphasize efforts to seek social support, actively solve the problem, and maintain a positive outlook on life tend to cope better than those who do not. Those parents who use emotionally-focused coping strategies when confronting problems by blaming themselves, believing the problem will go away, engaging in activities that prevent confronting an issue, and trying to keep their feelings from others are all evidence of passive appraisal. Judge (1998:263) argues that, although passively reacting to a problem may delay a family's active or immediate response, the use of these coping strategies may negatively impact on a family's sense of mastery or competence in providing care for a disabled child (Judge, 1998:263).

Dunn et al. (2001:39) state that the use of escape-avoidance as a coping strategy has been associated with increased stress and depression, whereas confrontation coping skills have been associated with reduced depression.

Hoare et al., (1998: 218) report that care-givers of children with severe physical or mental disabilities with greater distress and lower self-esteem may focus on using emotion-focused coping strategies more often, which may increase their stress levels. On the other hand, those with greater self-esteem may use more task-focused coping methods, and this may have positive results such as reduced stress and finding the caring role more fulfilling.

Using literature from Folkman et al.'s (1979) study, Savage and Bailey (2004:115) report that one of the main coping resources for mothers caring for school-going children with disabilities is general or specific beliefs. These include a sense of mastery or self-efficacy and religious beliefs. They report that low levels of self-esteem and mastery were associated with increased depression. Therefore enhancing a sense of mastery or self-efficacy empowers mothers and is therefore a particularly sustainable type of support (Savage and Bailey, 2004:115).

The following sections will look at the different coping strategies that mothers caring for their school-going children with mental or physical disabilities may use in order to tackle the negative experiences resulting from their full-time care-giving role.

4.5.1 Stress relief initiatives

Many measures can be used for examining care-giver stressors. Stress experienced by mothers caring for their school-going children with disabilities is affected by many factors, such as the child's condition (level of disability) and the availability of the resources or social support for the mothers (Hu et al*.,* 2010:30).

One of the support service programmes that could be provided for these mothers to alleviate their stress is the *stress relief programme*. This programme, which offers a variety of opportunities for mothers, has been used in different countries, such as Taiwan. The programme allows the mothers to explore the different stress management strategies and relaxation techniques that may meet their individual needs. Its goal is to help mothers remain comfortable and to improve their confidence. It also aims to empower the mothers in dealing with daily stresses, in term of adapting to and coping with the demands of caring for their disabled child (Hu et al., 2010:30).

Hu et al. (2010:30) state that one of the activities that may be included in this programme is a stress management workshop (lasting at least two hours) during which mothers receive booklets on how to deal with their stress. This booklet includes health information on the definition of stress, stress management tips, information on behavioural problems of children with disabilities, respite care and an introduction to social support (Hu et al*.,* 2010:30).

These mothers also need face-to-face professional workshops. The mothers are able to speak to social workers, teachers and psychiatrists. In their study Hu, Lin, Yen, Loh, Hsu, Lin and Wu (2010:31) found that the majority of their participants in Taiwan benefited from the face-to-face workshops with a professional. They noticed that stress and depression levels decreased after attending these workshops with professionals (Hu et al., 2010:31).

To relieve stress experienced by mothers caring for their disabled children it is important to consider optimal use of respite care and psycho-social intervention to encourage positive appraisal and problem solving for the mothers. Hu et al. (2010:33) also report that in one study carried out in Saudi Arabia it was found that the higher the amount of informal support resources available to the mothers, the lower the level of stress and the higher the sense of well-being they experienced. Positive thinking tips and techniques, visualisation, and scheduling activities for time

management are also useful as they reduce emotional exhaustion and burnout (Hu et al.*,* 2010:34).

As discussed in the previous paragraphs, care-giving can have a negative effect on the care-giver's mental health itself. With this in mind Savage and Bailey (2004:111) extrapolate that efforts to support care-givers should ideally reduce the negative physical and mental effects that caring can have on their health. They also report that some mothers experience a substantial negative impact while others are less affected by their care-giving role.

4.5.2 Respite care

The burden of caring for a child with disabilities affecting the important areas of the family unit include lack of family cohesion, conflict and problem-solving skills. It is therefore important to provide as much support as possible in order to alleviate strains on family functioning (Shelton, Duerden and Witt, 2010:8).

Research studies regarding the issue of alleviating stress on the families caring for disabled children have found that *respite care* (where the child is cared for by someone other than the parent for some time providing temporary relief for care-givers from the ongoing responsibility of caring for an individual with disabilities), has proved to be helpful in creating an opportunity for the mothers to 'recharge their batteries' and spend some time with their other children with no disabilities, or do other necessary things such as work or socialise with friends (Shelton, Duerden and Witt, 2010:8).

This is also supported by literature from Jeon, Brodaty and Chesterson (2005:300) where they found that respite care provided several benefits to the care-givers which included time to rest and relax, freedom to pursue other activities, improved self-esteem, improvement in family relationships, and improved sleep patterns. Other studies have also found that mothers who were provided with respite care for their disabled children reported less care-giving stress after their child had returned from the respite care facilities, such as camps. Mothers' level of psychological distress also decreased while their child attended respite care camps and feelings of well-being were greater and they experienced fewer depressed moods (Jeon, Brodaty and Chesterson, 2005:300).

In order to meet the needs of these mothers a strength-focused orientation has been applied. According to Girard (2010:6) the strength-focused orientation has been effective in reducing the symptoms of mental illness and improving interpersonal relationships. This is an intervention that helps one to focus on one's strengths during emotional distress rather than focusing on the emotional distress (Gold and Hartnett, 2004). This is supported by Sharman's (1998) research study in which he found that depressed participants benefited from a psychotherapy approach that raised awareness of their strengths.

Reid et al. (2005) also emphasize the value of care-givers´ experience in the creation of family interventions. According to Dyson (1993) professional support that utilises family strengths can assist mothers in managing stress, pessimism and family problems that arise from caring for a child with mental disabilities.

Dyson (1993) explains that raising a child with disabilities can negatively impact the family functioning and relationships. In turn the psycho-social climate of the home affects the social development of disabled children. Families that are able to cope successfully with the demands of caring for a child with disabilities are better adapted to increasing the social and cognitive adjustment of the child. Accordingly, the child's adjustment decreases the distress and disruption in family relationships (Girard, 2010:9).

This section has covered the different coping strategies that mothers caring for their school-going children may use in order to cope better in their caring role and therefore result in their own positive well-being. If mothers are informed about the different coping strategies they can use on a daily basis in their caring role it is likely that these mothers may be more positive in their caring role and also provide more effective care for their child.

4.6 INFORMAL SUPPORT

The following section will discuss the informal support that may be provided for mothers in order to help them with the different experiences that result from being a full-time carer of a school-going child with disability. Informal support is the support that is usually provided by families, friends, associates and co-workers and it is usually provided free of charge. It also cor-

responds with the social and cultural needs, and mental/psychological needs categories identified in the previous chapter.

4.6.1 Emotional support

Emotional support can be sought from other parents of children with disabilities by joining support groups or by having professionals help each family develop their own personal support directory that contains names of people who can provide emotional and informational support. Professionals can also help the families identify existing sources of informal and formal sources of support and untapped potential sources of aid and assistance that match family-identified needs (Judge, 1998:267). Often many existing and potential sources of support are overlooked by professionals because they fail to consider the full range of social support options available to families. The process of identifying both existing and untapped potential sources of resources and assistance can be accomplished either in an interview format or by mapping a family's social support network (Judge, 1998:267).

Research indicates that the adequacy of different types and forms of support, especially assistance that matches family-identified needs, enhances parent and family well-being, decreases time demands placed upon a family by a child with a disability and enhances positive parental perceptions of child functioning (Judge, 1998:267).

4.6.2 Social support

Social support may be provided both informally (by friends, family, social groups) and formally (by professionals and agencies). In their literature review Savage and Bailey (2004:114) provide evidence that the amount and quality of social support available to care-givers is an important factor in moderating the impact of caring for a child with mental or physical disability. Using data from the Victorian Carers Program, Savage and Bailey (2004:114) report that care-givers who reported having larger informal support networks, reported greater life satisfaction, greater perceived support from family and friends, and less resentment and anger than did care-givers reporting smaller or no informal support networks.

The effect of social support suggests that we should mobilise resources from different sources as a way of meeting family needs. In general, social support provided by members of informal personal networks has been found to be most important (Judge, 1998:267).

Kegan et al. (1999:371) explain that the need for specialist child care continues for longer where children have disabilities and the need for care can be more unpredictable. Where formal support is lacking, assistance from family and friends can assume ever greater importance. However, the informal support networks of parents of disabled children are likely to be small and confined to close family members, which leads to less availability of informal support and may predispose parents to higher levels of distress.

4.6.2.1 Strength-based approach

According to Judge (1998:263), the strength-based approach can be useful in promoting family functioning. This approach assumes that all families have strengths they can build on and that the family's strengths, including the social networks and informal supports already available to and within the family, should be the foundation upon which new supports are designed or provided.

The goal of the strength-based approach early intervention is to identify existing family strengths and capabilities so that interventions are built on things a particular family already does well. By using family strengths as building blocks and tools, the family becomes even stronger and more capable of supporting the well-being of individual family members and the family unit (Judge, 1998:263).

4.6.3 Non-governmental organisations (NGOs) and churches

In South African low-income communities the NGOs and churches are often provide a great deal of support to children with disabilities, such as providing food parcels. However, even though these NGOs provide support, most of them do not focus on helping the mothers who care for their children with disabilities (Children's Disability Center, 2010:1). For example, organisations such as Kanguru and Abraham Kriel Childcare provide relief to families with disabled children. They do this by supporting schools and homes for disabled children via funding and training from Germany. The Abraham Kriel Childcare organisation is one of South Africa's oldest and most respected childcare organisations with 106 years of experience in childcare. Therapeutic

services have been expanded, first by opening specialist houses for children with complex trauma and others with special needs and most recently with the opening of an 'Impact School' in an effort to ensure the healing and development of damaged children in an unthreatening environment. Within these two organisations there is no mention of providing support for mothers in order to meet their personal needs or deal with the experiences resulting from caring for their disabled children (*South African Disabilities,* 2011:2).

Other organisations include the Chaeli Campaign. This organisation mobilises the minds and bodies of children with disabilities by providing aids and therapies where required, as well as parent and family support. Child Welfare South Africa is also a well-known NGO. It offers social services to children, families and communities around South Africa. Its mission is to protect, serve and develop children and families. They are actively involved in all children's issues and rights, offering assistance, emergency and social relief to impoverished and indigent families. They run empowerment programmes covering parenting skills, child protection and domestic violence, and they are currently involved in HIV AIDS awareness and projects (*South African Disabilities*, 2011:2).

Churches also play a role in providing social and emotional support and most importantly meeting the spiritual needs of their members, which is very helpful in assisting them to cope with the experiences of caring for their mentally/physically disabled child. However, there is evidence that churches still do not provide enough support for families with disabled members. For example, Borchard (2011:1) reports that families with members with mental disabilities need more support from their churches and the congregation. She reports that families with mental illness stand to benefit from their involvement with a congregation. However, literature suggests that faith communities fail to adequately engage these families because they lack awareness of the issues and understanding of the important ways in which they can help (Garland, 2011:2).

In a study conducted in the USA which surveyed nearly 6,000 participants in twenty-four churches representing four Protestant denominations about their families' stresses, strengths, faith practices and desires for congregational assistance, it was found that families with mental illness ranked help from the church as a second priority. However, families without mental illness ranked it forty-second on their list of requests from churches.

According to Garland (2011:3) mental illness is not only prevalent in church communities, but is accompanied by significant distress that often goes unnoticed. Partnerships between mental health providers and congregations may help to raise awareness in a church community and simultaneously offer assistance to struggling families. This is also applicable in the South African context. However, many churches are not aware of how they can reach out to the mothers of children with mental or physical disabilities, as they lack knowledge of these disabilities and even have other beliefs with regard to disabilities.

Borchard (2011:3) provides some guidelines as to how churches might reach out to the families of those with mental disabilities. The first thing the church and its leadership must do is become educated about the mentally ill. Education will remove misconceptions, fear, and prejudice. It can be as easy as reading about different disabilities on mental health websites, checking out non-profit groups and others, visiting a library to see the available literature on mental illness or attending a lecture by an expert in the field at a nearby college.

Churches can also conduct sermons covering topics on disabilities and how the congregation can support members who care for family members with disabilities, as well as educating the congregation about the disabilities and the support they can render to those who provide care (Borchard, 2011:3).

Thirdly, churches can host support groups. Borchard (2011:4) explains that a church is a natural place to host a support group for those who have disabilities or care for the disabled. She reports that some churches do host such groups, but they never mention it in the Sunday bulletin or on the church website because many of these groups are started by an outsider to the church, so most members of the church do not have any idea that these groups meet.

Fourthly, churches should provide literature on different disabilities and how the carers can be supported in order to help them provide effective care. For example, National Alliance for Mental Illness and other non-profit organisations are usually happy to provide free brochures for churches, doctors' offices, wellness centres, or any location that would like them handy for people to pick up on their way in and out of these places. Moreover, most churches have a library of donated books (Borchard, 2011:4).

The following section covers the main theory used in this research and explains the different experiences of mothers caring for their disabled children in low-income communities, assessing the impact of the systems on these mothers' lives.

4.7 ASSESSMENT OF NEEDS WITH SUPPORT AVAILABLE IN SOUTH AFRICA

In Chapter III four categories of needs of mothers caring for their disabled children were identified: (1) access needs; (2) economic needs; (3) social and cultural needs; and (4) mental/psychological needs.

As explained at the beginning of this thesis, there is hardly any literature regarding this subject in South Africa, and this forms a large part of the rationale for this study. Consequently, it is hard to evaluate the support available regarding many of the needs identified here at this point of the study. Evaluating some of the access needs, the social and cultural needs, and the mental/psychological needs will only be possible after the interviews have been conducted. However, the existence of support for these mothers in meeting their economic needs is easier to evaluate at this stage of the study.

First and foremost, the precarious economic reality of a large part of the South African population has to be emphasized, as it strongly increases the economic needs of the care-givers, but, as pointed out before, it also affects the other needs categories. It could therefore be assumed that the economic situation of many South Africans also makes it much harder to meet those needs.

Few developing countries of similar socio-economic status as South Africa have as well developed social security systems, particularly with regard to social assistance provisioning. However, while South Africa's legislative framework is rated as one of the best in the world, with well established private insurance coverage, the problem remains that the majority of South Africans are poor, unemployed and, in the informal employment sector, they cannot access private measures. The other main issue in the South African context is a lack of, or ineffective, implementation of legislation and policies (Guthrie and Sait, 2001: 13). Moreover, while it is laudable that South Africa, in contrast with other developing countries, has a social security system which

benefits disabled people, their dependants and care-givers, it is questionable whether this economic support is sufficient to meet the needs of the target group.

While these are certainly important issues, they also emphasize to an important potential to improve the situation in South Africa, where the current Care Dependency Grant is limited to those severely disabled children requiring permanent home care, and fails to provide for the many children with moderate disabilities and chronic illnesses, whose needs are often greater. A differential scale of benefits based on the need of the applicant would also ensure channelling of resources to the most needy, although this would be cumbersome to administer. The South African Department of Social Development certainly needs to improve its administration of the grants and the turn-around time from application to receipt of grants. A system is required to fast-track applications by people, especially children, with severe chronic illnesses, in particular HIV/AIDS. Payment of at least part of the grant could begin immediately upon application.

Consequently, the assessment of the options available for mothers of disabled children to meet their needs in South African low-income communities found that while the legislative framework, including grants, is very good on paper, the practical implementation of many formal support options is far behind and insufficient to meet the economic needs of these mothers.

4.8 CONCLUSION

This chapter aimed to show how the needs of mothers caring for their school-going children with physical or mental disabilities identified in the previous chapters can be met in general, as well as within the South African context.

The first and essential point made at the beginning of this chapter was that a large part of the South African population lives in precarious economic conditions: a fact that affects all the needs identified in Chapter III and makes it harder to meet them. However, it was also found that very few reliable statistics exist on the prevalence and nature of disability in South Africa.

It was found that South Africa has a very good constitutional and legal framework to protect the rights of disabled people and to assist them in accessing equal and inclusive education. Furthermore, the social grant system is much more evolved than in other comparable countries and in-

cludes several grants to help mothers to meet some of their economic needs. However, the implementation of these policies and the distribution of grants lags far behind and makes it difficult for mothers, particularly in low-income communities, to access adequate formal support. Moreover, even if the implementation were more efficient, it is doubtful that it would be sufficient to help these mothers meet their economic needs.

Additionally, various coping strategies and informal support options were introduced in the course of this chapter, which could help to meet the needs of mothers caring for their disabled children. These coping strategies will be used in the next chapters to inform the development of the questionnaire exploring the experiences of the target group.

In concluding this chapter, it can be said that it helped to identify several ways to address the needs of mothers caring for their disabled children in a South African context, but also showed the need to further explore their experiences with the help of the interviews. The outcome of these interviews will be discussed and assessed in the following chapter.

CHAPTER V: A SITUATION ANALYSIS OF THE EXPERIENCES OF MOTHERS CARING FOR THEIR SCHOOL-GOING CHILDREN WITH MENTAL OR PHYSICAL DISABILITIES IN LOW-INCOME COMMUNITIES

5.1 INTRODUCTION

The previous chapters have discussed and explored the different types of children's disabilities, the care they need, the impact that their need of care has on their full-time carers (mothers) and the actual experiences that a mother providing full-time care to their school going disabled child has.

The literature review in the previous chapters formed a foundation of knowledge to understand the experiences of these mothers and identify their challenges and the resulting needs and therefore identify the support that they need in order to make their caring role more effective and a positive experience.

In accordance with the rationale for this thesis, the lack of data and knowledge about the experiences of mothers caring for their disabled children in **South African low-income** and corresponding with the fourth objective of this research study, this chapter will present and analyse the data collected in the empirical study. With this objective in mind, this chapter will focus on the presentation and analysis of the results of the collected data. Furthermore, a literature control will be done. The data will be presented in a table format, figure or narrative form with identified themes in order to best capture the findings of the study.

5.2 DELIMITATION OF THE INVESTIGATION

The participants interviewed for this research are mothers of disabled children, whose children attend a special school, in Cloetesville, a low-income community near Stellenbosch, Western Cape. The participants were identified by the special school, where the actual semi-structured interviews took place. The school head of the department who deals with research students con-

tacted all the potential participants using a form (Appendix B) asking them to take part in the study and indicating the time and date that they might want to attend.

The population consisted of biological mothers who were the full-time care-givers of their disabled children from the communities shown above, whose disabled children attended the special school on a full-time basis and who lived not far from where the semi-structured interviews were taking place. Other potential participants whose disabled children attended the school but lived very far from it were not contacted. This is because it would have been very difficult to get these participants to come to the school as they need transportation and also to have someone to stay at home with the other children. So all the logistics involved meant that only the mothers not far from the school were contacted, which of course could be regarded as a limitation of the study.

The sample was supposed to have twenty participants (n=20), however, because of some 'none' responses from potential participants indicating their availability to take part in the study, only 19 participants (n=19) took part. The sample was selected by means of a non-probability sample, namely; purposive/judgemental sampling (Babbie et al., 2007:202). This was done to ensure that all the participants were selected to meet the criteria of the study and meet the criteria for inclusion, as a result fulfilling the purpose of this research study while at the same time providing results that were valid and reliable.

5.3 EMPIRICAL STUDY

The results of the empirical study that was undertaken will be presented in the following sections. Before presenting the results the research design, methodology as well as data analysis that were used will be explained.

5.3.1 Research design

The investigation was a combination of exploratory and descriptive research, as described by De Vos et al. (2005:106) and Babbie et al. (2007:79-80). A combination of exploratory and descriptive research was conducted as a result of gaps in literature research on the experiences of mothers caring for their school-going children with mental or physical disabilities. As a result this research aimed to identify and explore these experiences and challenges as well as the resulting

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needs of the mothers and therefore identify the support that can be provided in order to make the mothers' caring role more effective.

5.3.2 Research methodology

A semi-structured questionnaire (**Appendix A)** was used during the interviews. Here the researcher administered the questionnaire by means of an interview, by which the researcher could ensure that the participants understood all the questions and terminology in the research instrument and if there were any uncertainties the researcher could clarify them.(Bless et al., 2006:184). The questions consisted of both open-ended and closed questions. Using open-ended questions ensured that the data that was collected was measurable and had some reliability and validity (Babbie et al., 2007:119-122). The questions were also used to explore the mothers' experiences, challenges and resulting needs as well as to determine the support that they need in order to make their caring role more effective.

The research used both qualitative and quantitative approaches. The quantitative results have been presented in tables and figures, whereas the qualitative results, which capture actual experiences and emotions of the mothers have been explained using themes.

As will be shown in table 5.3, none of the respondents has English as a first language; some speak isiXhosa or Afrikaans. For respondents whose comprehension of English was not sufficient, Afrikaans translations of the questionnaires were made available and the interviews were accompanied by an Afrikaans speaking fellow student to record and translate the open-ended questions. No questionnaires were translated into isiXhosa, as the English comprehension of these respondents was sufficient. In case of need for clarification, an isiXhosa-speaking teacher from the school made herself available during interviews.

5.3.3 Method of data analysis

De Vos et al. (2005:333) have defined data analysis as the process of bringing meaning and structure to the data that is collected. Macintosh (1996:1) has also defined data analysis as a body of methods that help to describe facts, detect patterns, develop explanations, and test hypotheses. Data analysis is used in all of the sciences. It is used in business, in administration, and in policy.

Analysing data enables the researcher to detect consistent patterns within the data (Bless et al., 2006:163). In this research study data was collected by means of the semi-structured question-naire which will be coded and represented by means of graphs and figures. This will allow for the data to be interpreted and for trends to be identified in the findings (Bless et al., 2006:163; De Vos et al., 2005:337). The data will then be summarised and interpreted in the research report and compared to the existing data in the literature study, referred to as the literature control process.

5.4 RESULTS OF THE EMPIRICAL STUDY

The findings of the empirical study and the interpretation of the data in comparison to the literature review will be presented below.

5.4.1 Identifying the particulars of the respondents

5.4.1.1 Marital status of respondents

The respondents were asked to indicate their marital status. The data is illustrated in Table 5.1 and Figure 5.1.

Table 5.1: Marital status of respondents

Marital status	Respondents (f)	Percentage (%)
Married	5	26
Single	5	26
Cohabiting	2	11
Divorced	5	26
Widowed	2	11
Total	**19**	**100**

n=19
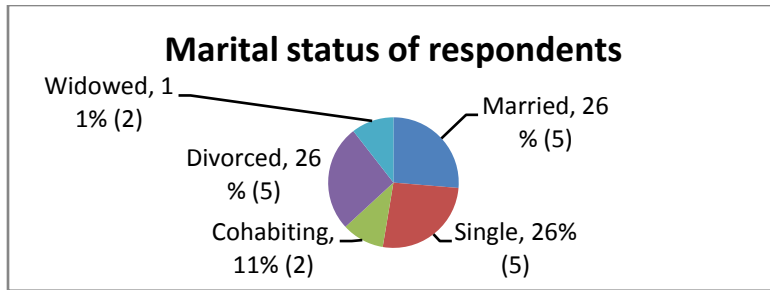
n=19

Figure 5.1: Marital Status of respondents

The results in Table 5.1 and Figure 5.1 illustrate that there was a balance within the marital status of the mothers: there were five married mothers (26%), five single mothers (26%) and five divorced mothers. Only two (11%) of the participants indicated that they were widowed and the other two (11%) were cohabiting with either their boyfriends or the fathers of their children.

5.4.1.2 Age of respondents

The age of the participants, namely the biological mothers of the physically or mentally disabled school-going children was investigated. This had to be determined in order to make sure that the mothers met the criteria of inclusion as the study focuses on the mothers between twenty and forty years of age. The results are illustrated in Table 5.2 and Figure 5.2.

Table 5.2: Age of respondents

Age	Respondents (f)	Percentage (%)
21-25 years	1	05 %
26-30 years	4	21 %
31-35 years	5	26 %
36-40 years	9	48 %
Total	**19**	**100**

n=19

Table 5.2 indicates that nearly half (nine or 48%) of the participants were between the ages of 36 and 40years of age. On the other hand, only five (26%) of the participants were between the ages of 31and 35years old. It can also be seen that only four (21%) of the participants were aged between 26 and 30years. It can also be seen in Table 5.2 above that only one participant (5%) indicated that they were between 21and 25years old. It can therefore be stated that all the mothers in

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the study met the criteria of inclusion as they fell within the designated age range. It was important to stick to the criteria of inclusion as this helped in providing results that were valid (Babbie et al., 2007:202). The results therefore show that any mother at any age can have a child with either mental or physical disability and that the causes are not age-based. These results support the literature by Office (2011:79) in which she explains that any mother at any age can have a child with disability.

5.4.1.3 Home language of respondents

The respondents were asked to indicate their home language. Their responses are illustrated in Table 5.3 and Figure 5.3.

Table 5.3: Home language of respondents

Language	Respondents (f)	Percentage (%)
isiXhosa	05	26 %
Afrikaans	14	74 %
Total	**19**	**100**

n=19
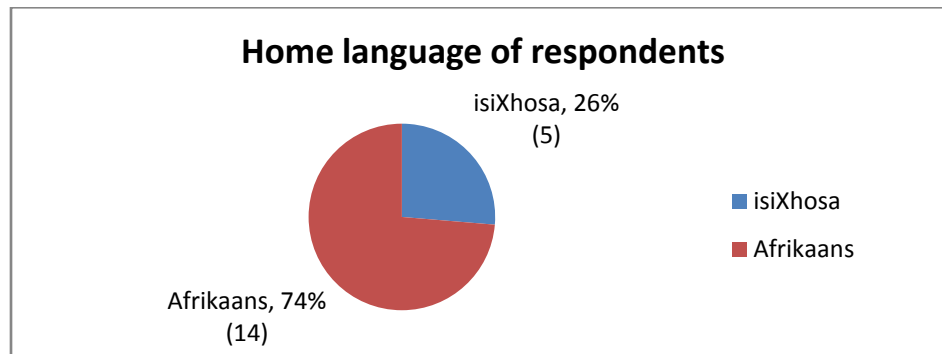
n=19

Figure 5.2: Home language of respondents

As indicated in Figure 5.2 above, fourteen (74%) of the participants were Afrikaans-speaking, whereas only five (26%) of the participants stated that they were Xhosa-speaking. An explanation for the higher percentage of the participants being Afrikaans-speaking may be that the research study took place in Cloetesville, which is an Afrikaans-speaking, mostly Coloured, community. These results are supported by the Cape Town Census (2001). Additionally, the disabled

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children of the majority of black African people living in low-income communities in the Stellenbosch area do not attend this school, for various reasons, which will be discussed later in the chapter.

5.4.1.4 Highest qualification of respondents

The respondents were asked to indicate their highest level of qualification. The data is illustrated in Table 5.4 and Figure 5.3.

Table 5.4: Highest qualification of respondents

School standard	Respondents (f)	Percentage (%)
None	0	0 %
Sub A – St.2 / Grade 1-4	0	0 %
St. 3-5 / Grade 5-7	4	21 %
St. 6-7 / Grade 8-9	9	47 %
St. 8-9 / Grade 10-12	6	32 %
St. 10 / Grade 12	0	0 %
After school training	0	0 %
Total	**19**	**100**

n=19
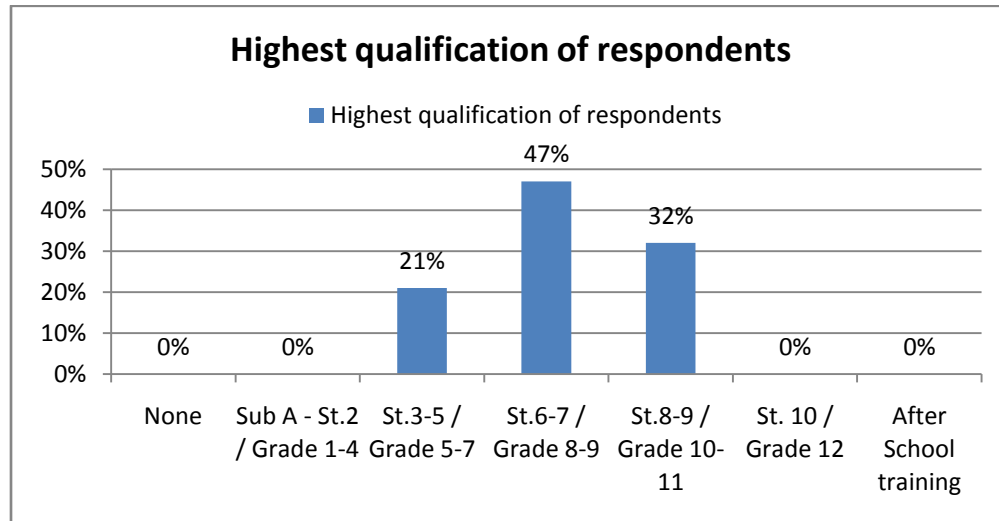
n=19

Figure 5.3: Highest qualification of respondents

The findings in both Table 5.4 and Figure 5.3 illustrate that the participants in the study had different levels of highest qualification. None of the respondents had no qualification; neither did any only obtain a Grade 4 qualification. It can also be clearly seen that none of the mothers had

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any higher qualifications or after-school training. The graph also illustrates that only nine (47%) of the mothers have the highest qualification of Standard 6-7 (Grade 8-9), whereas only six (32%) of the mothers have acquired Grade 10 qualifications. Only four (21%) of the mothers stated that they only went up to Grade 5-7(Standard 3-5).

The low level of education found in all the respondents indicates the minimal chance of these women getting a well-paid job and is consequently an indication of their generally precarious economic situation. These results support literature from Hanson and Sporakowski (1986:4) which found that many mothers with disabled school-going children living in low-income communities and from low socio-economic circumstances also tended to have a very low level of education and training, limiting them to very poorly paid jobs, resulting in a greater burden as they have to care for their disabled child and their family (Hanson and Sporakowski, 1986:4). These results indicate that the mothers need financial support.

5.4.2 Details of the disabled child

5.4.2.1 Age of the children

The age of the disabled children whose mothers participated in the study was investigated. The data is illustrated in Table 5.5 and Figure 5.4

Table 5.5: Age of the child

Age	Respondents (f)	Percentage (%)
7 years	1	05 %
8 years	4	21 %
9 years	3	16 %
10 years	2	11 %
11 years	1	01 %
12 years	3	18 %
13years	0	0 %
14years	2	11 %
15years	1	05 %
16years	1	05 %
17years	0	0 %
18years	1	05 %
Total	**19**	**100**

n=19
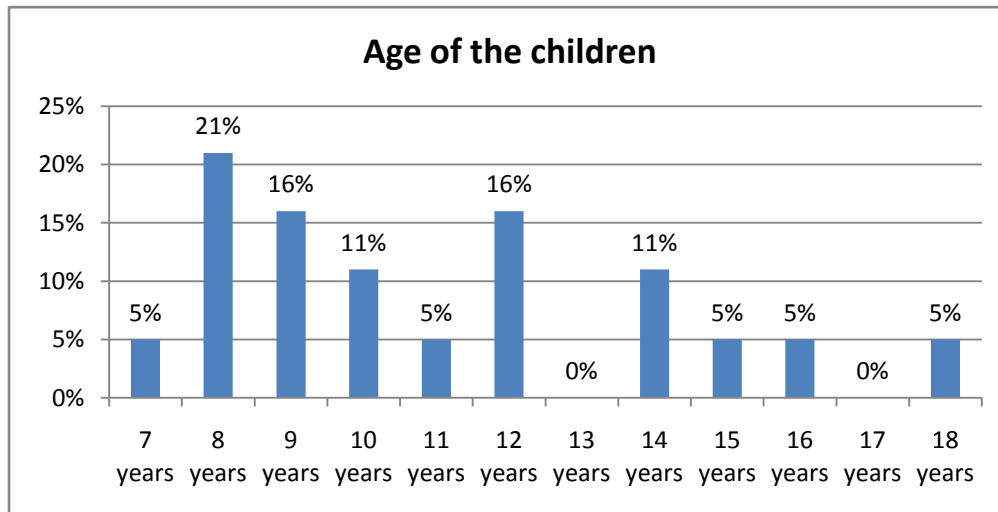
Age of the children

n=19

Figure 5.4: Age of the children

The graph above illustrates a range of ages. Of the total number of mothers interviewed (n=19), four (21%) indicated that their child was eight years old. Three (16%) of the mothers indicated that their child was nine years old. Another three (16%) indicated that their child was twelve years old. The graph also shows that two (11%) of the mothers indicated that their child was ten years old and another two (11%) stated that their child was fourteen years of age. Only one (5%) of the mothers indicated that her child was seven years old and another participant (5%) indicated that her child was eleven. One child was sixteen and another eighteen. It should be noted that the ages of the children varied, as the research focused on all school-going children as the special school where the research was took place accepts children based on their disability level rather than their age. This means that a child who was said to be sixteen years old could, as a result of disability, behave like a ten-year-old. These findings are in line with information provided by the Resources for Cerebral Palsy (2011:1) and the National Institute of Mental Health (2010), as they explain that mental or physical disabilities may affect the child's brain development, which leads to delay in certain motor skills and general development meaning that they may be behind in their development.

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5.4.2.2 Type of disability

The total number of children with physical and mental disabilities in the study is illustrated in Table 5.6 and Figure 5.5

Table 5.6: Type of disability

Disability	Respondents (f)	Percentage (%)
Physical disability	7	37 %
Mental disability	12	63 %
Total	**19**	**100**

N=19
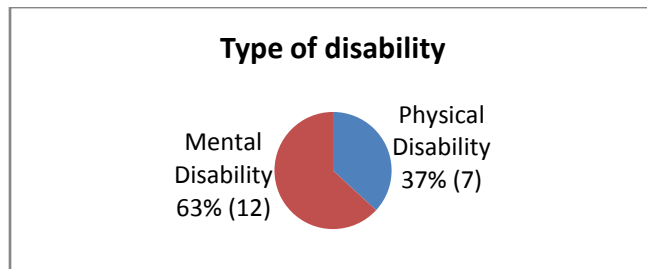
n=19

Figure 5.5: Type of disability

The diagram above illustrates that over half of the respondents, twelve (63%) indicated that their child had a mental disability, whereas only seven (37%) stated that their child had a physical disability.

Regarding the specific disabilities of the children it has to be stated that the respondents did not always know the specific medical term, but were rather asked to describe the type of disability and the following Table 5.7 and Figure 5.5 reflect multiple disabilities in one child.

It should also be noted that respondents were allowed to identify more than one specific type of their disability.

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Table 5.7: Specific types of disabilities

Type of disability	Frequency (f)	Percentage (%)
Epilepsy	3	16 %
Cerebral Palsy	3	16 %
Intellectual Disability	2	11 %
Learning Disability	7	37 %
Fetal Alcohol Syndrome	2	11 %
Developmental Disability	2	11 %
Autism	2	11 %
Hearing impairment	2	11 %
Visual impairment	2	11 %
Down Syndrome	1	05 %
Vocal impairment	1	05 %
Dyslexia	1	05 %
Other physical impairment	1	05 %
Total	**27**	

N=19

Specific type of disability of respondents´ children
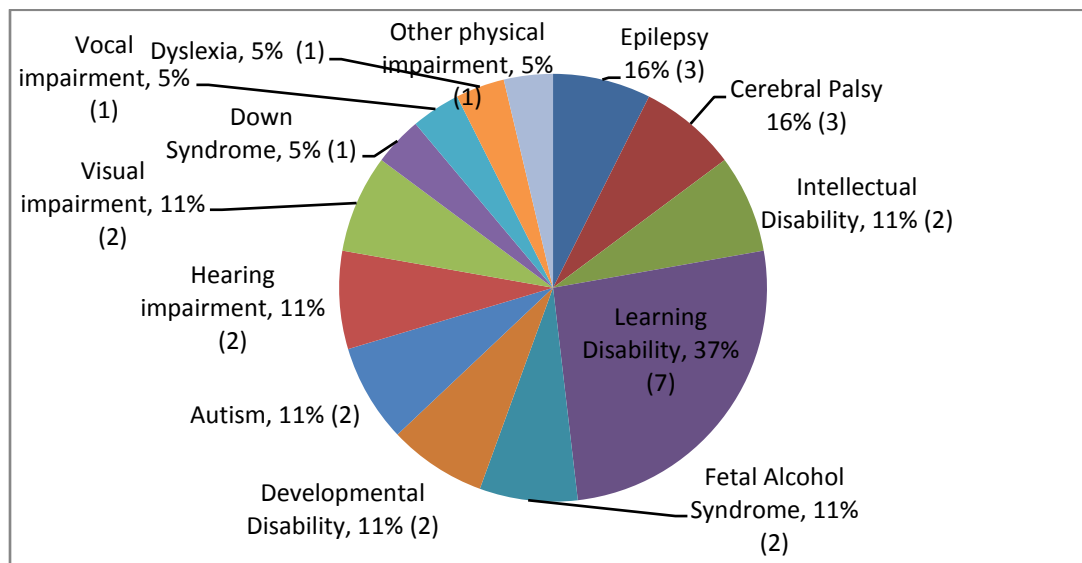
n=19

Figure 5.6: Specific type of disability of respondents´ children

It can be seen in the figure above that just more than a quarter (seven or 37%) of the participants indicated that their child had a learning disability. About three (16%) indicated that their child had epilepsy and the other three (16%) also indicated that their child had cerebral palsy. The other common disabilities included visual impairment, two, (11%), hearing impairment, two

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(11%), intellectual disability, two (11%), developmental disability, fatal alcohol syndrome, two, (11%). It can also be seen that one (5%) participant identified her child as having a vocal impairment, and another (5%) identified her child as having Down syndrome; the other one (5%) indicated dyslexia and another, (5%) physical impairments. It can be seen that there are many different types of disabilities that school-going children may have: it is therefore necessary that mothers should be fully equipped with the knowledge of the specific knowledge of medical terms for their child's disability. This should be done so that they are able to access appropriate services to meet the child's needs and get treatment, if needed. Through this mothers will be better able to provide effective care for their child and meet their own needs as well. These findings are supported by Schall (2000:417) where it is indicated that mothers need to be provided with enough information about their child's disability to understand how to care for the child, and in so doing, become a better carer.

5.4.2.3 Definition of the child's disability

(a) The mothers' definitions of their child's disability

The respondents were asked to explain how they define their child's disability. Table 5.8 illustrates their responses.

Table 5.8: The mothers' definitions of their child's disability

Definition	Frequency	Percentage (%)
Slow (mentally)	13	68 %
Hyperactive	02	11 %
Hearing problems	05	26 %
Eye sight problems	05	26 %
Coordination	02	11 %
Seizures	02	11 %
Abnormal facial features	03	16 %
Learning disability	04	21 %
Cannot walk	02	11 %
Mood swings	02	11 %
Not talking	02	11 %
Total	**42**	

n=19

It should be noted that the mothers were allowed to identify more than one definition that described their child.

When mothers were asked to define their child's disability, most did not know the actual medical definition for their child's disability. They tended to identify a specific characteristic that differentiated their child from other children. It may be that mothers from different backgrounds define their child's disability differently from others, and differences in how professionals define the disability. This unfortunately may result in not accessing the proper support services (Harry, 1992:27). For example, one of the participants explained:

'...the doctor says that he has a thing called ADHD (hyperactive), and so I must always give him his medication to calm him down. But I think he is just a busy little boy and I should just give him fewer sweets...'

It can be seen in Table 5.8 above, that thirteen (68%) of the participants defined their child's disability as a slowness. Five (26%) participants defined their child as having hearing problems. Another five (26%) stated that their child had eye-sight problems. The other four (10%) said that their child had a learning disability. About three (16%) of the participants indicated that their child had abnormal facial features. Two (11%) participants defined their child's disability as hyperactivity. Two (11%) defined their child's disability as having co-ordination problems, and another two (11%) indicated that their child had seizures. Two (11%) defined their child's disability as an inability to walk. Two (11%) of the respondents indicated that their child had mood swings, and the other two (11%) indicated that their child was not talking.

A possible explanation for the mothers´ preference to give the characteristic of the disability rather than the actual definition could be that this would label their child as mentally retarded. This is supported in the literature reviewed in Chapter III of this research study where literature by Harry (1992:28) explains that in one study mothers were offended when the professionals defined their child as having a specific disability as that implied that their child's competence was severely impaired or that they were mentally deranged.

(b) Help with coming up with a definition of the child's disability

The mothers were asked to explain how they came to define their child's disability. Table 5.8 illustrates their responses.

Table 5.9: Ways of coming up with the definition of the child's disability

Ways of coming up with the definition of the child's disability	Frequency	Percentage (%)
Through community members	01	05 %
Through crèche teachers	01	05 %
Through mainstream teachers	06	31 %
Through doctors/specialists	13	68 %
Sisters	01	05 %
Nurses	02	11 %
Family members	03	16 %
Friends	01	05 %
other	03	16 %
Total	**31**	

n=19

When the mothers were asked to indicate how they came to define their child's disability, it can be seen in Table 5.9 that nearly half (thirteen or 68%) of the mothers had been informed by the doctor about their child's disability. During the semi-structured interviews most of the mothers who had learned about their child's disability from the doctor explained that after they went for a checkup, having noticed something different about their child, the doctor confirmed that their child had a disability. Here follows two narratives from two different participants:

'...After a few months at home when my child was born I noticed that something was not right! You know that feeling; I could see that he was not the same as my other children like the two boys I had. So I went to the clinic here, and they told me to go to the university in Stellenbosch where the doctor confirmed that my child had a disability...'

'...I think it was the psychologist or the speech therapist at the university. They said that there was something wrong with his brain...I can't really remember the exact words; I just remember that they said he would be slower than the other children...'

From the results above and the narratives it can be seen that doctors are very important in providing confirmation of the child's disability. It is very important that disabilities be diagnosed carefully by the qualified doctor/specialist. The South African Epilepsy Organization (2011) confirms that diagnosing epilepsy can be difficult and it is therefore important that a qualified doctor/specialist conducts the assessment and provides the correct diagnosis. This is supported by

the National Institute of Mental Health (2010) as the authors indicate that qualified doctors/clinicians should be the only ones to provide the diagnosis of a disability.

The above Table 5.9 also illustrates that six (31%) of the respondents indicated that they came to define their child's disability after they were informed by the school teachers from the mainstream school. In this category these mothers explained that when their child was in Grade 1 or Grade 2 in the mainstream school, they noticed that the child's progress was really bad compared to the other children and they therefore needed to repeat a year. It was only when teachers noticed their disability and sent them for assessment that a disability such as dyslexia was confirmed. Below is another mother's response:

'...the teachers called me into the school and they told me that something was wrong with my child...I was very upset with them to say that...of course I knew that he was doing really bad in his work but I didn't think that something was wrong with him. But the teachers were very patient with me...they explained to me that he was slow and needed extra attention and they knew the right school where he can go...'

Only three (16%) of the participants indicated that they came to define their child's disability through a family member. This was the case where the participants indicated that their family member had a child with a similar condition or they knew someone with a similar disability.

In the 'other' category, participants indicated that they either had seen a similar affliction on the television or heard about it on the radio. An example of this can be seen in the narrative by a mother whose child had fetal alcohol syndrome below:

'...I knew that my child had this disability, because my other child had it too and I was also drinking while I was pregnant with this one so I just knew that it was also going to be the case; I know it's not right but I tell you I am a good mother...'

The results in the table above also illustrate that two (11%) of the participants came to define their child's disability after the nurses at the clinic told them. Only one (5%) of the mothers explained that she came to define her child's disability after one of the people in the community informed her. The other one (5%) participant stated that she came to define her child's disability when the teachers at the crèche that the child attended informed her about her child's disability. One (5%) of the mothers stated that it was through her friend that she came to define her child's disability.

Based on the results presented in Table 5.9, it can be stated that health professionals play an important role in helping mothers to understand the definition of their child's disability. However, it should be noted that health professionals should also support the mothers to accept the definition and how to cope with a stigma or any barriers, as explained by Leiter et al. (2004:382).

5.4.2.4 The special needs of the disabled child

The respondents were asked to indicate the special needs of their child, based on the child's disability. Table 5.10 illustrates their responses.

Table 5.10: The special needs of the disabled children

Special needs	Frequency (f)	Percentage (%)
Individual attention	6	31 %
Medication	7	37 %
Wheel chair	2	11 %
Hearing aids	3	16 %
Personal care (hygiene)	3	16 %
Special education	6	31 %
Therapy	7	37 %
Other (full-time care)	6	31 %
Total	**40**	

n=19

As discussed in the previous chapters, children with mental or physical disabilities have special needs. The child's level of disability may also determine the specific needs of the child, as explained in literature by Dorman and Pellegrino. The table above illustrates that seven (37%) of the mothers indicated that their child's special need was to take medication daily, the other participants, seven, (37%) indicated that their child needed to receive therapy. For example, seven 378%) of the participants who indicated that their child had a physical disability, namely cerebral palsy, explained that their child needed to see a speech therapist and a physiotherapist on a regular basis. This is supported by literature on cerebral palsy (Resource for Cerebral Palsy, 2011:2), discussed in Chapter 11, which explains that children with this type of disability usually need a great deal of therapy.

It can also be seen in the graph that six (31%) of these children need individual attention as a result of their disability. The six (31%) respondents indicated that their child's special need was to receive special education, as their child was not able to attend mainstream education as a re-

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sult of the disability. Another six (31%) indicated that their child's special need was to receive full- time care.

These results support the literature of Smith et al. *(*2009:167) and Kegan et al. (1999:370-373) discussed in the previous chapters, which indicated that children with disabilities may place a number of demands on the care-giver as they have special needs that have to be met. If these needs are not met, a great deal of strain is placed on mothers who are the sole care-givers of their children, leading to high levels of stress and anxiety as they battle to meet their own needs and have to sacrifice their own lives on a daily basis (Read, 1991:561).

5.4.2.5 Education

(a) Class level of the disabled child

The participants were asked to indicate the class level that their child was in. Table 5.9 illustrates their response.

Table 5.11: Class level of respondents´ disabled children

Class level	Respondents (f)	Percentage (%)
R-1	8	42 %
2-3	8	42 %
4-5	3	16 %
Total	**19**	**100**

n=19

It can be seen in the graph that eight (42%) of the participants indicated that their child was in level R-1. Another eight (42%) indicated that their child was in level 2-3. Three (15%) partici-pants indicated that their children were in level 4-5. The school where the research took place does not have specific grades for children, so they place them in *class levels* based on their level of disability. When the mothers were asked to indicate the class level that their child was in, most of them were not sure as they did not know about the levels system. The researcher there-fore had to get the class list from the teachers in order to establish the class level of the child to inform the mother. The mothers clearly lack knowledge about what is going on in the special school that their child attends, and therefore these results are in line with Leiter et al. (2004:382), as explained in Chapter III. Shearn and Todd (2000:115) explain that it could be beneficial for the school or professionals to ensure that the parents become involved in the school and their child's progress, by informing them about their schooling system and the special programmes

that the school offers. By doing this the mothers may become more involved in their child's education and even reduce the stress of worrying that their child requires special education (Kayama, 2009: 19).

(b) Age of the child when started schooling

The ages of children when starting school were investigated. The results are presented in Table 5.12 and Figure 5.7.

Table 5.12: Age of disabled child when he/she started school

Age	Respondents (f)	Percentage (%)
6 years	2	11 %
7 years	5	26 %
8 years	5	26 %
9 years	4	21 %
10 years	3	16 %
Total	19	100

n=19
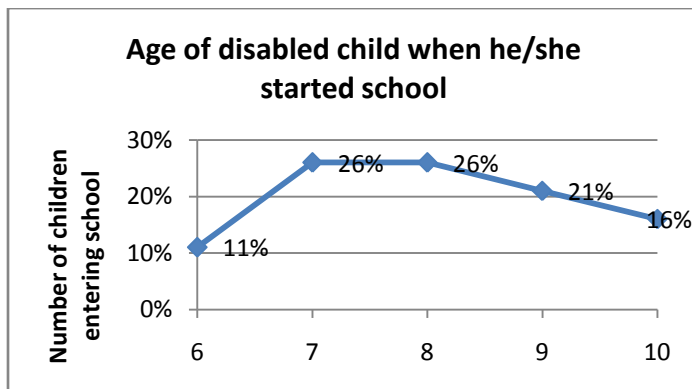
n=19

Figure 5.7: Age of disabled when he/she started school

Figure 5.7 shows that five (26%) of the participants' children started school between the ages of seven and eight years old. About four (21%) of the participants started school at the age of nine years. Only three (16%) of the participants indicated that their child started school at the age of ten years old. Lastly, Figure 5.10 illustrates that two (11%) indicated that their children started school at the age of six.

5.4.2.6 Admittance of the child to the special school

The process to admit the child to the special school was investigated. Table 5.13 illustrates the results.

Table 5.13: Process to admitting the child to the special school

Process	Frequency (f)	Percentage (%)
Easy	11	58 %
Difficult	05	26 %
Referred by crèche	03	16 %
Referred by doctors	02	11 %
Referred by school	04	21 %
Referred by friend	01	05 %
Referred by social worker	01	05 %
Other	01	05 %
Total	**28**	

n=19

It can be seen in the above table that eleven (58%) of the respondents indicated that it was very easy for their child to be admitted to this school. Five (26%) of the participants indicated that it was very difficult for them to get their child into the special school. Only four (21%) indicated that they were admitted to the school through teachers. The mothers who had sent their child into mainstream education not knowing that that child had a disability stated that after the school noticed that the child had either a physical or mental disability they referred the child for assessment to the specialist who then helped with the diagnosis that allowed the teachers to refer the child to the special school (Phelps, 2009:29).

Three (16%) participants indicated that their child was admitted to this school through the crèche that the child had been attending. This meant that when the child was in a crèche and it was time to go into a mainstream school the crèche helped the mothers to process the forms and apply for admittance of the child to the special school. Two (11%) indicated that they were referred by doctors. Only one (5%) participant indicated that she was referred by a friend. Another one (5%) indicated that she was referred by a social worker. One mother said that she had simply seen the school, asked about it and decided that it would be a suitable school for her child as she knew that something was not right with her child.

Consequently, it can be stated that accessing special education was generally easy for the mothers. The results also highlight the importance of the role of educators in crèches, who help in

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diagnosing a disability and referring the child to the right school and specialists. The children were also admitted to the school very easily and this could attest to the fact that the South African Child Care Act, 38 (2005) emphasizes that every child, whether normal or disabled, has a right to access education and to be treated equally by others.

5.4.2.7 School selection for the disabled child

Participants were asked whether this school was their first choice. Results are illustrated in Table 5.14 and Figure 5.12

Table 5.14: First school choice for the disabled child

Responses	Respondents (f)	Percentage (%)
Yes	14	74 %
No	05	26 %
Total	**19**	**100**

n=19
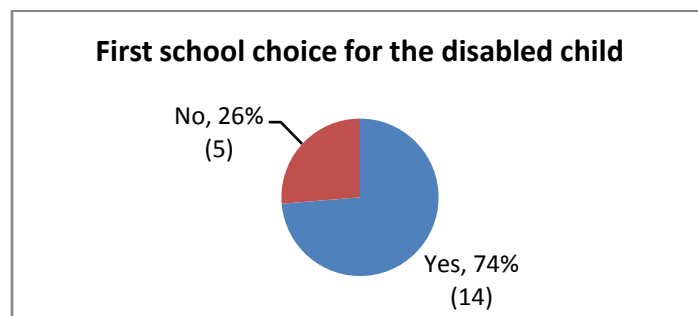
n=19

Figure 5.8: First choice for the disabled child

When the mothers were asked whether this was their first school choice, over half (fourteen or 74%) of these mothers indicated that it was. Only five (26%) indicated that this was not their first school choice. The fourteen (74%) who indicated that this was their first school choice explained that this was because it was the only school for children with disabilities in the community and they were not aware of any other special schools and therefore had no choice. These findings support the literature of Ceglowski et al. (2009:498) and Wickman-Seal (1992:9) in which they explain that low-income communities have limited resources for children with disabilities, therefore it is difficult for the mothers in these communities to send their children to very good special schools in other areas. This could explain why the mothers in this study indicated that the special

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school that their child attended was their first choice. This is because there are not any other special schools in their community making this school the only option. Furthermore, the answers to this question showed quite clearly that proximity to the school was the prevailing reason for choosing the special school.

For those five (26%) who indicated that this was not their first school choice, it was because they did not expect their child to be disabled needing special education. One of the mothers explained:

'It took me time to allow them to send her to this school, because when everyone sees that red uniform that the kids at this school wear they think they are just stupid, and I didn't want people to think my child was stupid. So I thought I could send her to another special school far from here...but then I couldn't; she just had to come here...'

This narrative shows that it is not easy for mothers to accept the fact that their child has a disability and should receive special care or education as they fear the stigmatisation from others within the community. According to Cichoni (2004:40) mothers who have children with disabilities face a dilemma and barriers when they want to seek or access special services for their child as they fear the prejudice and discrimination that they may receive from the people in the communities as well as that of the service providers themselves. All the points discussed above concur with Harry (1992: 27) where he explains that mothers may not accept the idea that their child is disabled as they fear being labelled and stigmatised.

5.4.2.8 Awareness of the resources available from the school

(a) Resources available to meet the needs of the disabled child

Respondents were asked to indicate if they were aware of the resources that were available in the school to meet the needs of their disabled child. The results are illustrated in Figure 5.12.

Resources available to meet the needs of the disabled child in the school

special equipment, 5% (1)

Supervision, 5% (1)

meals, 11% (2)

Don't know, 21% (4)

Nurse, 5% (1)

Small groups, 5% (1)

Special classess, 21% (4)

Wheel chair access, 5% (1)

Trained teachers, 42% (8)

Computers, 16% (3)

Therapist, 16% (3)

Psychologists, 37% (2)
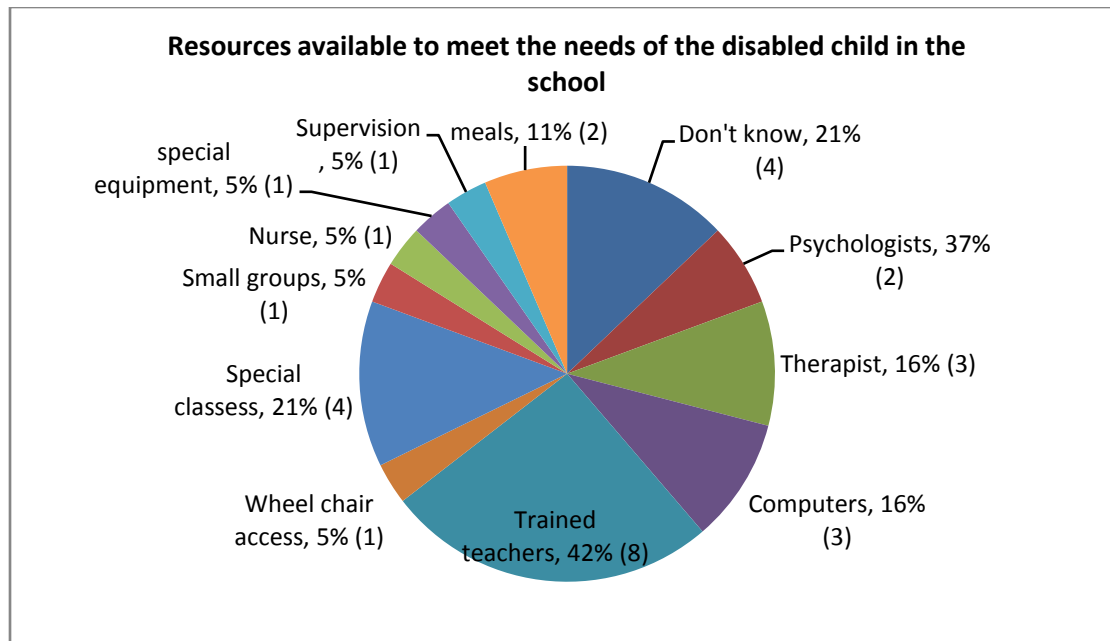
n=19

Figure 5.9: Resources available to meet the needs of the disabled child in the school

The results illustrated in the pie chart above show that nearly half (eight or 42%) of the respondents indicated the presence of trained teachers as a resource to meet their child's needs at the school. This might be because the mothers thought more carefully about their child's education and felt that their child's educational needs could only be met at this school as their child was unable to attend mainstream education (Burton, Lethbridge and Phipps, 2008:360).

However, four (21%) of the respondents indicated that they were not aware of any resources available at the school to meet the needs of the disabled child. These results indicate that as much as the mothers are aware that their child is receiving special education they are not fully informed of the resources that the special school offers (Blackburn and Read, 2005:507).

Another four (21%) indicated that the resources in the school were special classes. This meant that the school provided special classes for the child based on the child's level and understanding and the child was given enough attention in order to progress, compared with the attention that the child would have received in the mainstream education in accordance with the White Paper 6 on Special Education (2001), (Epilepsy South Africa, 2010) and (Guthrie, 2001:33). These results are also supported by Read (1991:563) where he stipulates that children with mental or physical disability should be placed in special education where they can receive full-time atten-

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tion with educators to help them to achieve their full potential, which would have been impossible had they attended a mainstream school. These results are also supported by Epilepsy South Africa (2010), where they indicate that parents should be able to send their child to a special school if underachievement is suspected and careful psychometric assessment is done. They should then be provided with special support in the school.

It can also be seen in Figure 5.9 that three (16%) of the participants indicated that they were aware that the school had therapists who see their child on the regular basis. The other three (16%) of the participants indicated that the school had computers on which the children could work. The mothers were very happy about this, as they stated that it enabled their child to at least receive some computer training and be like other children. It can also be seen that two (11%) of the participants were aware that the school had a psychologist. Only one (5%) indicated that they knew that the school employed a nurse. One of the mothers explained that her child has to take medication regularly so the nurse helps her out, which is how she came to know that there was a nurse in the school. The other two (11%) participants indicated that they knew that their child was getting meals at the school which they thought was the most important resource that the school provided for their child, as they could not afford to provide such healthy meals for their child at all times. Only one (5%) of the mothers knew that the school had wheelchair access. This was important for the child as he was able to move around without being pushed or lifted at all times.

Only one (5%) participant indicated that small groups were a resource that was available for their child. Another one (5%) of the mothers indicated that the school had special equipment for the disabled child such as puzzles, something that the mother could not afford to buy for herself. The results also indicate that one (5%) of the mothers knew that when the child was at school she/he was receiving full supervision from specially trained teachers. (Buell, et al.,1999:218).

5.4.2.9 Contact with school educators

The mothers were asked how often they met with the child's educators to discuss their child's progress. The results are presented in Table 5.14 and Figure 5.10

Table 5.15: Meetings with the child´s educators to discuss the child´s progress

Meetings	Respondents (f)	Percentage (%)
Every day	3	16 %
Once a week	5	26 %
Once a month	8	42 %
Every six months	1	05 %
Never	0	0 %
Other	2	11 %
Total	**19**	**100**

n=19
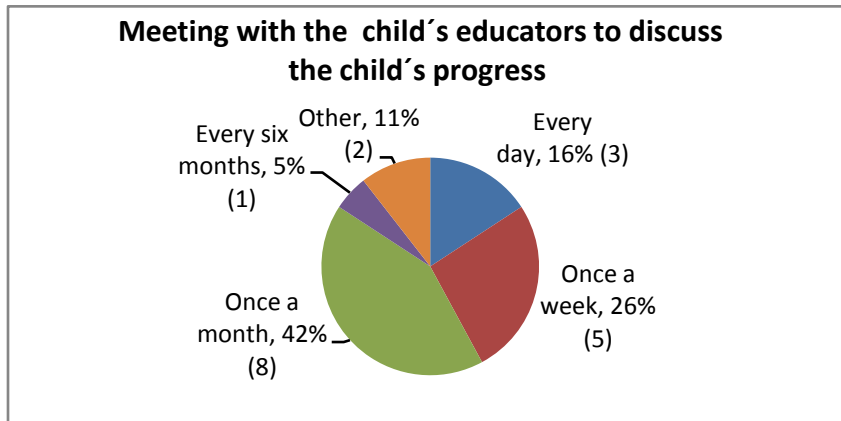
n=19

Figure 5.10: Meetings with the child´s educators to discuss the child´s progress

It can be seen in Figure 5.10 that the majority of the mothers, eight or 42%, meet their child's educator at least once a month. These participants explained that it was important that they met their child's educator at least once a month as they get to know how their child is doing and learn anything that they need to be doing to help the child. Leiter et al. *(*2004: 382) explain that caring for a disabled child requires specialised knowledge and full cooperation with the professionals who are working with the child as they learn different ways to help the child at home. This means that the mothers are encouraged to meet with the educators and the professionals on a regular basis in order to discuss their child's progress.

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About five (26%) of the respondents indicated that they met their child's educator once a week. Those who meet the educators once a week help out at the school, so they see the educators around and can easily ask the teachers how their child is doing. Only three (16%) indicated that they met their child's educator every day. This correlates with the result identified above where mothers have the opportunity to meet the child's educators regularly as a result of working within the school. The two (11%) respondents that indicated 'other' explained that they only met their child's educators if they were called in by the teachers or if there was a workshop. Only one (5%) indicated that she met the child's educator every six months. None (0%) of the participants indicated that she had never met the child's teacher.

Table 5.15 and Figure 5.10 show a lack of knowledge about the school and it can therefore be stated that there is a need for mothers to meet with their child's educators in order to develop a professional working relationship with them. This is supported by literature discussed previously by Office (2011:96), who explains that there has to be a parent-teacher partnership, where mothers need to come into the school on their own initiative to find out about the progress of their children, without waiting for the teachers to call them in. The teachers can educate the parents in this regard during orientations and parent meetings by showing them the importance of the parent-teacher partnership.

(a) Educators comments about the child's progress

The mothers were also asked to explain what the educators say about their child's disability. Table 5.16 illustrates the common comments of mothers.

Table 5.16: Educators' comments about the child's progress

Comments	Frequency (f)	Percentage (%)
The child is very bright	06	31 %
Good progress/improvement	11	58 %
Does well under supervision	07	37 %
Other	10	53 %
Total	**34**	

n=19

Table 5.16, shows that eleven (58%) of the respondents said that teachers have indicated a great improvement in the child's progress. Within this category the mothers explained that the child had made tremendous progress compared with when the child attended mainstream education.

This may be a result of the fact that the children at the special school are given the special attention that they need as a result of their disability, such as a learning disability. The South African Constitution, Act 108 of (1996) makes provision for every child to have access to education without being discriminated against on any level, and this is also in line with the South African Schools Act of 1996, however the White Paper on Special Needs Education (1997) is having a positive impact because it has introduced the special education system where children with disabilities in special schools can be educated in small groups and be monitored, and this leads to improved progress in the children's work (Guthrie, 2001:33).

Ten (53%) of the respondents who indicated 'other' either did not answer or could not remember. Seven (37%) of the mothers indicated that the educators stated that their child does well under supervision, meaning that the child has to be watched at all times, as can be seen in the narratives below:

'...they say that he is clever, and good with his work when he is sitting with someone helping him, otherwise he loses interest...'

'The teacher said that...in class she always has to keep an eye on him otherwise she loses him....'

Only six (31%) of the mothers stated that the educators had stated that the child was very bright.

'..They say that he is very clever than normal...'

'The other day the teacher told me that my child is well clever and he thinks ....'

Consequently, a trend can be seen in the results above, where the teachers seem to see some kind of positive development or behaviour in most of the children, which Hu, et al. (2010: 31) explain could be a form of encouragement for the mother, which nonetheless can have a positive effect on the emotional state of the mother.

5.4.2.10 Meeting the needs of the disabled child in school

(a) Meeting the needs of the disabled child in school

The mothers were asked to explain how they thought their child's needs were being met when the child was in school. Table 5.16 illustrates their responses.

Table 5.17: Meeting the needs of the disabled child in school

Needs that are met at school	Frequency (f)	Percentage (%)
Socialise (e.g. being with other children like them)	07	37 %
Special attention (small classes)	10	53 %
Education	06	31 %
Meal provided	01	05 %
Other	07	37 %
Total	**31**	

n=19

When asked how they thought their child's needs were met when the child was in school, ten (53%) of the mothers indicated that their child was receiving special attention at the school as a result of small classes. It can be seen that special education had a very positive impact on the disable child, as the mentally and physically disabled children usually require full-time care and supervision. These results support literature from Epilepsy South Africa (2010) where it is clearly stated that children with disabilities need full-time care and, because they usually have other disabilities and effects as well, it means that they need to be monitored at all times. If this is achieved through special education, then the children may reach their maximum potential (Resource for Cerebral Palsy, 2011:2).

Table 5.14 shows that seven (37%) of the participants felt that their child's need to socialise with other children was met, making the child happy. Here is one of the narratives:

'...it's good that he gets to go to this school, because here there are other children just like him so he gets to play with them without feeling left out like at his old school...'

This result supports Buell et al. (1999:218) who indicate that socialisation is the key factor in selecting a school for the disabled child. This means that the disabled child is freer at the special school because there are other children that are also disabled; therefore the child feels less out of place, especially if there are other children who have the same disability as him as this makes it easier for the child to make friends and play (Buell et al., 1999: 281).

Within the 'other' section seven (37%) indicated that they felt that the school was much safer for them child to be in as the teachers are always on the lookout. Six (31%) indicated that their child's educational needs were being met and only one (5%) indicated that her child's nutritional needs were being met.

In interpreting these results it should be kept in mind that the majority of the children suffer from some kind of learning disability, which necessitates, as pointed out in Chapter 1.1, special attention, through, for example, smaller classes (Logsdon, 2011:6).

(a) Helpfulness of the special school for the disabled child

The mothers were asked to explain how they thought the special school was helpful for their child. Figure 5.11 illustrates their responses.
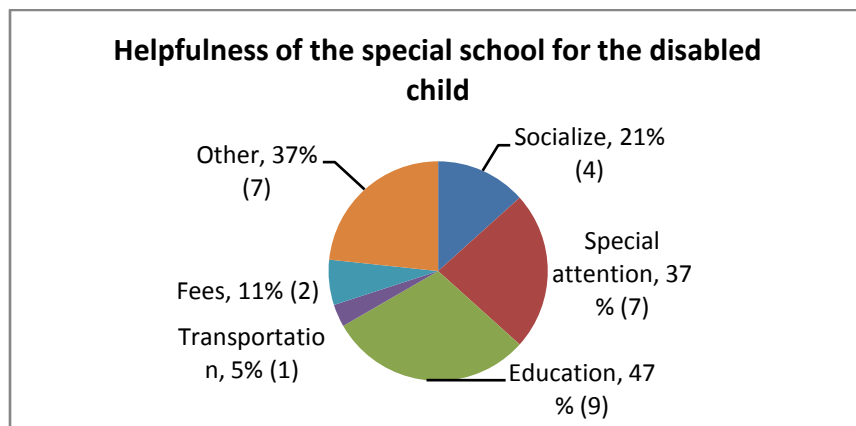
n=19

Figure 5.11: Helpfulness of the special school for the disabled child

There is a positive correlation between the results in Table 5.16 and the results in Figure 5.11. This is because in both diagrammes the special school seems to be meeting the educational needs of the disabled children on a higher level as a result of having small groups and subsequent special attention (White Paper 6 on Special Needs Education, 2001).

It can also be seen in the figure above that nine (47%) of the participants indicated that their child's educational needs are being met. Only seven (37%) indicated that the special education was very helpful in providing special attention for their child. About four (21%) of the participants indicated that the school helped by allowing their child to socialise with the other children

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in the school. Only two (11%) of the participants indicated that the school helped the mother with financial support by paying the tuition fees for the child. Only one (5%) of the participants indicated that the school was helpful in meeting the transportation needs of the child, and the child to was picked up from home and dropped off at home again after school. This fulfils the promise of the South African Schools Act of 1996, the White Paper on Special Needs Education and most importantly, the Child Care Act 38 (2005), in emphasizing the need for every child to have equal access to education allowing schools to have some provisions for those children who cannot attend school because of aspects such as transportation, by providing them with a subsidy (Dube, 2005: 12).

5.4.2.11 Barriers at the school

The mothers were asked to indicate if there were any barriers at the school, which impacted on their child's schooling or any other aspects. Results are illustrated in Table 5.12.

Table 5.18: Barriers at the school

Barrier	**Respondents (f)**	**Percentage (%)**
No barriers	12	63 %
Other children bullying the child	02	11 %
Different disability affect socialization	01	05 %
Other	04	21 %
Total	**19**	**100**

n=19

The results in the table above indicate that twelve (63%) of the participants did not see any barriers for their child in the school. This might mean that these mothers are very satisfied with all the services that the school offers for their child. Four (21%) of the participants indicated the 'other' section. This was a result of the fact that they did not answer the question or they could just not think of the correct answer. Only two (11%) of the mothers indicated that they perceived children bullying other children with more severe disabilities as a barrier within the school. The other barrier identified by one (5%) of the participants was that if the child had a completely different disability compared with the other children in the school, the child seemed to become isolated and unable to properly socialise with the other children. In this case, the child had a wheelchair and the mother stated that because the other children could walk properly her child sometimes felt left out as he could not walk or play with them. This may result in the mother not wanting to send her child to the special school any more as she may feel that the child's need to

socialise is not being met (Dyson, 1993), which again may lead to struggles in finding another school for the child. In the end the mother may again become stressed as the child will not be receiving education or socialising with other children (Shearn and Todd, 2000:116).

5.5 MEETING THE NEEDS OF THE MOTHER

5.5.1 Special school meeting the needs of the mothers as a full time care giver for her disabled child

The mothers were asked to explain how they thought the school helped them meet their different needs such as; economic, emotional/psychological and physical needs resulted from their full-time caring role. The themes and sub-themes that were derived are discussed in table 5.12.

Table 5.19: How the school meets the needs of the mother

Theme: How the school helps to meet the mothers' needs			
Subtheme	**Category**	**Narrative**	**f (%)**
No help		*"No I don't receive any help at all from there, apart from my child attending the school "*	10 (53%)
Economic	Fees and transportation	*"It is such a relief that I don't have to pay school fees and transport money because the school pays for that I would have not made is at all"* *I help out in the school kitchen so that the school can allow my child to attend for free. They also pay me something at the end of the month so am better off with money now even if it only small amount"*	9 (47%)
	Access to grants	*"The school is really helpful in helping us to apply for the grant. They did the forms for me as I cannot write"*	8 (42%)
Subtotal			*27*
Emotional/psychological	Gives mothers time to themselves	*"When the child is in school I get at least two hours of sleep or just to relax before the marathon starts again."*	1 (5%)
	Professional assistance	*"The psychologists and the teachers at the school always tell me that if I need to talk I can always go by the school, but I don't want to be a burden on them.*	3 (16%)
Subtotal			*4*
Other: needs of the child		*"I think it´s more about my child's needs than for them to deal with my own problems.*	1 (5%)
Total			**32**

n=19

(a) No help

It can be seen in the above table 10 (53%) of the participants indicated that the school did not meet any of their own needs resulted from the care they provided from their fulltime caring role ("*I don't receive any help at all from there").* According Shelton, Duerden & Witt (2010:8) caring for a child with mental or physical disability affect the important areas of the family as well as having a negative impact on the sole care giver who is usually the mother (Read, 1991:562). It is therefore necessary that the schools should do their best in helping the mothers to meet the different needs in order to avoid their caring role to have a negative effect on them (Savage and Bailey, 2004:111). An interesting point is that the school might actually be willing to help the mothers meet their needs however because the school already has limited resources it means that the mothers needs are neglected (Guthrie, 2011:31), which in the end results in greater frustrations especially if the mothers lacks any coping strategies (Judge, 1998:263).

(b) Economic help

It has been explained in the previous chapters that having a mentally or physically disabled school going child can have a negative impact on the economic situation of the mothers (Anderson, Dumont, Jacobs and Azzaria, 2007:4). This means that these mothers are usually in need of the economic support if they are to provide adequate care for their child or to reach a state of congruence (Johnson and Yanca, 2007:13) in their caring role and on the level of their well being. In this empirical study it was also found that the mothers were in need of economic support and about nine (47%) of the participants indicated that the school helped them in paying *fees and transportation* for their child at school. Below is one of the respondent's narratives:

"...I don't have to pay tuition or transport money as I get a government subsidy that the school assisted me to access to. So that it a big load of my mind as I was really struggling to make ends meet..."

Another way that the school helped the mothers' economic needs was through helping them to access to the *care dependency grant* and the *child support grant* which is usually the main income that they rely on this was shown in the eight (42%) of the participants. According to Lombard (2008:157) and Guthrie (2001:32) the Social Assistance Act, 13 of (2004) makes provision for these mother to receive the *care dependency grant* and the *child support grant,* in the form of cash benefits as they meet the eligibility criteria that is determined by the *means test*

(Kirst-Ashman, 2007: 216). This economic support is very important to these mothers and it has had a positive impact on the mother and their disabled children as for the majority of these mothers this is their only source of income for their household (Lombard, 2008:155).

(c) Emotional/psychological help

It can be seen in table 5.19 t in the second subtheme namely *emotional/ psychological help* that only three (16%) of the participants indicated that the school met their emotional/psychological needs by offering them *professional assistance*. The mothers explained that the teachers at the school are very open and they encourage the mothers to come in if they want to speak to someone such as the nurse or the psychologist they just need to come in advance *("...I can always go by the school, but I don't want to be a burden on them...").* It can be seen that the teachers at the special school somehow realizes that the mothers that have children with mental or physical disabilities have emotional and psychological needs as a result of the care demands that their disabled child places on them (Girard, 2010: 12) and (Figley 1995: 11).

Although this emotional/psychological help is offered by the professionals it can be seen that the mothers are hesitant to use it as they feel that they may be seen as a burden ("*I don't want to be a burden on them...").* This may be supported by Shearn and Todd (2009:19) who explain that mothers may avoid to use the resources provided by professionals as they may feel that it would be pointless since the resources are limited in any case and the mothers may be interpreted as being selfish for seeking support, when they should only focus on their children's needs.

The other professional assistance is also provided through referrals. So when the mothers have a problem and they come to the school to report it, the school usually refers them to the relevant resources. Another way of how the school meets the mothers emotional/ psychological needs is that it gives the mother *sometime for themselves* to think things through when the child in school. This can be seen in the table where one (three percent) indicated that when the child was in school she usually got some time for herself (*"I get at least two hours of sleep or just to relax").* This is supported by Leiter, Kraus, Anderson & Wells (2004:382) where they explain that caring for a mentally or physically disabled child may involve high level of intensity and complexity depending on the kind and severity of the child's disability this leaves the mother with less time for herself to socialize, relax and spending time with the other children as she constantly has to

monitor and care for the disabled child at all times. This shows that mothers with children with disabilities need to be provided with a lot of emotional/psychological support. Shelton, Duerden & Witt (2010:8) also support the above results by indicating that by having the child being looked after by someone else for few hours such as being in school, it gives the mothers a temporary relief from the ongoing responsibility of caring for an individual.

(d) Other help: Needs of the child

In this category only one (three percent) of the mother did not have any specific responses to how they thought the school met their own needs as she thought that, the school´s focus was on the child's needs only ("…*its more about my child's needs...").* With this result is can also be stipulated that, even though the mothers have their own needs they mainly focus on their child's needs as this is seen as the priority and neglect their own need if they are to fulfil the good mother identity (Shearn and Todd, 2001:119). This can be very dangerous for the mother as it can lead to anxiety as well as feeling of guilty which may also lead to the mother being burnout; this is also supported by literature discussed in Chapter three of Burton, Lethbridge & Phipps (2008:361).

The need for economic assistance and help to access it indicated in all the responses in table 5.19, supports the argument made previously about the high direct and indirect costs of having to care for a disabled child, which will be further explored in the following section. As well as literature by Lukemeyer et al. (2000:405) who explains that having a disabled child impacts on the family negatively leading them to slide into poverty as a result of the major direct costs on the behalf of the disabled child.

5.5.2 Economic needs of the mothers

5.5.2.1 Employment situation before and after birth of disabled child and when the child started school

The mothers were asked to indicate what was their employment situation within the three categories namely; before birth of disabled child, after birth of disabled child and when disabled child started school. Their responses are illustrated in table 5.13.

Table 5.20: Employment situation

Employment situation	Before birth of disabled child		After birth of disabled child		When disabled child started school	
	Frequency (f)	Percentage (%)	Frequency (f)	Percentage (%)	Frequency (f)	Percentage (%)
Employed	9	47 %	6	31%	06	31%
Unemployed	9	47 %	11	58 %	10	53 %
Other/no re-sponse/	1	5%	2	11%	2	11%
Total						57

n=19

It should be noted that within this question mothers were allowed to give more than one re-sponse.

Table 5.20 shows that before the birth the disabled child nine (47%) of the mothers were unemployed and the other nine (47%) were employed. However, after the birth of the disabled child the rate of the employed mothers was reduced from nine (47%) to only six (31%) of the participants, while 11(58%) respondents said they were unemployed after the birth of the child. On the other hand the number of those unemployed increased to 11 (58%) after the birth of the disabled child. When the child started school the number of participants that were unemployed remained the same six (31%). When the child started school the level of the mothers unemployed did not change drastically only with one percent difference leaving it to 10 (53%). Within the "other" response-category, the mothers did not know, did not answer or the employment situation was not related to the birth of the disabled child.

It can therefore be concluded that, while the career of some of the mothers seems to have been negatively affected by the birth of the child as explained by Thyen, Kuhlthau and Perin, (1999:1253) in , it did not have as much of a negative impact on it as could have been expected from the literature review. Additionally, no positive effect of the child attending school on the employment situation could be found in this study.

5.5.2.2 Kind of work that respondents can do

Mothers were asked to indicate the type of work that they can do. Results are illustrated in table 5.21 and figure 5.12.

Table 5.21: Kind of work that respondents can do

Type of work	Respondents (f)	Percentage (%)
Unschooled	13	69 %
Schooled	05	26 %
Professional	01	05 %
Total	**19**	**100**

n=19
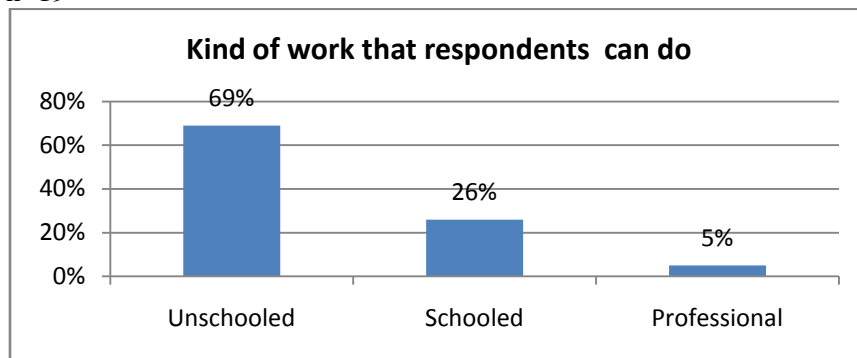
n=19

Figure 5.12: Kind of work respondents can do.

The data in the above figure 5.12 identifies the types of work that respondents could do, ranging from unschooled work to professional work. It can therefore be seen that the majority of the respondents 13 (69%) of the respondents stated that they could only do unschooled work, this could be the result of their low level of education. It can also be seen that five (26%) indicated to be capable of doing schooled work. There was only one (five percent) that indicated that she was able to do professional work. These results may support the results on the level of education for the participants on page seven of this chapter, as well as Richards and Schmiege's (1993:274) findings, that many mothers lacked skills and qualifications required for well-paid jobs. As a result these mothers ended getting into jobs that had low wages and were very unstable, (Richards and Schmiege 1993:274).

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5.5.2.3 Income group of respondent´s household

The income group of the respondents was investigated. The results are illustrated below on the next page in table 5.22.

Table 5.22: Income group of respondent´s household (monthly income)

Income group	Respondents (f)	Percentage (%)
R0-1000	02	10 %
R1001-2000	10	53 %
R2001-3000	03	16 %
R3001-4000	03	16 %
R4001-5000	0	0 %
R5001+	01	05 %
Total	**19**	**100**

n=19
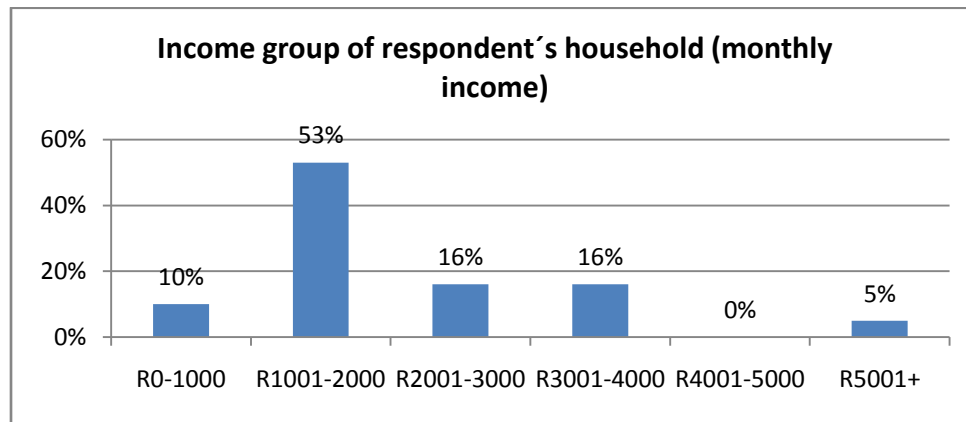
n=19

Figure 5.13: Income group of respondent´s household (monthly income)

The data in figure 5.13 and table 5.22 identifies the range of income between R0 and R5000 or plus per month in intervals of a R1000. It can be seen that the highest income (ten or 53%) of the respondents' household falls in the category of R1001-R2000. Only three (16%) of the respondents indicated their income to fall in R2001-R3000 bracket. Another three (16%) indicated that their income was within R3001-R4000. Only two (10%) of the respondents fall in the lowest category of R0 to R1000 and only one (5%) indicated to earn R5001 or more.

Looking at these results in combination with the direct and indirect costs of caring for a disabled

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child they support literature by Lukemeyer et al. (2000: 406-407) where they explain that the direct and indirect cost for caring for a child with mental or physical disabilities can be much higher than for raising a "normal" child, this gives an indication as to how the already precarious economic situation of mothers in a low-income community can be aggravated by having to care for a disabled child. As explained in the previous sections using Lombard (2008:155) and Guthrie, 2001:32), it was stated that the income that these mothers indicated was their only source of income, again just by looking at all the needs of the disabled child it can be indicated that it is difficult for the mothers to think of going to work as they may be of low income and inflexible leading to higher levels of stress (Ceglowski et al., 2009: 498).

5.5.2.4 Knowledge of financial support available

Mothers were asked to indicate whether they were aware of the support that is available for them and for their disabled child based on the rights they have. Results are illustrated in table 5.23 and figure 5.14 below.

Table 5.23: Awareness of rights for the mother and the child with regards to financial support

Response	Respondents (f)	Percentage (%)
Yes	17	89 %
No	02	11 %
Total	**19**	**100**

n=19
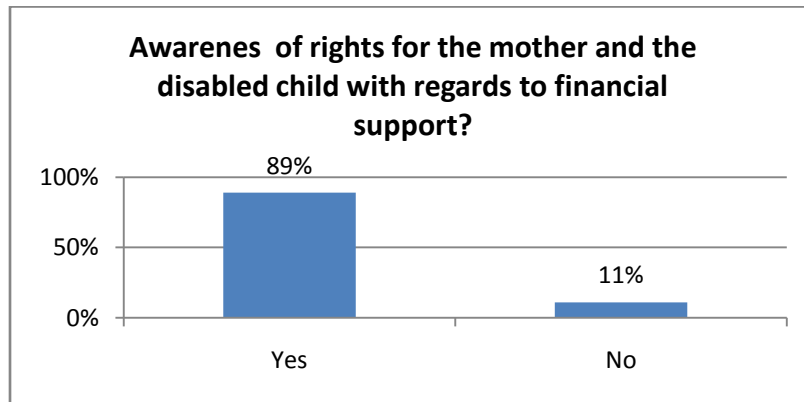
n=19

Figure 5.14: Awareness of rights for the mother and the disabled child with regards to financial support.

It can be seen in the figure and the table above, that the majority of participants 17 (89%)

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claimed to be fully aware of their rights as well as that of their disabled child, which would allow them to protect and support their child. Only two (11%) indicated that they were not aware of their rights at all. It is a very good indication to see that the majority of the mothers know their rights in terms of how to access the social security benefits for themselves as well as that for their mentally or physically disabled child. This might help to explain why there has been an increase in the number of people accessing and receiving social security grants as indicate by the South African Social Security Agency (SASSA) (SASSA, Western Cape Presentation, 2011:3). Another explanation to the increase in the total number of people receiving the grants namely the care dependency and the child support grant may be due to the fact that there is high total rate of children living with disabilities and being cared for by their single mothers in the low income community with no other income and living under the poverty line (Hanson and Sporakowski, 1986: 3) and (Guthrie, 2001: 24).

Mothers were also asked to indicate how they became aware of their rights with regards to accessing social security benefits as well as their child's right as a disabled. The results are presented in table 5.24.

Table 5.24: Mother becoming aware of their and their child´s rights to accessing social security

Theme: How mothers became aware of rights			
Subtheme		**Narrative**	**f (%)**
Profes-sionals	**Read at clinic**	*"Usually when you walk into the clinic they have posters on the wall about these things so I read"*	7 (37%)
	Told by doctors	*"When I went for a checkups with my daughter the doctor told me that I qualified for a dependency grant because I was looking after my disabled child full time and I met all the criteria and he told me about the child support also"*	2 (11%)
	Told by school	*"When we went for a school meeting they mentioned something about them"*	6 (31%)
Subtotal			*15*
Other	**Heard / seen on ra-dio/television**	*"There is a programme on the radio about rights that I like to listen to on Sunday afternoon. They also repeat it Monday mornings.*	4 (21%)
	not answered/not sure	*"I just know them through common sense"*	9 (47%)
Subtotal			*13*
Total			**28**

n=19

(a) Professionals

When the mothers were asked how they became aware of the rights stated above, in total 15 or (79%) indicated that they became aware of them through professionals. Their responses were with regard to professionals were divided into subthemes. These subthemes included; *read at the clinic*, *told by doctors,* and *told by the school.*

In the first subtheme *read at the clinic,* about seven (37%) of the participants answered that they had read about their rights and their child's rights with regards to access to grants at the clinic, when they had gone for checkups or if their child was sick *("...posters on the wall...I read...").* The respondents stated that at the clinic they have all these different posters showing these things.

In the second subtheme namely; *told by the school,* about six (31%) of the participants said that they become aware of the rights after the *school* had informed them about them, especially when they were trying to access their support grant *("...when we went for a school meeting...").*

In the third subtheme, *told by the doctor only* two (11%) of the participants indicated that they became aware of their rights after the *doctor* had informed them *("...the doctor told me that I qualified for a dependency grant...").* In these situations it was usually when the mother had gone to the doctors with the disabled child for assessment on the disability and the doctor had to complete the form indicating whether the child and the mother needed to receive disability grant and so on.

Within all these subthemes it can be seen that the professionals play a big role in informing the mothers on the rights that they have and how they can access these grants. It can therefore be explained using the literature discussed in chapter four by Pillay & Proudlock (2000:72) that professionals are equipped and well informed about rights and the support that is available and how it can be accessed, it is therefore their duty to provide this information to the people that are in need and meet the criteria to access the them.

(b) Other

Within this theme only four (21%) of the respondents indicated that they became aware of the rights as they had them from the radio, or something about it on television. One of the respondents explained that:

"*They have the* <u>*program on the radio*</u> *on Sundays and Mondays talking about these things so I usually listen...*"

With these results it can be seen that the South African Constitution (1996) has done well in reaching out to those that are disabled and those that are providing full time care for the disabled to have access to social security as a result alleviating high levels of poverty. This is evident as seen in Lombard (2008: 155-157) where she explains that the social grants have definitely made a positive impact on those that are receiving them as these grants are developmental in nature.

The nine (47%) other respondents did not give a specific response as they indicated that they just came to know the rights and there was not any specific way that they had learned. For example:

"*...with the children's rights whether they are normal or disabled* <u>*it is a mother's common sense*</u> *to make sure that, that child is fully feed, looked after and taken to the hospital when sick.....(laughs)!*"

The finding above can support Read (1991:562) where is he explains that mothers are usually automatically seen to be the care takes of their children with disability. In line with these finding is Wickham-Seal's (1992:6) where he states that the social identity that is labelled on the care-giving can help in giving an explanation for the fact that the majority of parental care is provided by mothers. This is because mothers are seen to be more nurturing and it is their duty to provide the care that their disabled child needs. These expectations can add a lot of pressure on the mothers which may result in the getting emotionally drained and becoming withdrawn and isolated (Smith et al., 2009:167)

It is therefore necessary that mothers caring for their children with mental or physical disabilities should still be provided with support at their level of need and be encouraged not to ignore their own well-being as they feel that they have to fulfil their social identity of being a caring mother which brings a lot of demands and pressure on the mother leading to burn out (Spalding and Mckeever, 1998:234).

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Using literature by Cichoni (2004: 39), Kegan *et al.* (1999: 370-371) and Lukemeyer et al. (2000: 400-407) economic needs of mothers caring for their disabled children were identified. These needs resulted from various challenges, mostly the high direct and indirect costs of caring for a disabled child, and it was stated that the pre-existing economic situation of the mother, education, employment situation, marital status and economic environment, i.e. low-income community, influence and possibly increase the economic needs of the mother. This was supported by Lombard, (2008:155-157), Dube (200517-18) and *White Paper on Social Welfare of (1997)*, where several ways of meeting these economic needs were identified, in the form of formal support through guaranteed rights, grants (the dependency grant and the child support grant, benefits and schools). For example the mothers needs to provide for her family and the disabled child was met through receiving the financial support 'care dependency grant' which was usually the only source for her household (SASSA Presentation, 2011:11).

5.5.3 Physical needs of the mother

Smith et al. (2009: 167) extrapolate that mothers caring for their disabled child have certain physical needs associated with the process of caring for their child. These needs may differ depending on the specific disability of the child. For example other mothers may need accommodation that would be safe and fitting in relation to their child's disability. In order to find out what their physical needs were the mothers in this study were asked to indicate whether they thought their house and environment was accessible and suitable for their disabled child. The results are discussed below.

5.5.3.1 Accessibility of the house for the disabled child

The mothers were asked to explain whether they thought their house was accessible to their disabled child. Table 5.25 illustrates their responses.

Table 5.25: Equipment of the house

Equipment of the house	Frequency (f)	Percentage (%)
Fully equipped	13	68 %
Not equipped	07	37 %
Other	03	16 %
Total	**23**	

n=19

(a) Fully equipped

Over half of the respondents (13 or 68%) indicated that their house was equipped. Most of these mothers that indicated that their house was fully equipped stated that their house was fully equipped because they had *running water, electricity* and *toilet* in the house. Three of the mothers indicated that their house was fully equipped in the sense that it had a *carpet on the floor* and the house was a ground floor house *without any steps* which was very safe for their children that had disabilities. Below are some of the respondents' explanations with regard to how they expressed how their house was *fully equipped*:

"...well there is <u>water and electricity in the</u> house and we have <u>a flush toilet</u> in the house too, so it's very easy when he wants to go to the toilet especially in the night and then it's also safe you see!".

"I put a <u>carpet</u> in the whole house...it's on the ground floor without steps. This is important because, because of his epilepsy he gets seizures so he can fall anywhere and having a house with a carpet helps as he can fall anywhere and not hurt his head...and this makes me less worried as I know that even if am not there with him and he is in the house I know that he is safe".

"...she uses a wheel chair, so it's nice that we have a bath tub in the house because it's much easier for me to bath her there".

It can be seen from these narratives that the mothers experiences less stress levels when they feel that their environment is safe and meets the needs of their child, resulting in the mothers good physical well-being. Savage and Bailey (2004:112) confirm that mothers may experience positive feelings of being at peace and less stressed and worried if they feel that the environment that they are is safe and enhances their caring role and this also has a positive impact on their health physical well-being. These results also supports Johnson and Yanca's (2007:13) literature where they argue that when there is an agreement or harmony between the mothers and their environment and as a result meeting the needs of their disabled child positively a state of congruity exists.

(b) Not equipped

The results in table 5.25, also illustrate that seven (37%) of the respondents indicated that their house was not fully equipped for their disabled child. Those that stated that their house was not equipped properly said that their house only had a *toilet outside* of the house, and this was not safe for the disabled especially in the night, meaning that if the child wanted to go to the bath-

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room in the night the mother had to go with that child at all times. Another answer stated that the house was not equipped as it is located in the *dangerous neighbourhood.* For example, one of the respondents stated that her house is *right by the road* and there is also of this happening there such as gunfights, selling of drugs. Below is a narrative explaining why one of respondents thinks that her house is not equipped:

"*My shack is <u>right by the road</u>, so there are usually drugs <u>being sold</u>, <u>fights all the time</u> and that it's <u>not safe</u> at all for my children as well as myself. Every night am constantly wondering what will happen in the night I worry a lot because then I have to be very protective over him so that he doesn't get attracted to such life style…*"

In supporting literature by Anderson *et al.* (2007: 4) it can be seen that low income communities are more likely to have poor housing as it can be seen in the quote *("...shack...").*

These results also confirm that in low income communities there is a lot of crimes, and lack of support services as well as high levels of poverty. All these factors contribute to the problems that arise within these communities, for example people selling drugs as a result of poverty and unemployment and that is the only way that they can make their ends to meet (Duncan and Ratele, 2003:46).

It can also be seen that these mothers need to be protected in their communities from the dangers stated above in order to avoid their physical well-being to be affected and also for them to provide effective care for their disable chid, this result correspond with Ceglowski et al., 2009:497-498*).* The results above also confirms the literature from the Department of Social Development (2006:24) where they stated that social welfare services should aim to meet the needs and building on the strengths of the individuals and communities. This should be done through the provision a comprehensive range of services and programmes extend beyond the inherent capacity of individuals and their natural support networks. These services may include protection services where their aim is to safe-guard the well-being of individuals and families. Protection services are usually provided within the legislative framework and include statutory services. These empower designated people or institutions to take specific actions that are deemed necessary to protect the integrity and well-being of the person within the social context of the family and community. Protective services work towards having families, children and individuals living in a

safe and nurturing environment where their rights are promoted and their well-being is ensured, (Department of Social Development, 2006:26).

It can also be seen that not only having a disabled child can negatively influence the mothers well-being but the environment where they are in, also impact their physical well-being (Greson, 2001:24) and (Schaffer and Emerson, 1964:1). This is because they are constantly worried about their environment that they are in. It is however difficult for these mothers to get out of such environment as they are already living in poverty and can therefore not afford to move to a better area where they would feel safe for their disabled child to grow up in (Hanson and Sporakowski, 1986:4).

(c) Other

The other three (16%) did not respond to this question, as they were not sure whether their house was equipped or not equipped especially for the needs of their child, as they only had learning disability.

These results firstly reflect the fact that due to the specific disabilities of the children of the respondents in this study, not many have the need for a specifically equipped house, but rather desire a generally safe house with basic amenities, this can be supported by Butler and Roberts (2004:59). This last point can furthermore be seen as indication of how the low-income environment of these mothers influences their perception of what means "equipped for the needs of the child", as the answers indicated aspects that possibly would be taken for granted by mothers in a different socio-economic environment (Kegan et al. 1999:371).

5.5.4.1 Special equipment for disabled child

Mothers were asked if their child needed or was using special equipment as a result of his/her disability. Results are illustrated below in table 5.26 and figure 5.15.

Table 5.26: Special equipment for the disabled child as a result of disability

Response	Respondents (f)	Percentage (%)
Yes	06	32 %
No	13	68 %
Total	19	100

n=19

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Special equipment for the disabled child as a result of disability

100%	68%
50%	32%
0%	
Yes	No
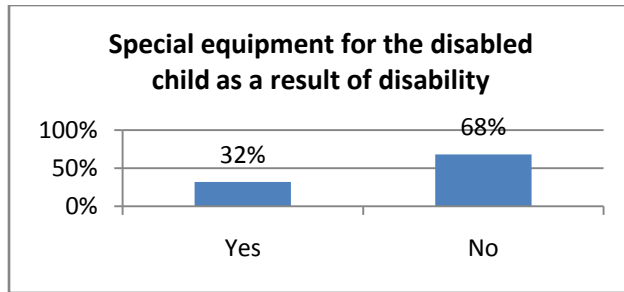
n=19

Figure 5.15: Special equipment for the disabled child as a result of disability

The results in the figure above illustrate that the majority 13 (68%) of the respondents said that their child did not need special equipment as a result of his/her disability. Only six (32%) indicated that their child needed a special equipment. These results confirm Smith et al. (2009:168) that the needs of children with disabilities differ as a result of their level and type of disability.

(a) Type of special equipment for the disabled child

The mothers were asked to name the type of special equipment that their child needed as a result of the disability. Results are illustrated in table 5.27.

Table 5.27: Special equipment needed for the disabled child

Equipment	Frequency (f)	Percentage (%)
None	12	63 %
There is a need but not specified by the respondent	02	11 %
Wheelchair	02	11 %
Hearing aids	02	11 %
Glasses/spectacles	04	21 %
Other	02	11 %
Total	**24**	

n=19

Four (21%) of the respondents indicated that the special equipment that their child needed was spectacles. Only two (11%) of the respondents stated that their child was in need of some sort of equipment but they were just not sure what it was. The other two (11%) said indicated that their child needed a wheelchair, in one case due to cerebral palsy. Another two (11%) of the other participants indicated that their children needed hearing aids as their mental/physical disability has affected their hearing ability. The last two (11%) of the participants were not sure of the answer so they did not respond.

These findings correspond with the literature by, Smith et al. (2009:168), Ceglowski et al. (2009:498), Kegan et al. (1999:370-371) and Leiter et al. (2004:382) discussed in Chapter three, where it was pointed out that the needs of the disabled child and consequently those of the care-giver are dependent on the specific disability. The high number of children who do not need any specific equipment can be explained by the fact that many of children in this study "only have a learning disability.

(c) Obtaining the special equipment

The mothers were furthermore asked to explain how they obtained the special equipment if needed. Results are illustrated in table 5.28

Table 5.28: Obtaining the special equipment for disabled child

Obtaining special equipment	Respondents (f)	Percentage (%)
Doctors prescribed it and they got it	06	32 %
Other	13	68 %
Total	19	100

n=19

The above table illustrates that 13 (68%) of the respondents obtained their equipment through other ways, or did not need any. The other ways other than the equipment being prescribed by the doctor included; buying themselves or receiving from other people. The equipment which six (32%) respondents indicated that they got from the doctors were mostly wheelchairs, hearing aids and spectacles. The respondents indicated that they had to get such equipment from the doctors as they could not afford it. Another point is that their child needed to be examine properly in order to meet the criteria to receive needed equipment these, these findings are confirmed by Lukemeyer, et al. (2000:405) as they indicate that equipment such as wheelchairs are part of the direct costs that mothers have to spend on and these are usually very expensive. Office (2011: 110) also supports these results, as in her research she found that most of the participants could not afford such equipment as a result they had to be provided by orthopaedic hospitals, physiotherapists, charity organisations, schools or the rehabilitation officer.

5.5.4.2 Medical check-ups for the disabled child

(a) Regularity of going for medical check-ups with the disabled child.

The mothers were asked to indicate how often they went for checkups with their child. Results are illustrated below.

Table 5.29: Regularity of going for medical check-ups with the disabled child

Regularity	Respondents (f)	Percentage (%)
Daily	0	0 %
Once a week	4	21 %
Once a month	6	32 %
Once a year	3	16 %
Never	2	10 %
Other	4	21 %
Total	**19**	**100**

n=19
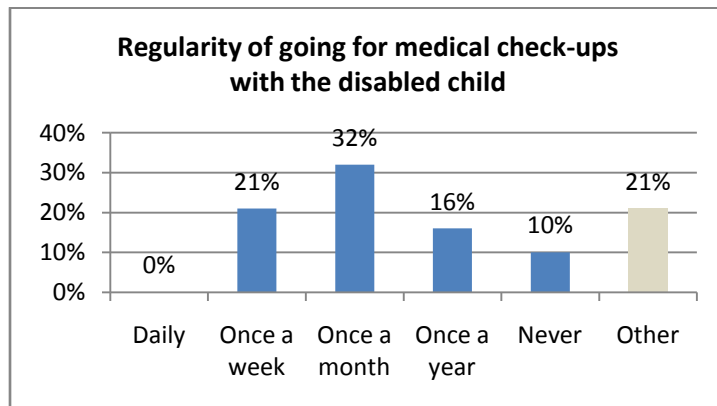
n=19

Figure 5.16: Regularity of going for medical check-ups with the disabled child.

According to Leiter et al. (2000:115) all children may need to go for checkup at their doctors or specialists. However children that have disabilities may need to go for checkups more often than the children without disabilities. This can be a positive or a negative experience for the mothers who are the sole caregivers (Resource for Cerebral Palsy 2011: 3), (Lukemeyer et al., 2000:405) and (Kegan et al., 1999:372). As most of them are unemployed, they need assistance, and without it they can have an effect on their well-being as well as on their caring role.

It can be seen in figure 5.21 above, none (0%) of the respondents indicated that their child needed to go for medical check-ups daily. About four (21%) of the respondents stated that there

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child needed to go for check-ups at least once a week. The highest number of the respondents six (32%) indicated that their child needed to go for check-ups at least once a month. Most of these were checkups in order to receive medication and checking the progress of the child. The other three (16%) indicated that their child needed to go for medical checkups only once a year. Lastly four (21%) of the mothers choose the other option, where categories such as when the child gets sick or I have been invited were applied.

With these results it can be stated that medical check-ups are very important for children with mental or physical disabilities even though they do not go for check-ups every day, the results still indicates that the children have to be monitored on a regular basis even if it is only *once a month*, which clearly supports Leiter et al. (2000:115).

(b) The place that the disabled child goes for medical check-ups

The mothers were asked to indicate where they took their child for medical check-up.

Table 5.30: The place that the disabled child goes for medical check-ups

Place for check-ups	Respondent (f)	Percentage (%)
Stellenbosch	04	21 %
Tygerberg	04	21 %
Cloetesville	10	53 %
Kuilsriver	01	05 %
Total	**19**	**100**

n=19
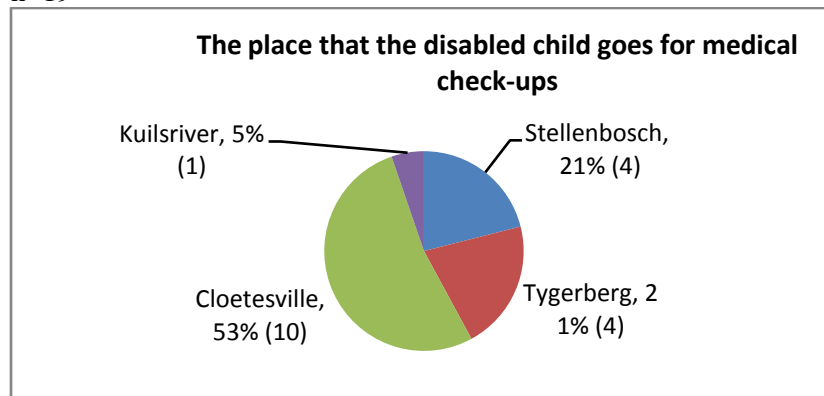
n=19

Figure 5.17: The place that the disabled child goes for medical check-ups

The results in table 5.30 and figure 5.17 indicate that the just more than half (ten or 53%) of the respondents go to Cloetsville clinic for their child's checkup. It can also be seen that four (21%)

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of the respondents take their children to Tygerberg hospital, and the other four (21%) take their children to Stellenbosch hospital. Only one (5%) respondent indicated that they go all the way to Kuilsriver. Those respondents that indicated that they go to Cloetsville clinic they stated that it was because it is near as it is located right in their community. Another reason was that, that was the only clinic in the community that they could take their child to. These results confirm Phelps (2009:29) literature that the low income communities have limited resources such as health care services and other support services.

(c) Distance

The mothers were asked to indicate how far they have to go to get to the place where their child received checkups.

Table 5.31: Distance of place for check-ups from home

Distance	Respondents (f)	Percentage (%)
It is near our home/walking distance	10	53 %
Far, I have to drive	09	47 %
Total	**19**	**100**

n=19

It can be seen from the table above that just over half (ten or 53%) of the respondent live in Cloetsville, this explains why they go to Cloetesville clinic, as it is in walking distance near their home. About nine (47%) indicated that the place where they had to go for checkups was quite far and they had to drive to get there. This meant that they had to arrange transportation to get there, this was quite stressful for the mothers as sometimes they did not have money for transportation. Below is one of the narratives from one respondent:

"...we have to go to Tygerberg children's hospital, it is far and we need to go by car, so I have to save money for that and it can be expensive because the money that I get is his child support and the dependency grant. It is stressful if there is no money because I have to wait for the transport from the hospital..."

It can be seen that just over a quarter of those respondents that indicated to have to drive to the hospital for check-up it was stressful for them as they did not have transport money. This confirms the research results by Anderson et al. (2007:4) and Lukemeyer, Meyers, Smeeding, 2000: 399; Vecchio, Cybinski, & Stevens, 2008:784) done in the USA, where they found that 40% of the mothers that had children with disabilities experienced feelings of stress as especially when

they had to take their child for checkup as a result of financial constraints especially when it came to transportation.

(d) Need for transportation

The mothers were furthermore asked to indicate whether they needed transportation to get to the places for their child's checkups.

Table 5.32: Need for transportation to go to place for check-ups with the disabled child

Response	Respondents (f)	Percentage (%)
Yes	10	53 %
No	09	47 %
Total	**19**	**100**

n=19
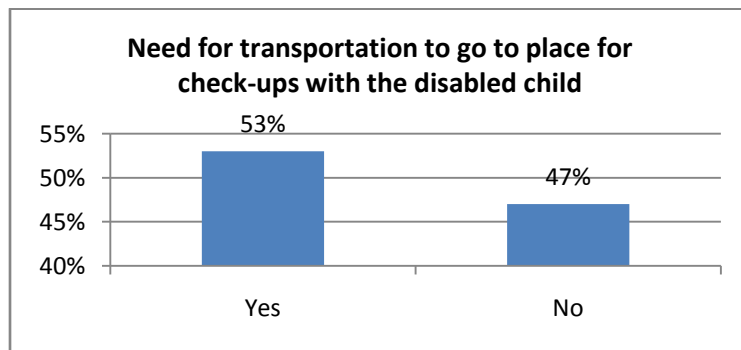
n=19

Figure 5.18: Need for transportation to go to place for check-ups with the disabled child

It can be seen from the results above that 10 (53%) of the respondents need transport to the place for their child's checkups. Only nine (47%) indicated that they needed to get transport to get there. This indicates that most mothers in these low-income communities do not choose a clinic due to the best medical expertise available there, but rather on grounds of proximity, which limits their alternatives on accessing possibly better medical treatment for their child, these results can be supported by Wickman- Seal (1992:9).

(e) Mothers' feelings about the child's medical check-ups

Mothers were asked to explain how they felt and experienced the idea of taking their child for checkups. The theme and categories were derived are discussed in table 5.33.

Table 5.33: Mothers' feelings about the child's medical check-ups

Theme: Feelings about child´s medical check-up		
Category	**Narrative**	**f (%)**
It is fine	*"I don´t mind as they are best for my child. We only go there to collect his medication so <u>it's fine</u>, because he has to take his medication"*	2 (11%)
It is very helpful	*"they are always <u>very helpful</u> because <u>they check if she is doing okay and if there are any problems that have risen</u>"*	9 (47%)
It is exciting for the child	*"<u>it is very exciting for my child</u>, because we go for checkups in Tyger-berg so it's a quite a drive then my child gets excited to be on the road and shows me places where she has been during school trips, so am always happy to see her excited like that"*	2 (11%)
It is a waste of time	*"The thing is that he is just too hyper and has some sort of learning disability which we manage well at home so <u>I don't see the point going to have him checked at all times</u> so <u>it is a waste of time somehow</u>, because his tablets already helps him"*	1 (5%)
Other/not an-swered/not sure	*"I am very happy that <u>we don't have to go for checkups at all</u> times because it is expensive to go all the way to the big hospital for children and if we had to go I guess it would be a normal thing..."*	8 (42%)
Total		**22**

n=19

It should be noted that the mothers were allowed to give more than one response with regard to how they felt and experienced taking their disable child for check-ups. Each of the categories that has been identified above within the theme in table 5.33, will be discussed separately below.

(i)   It is fine

Only two (11%) of the respondents in this category indicated that the medical check-ups for their child were fine and they know that they were important for their child *("its fine...best for my child...").*

(ii)   It is very helpful

In this category it can be seen that nearly half (nine or 47%) of the respondents indicated that medical check-ups were very helpful for their child *("...very helpful...")* as they knew that their child needed these checkups in order to make sure that all the needs were being met. Another point which might explain why the mothers found these medical checkups to be useful is because

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they get to hear about their child's progress and learn if there are any new needs that have developed (*"...they check if she is doing okay and if there are any problems that have risen..."*) and learn how they could deal with them which in the end could help in reducing feelings of stress and anxiety in the mothers, these results are in line with Graungaard and Skov, 2006:301). This is because they explain that once the mothers/parents go to the doctors for checkups with their disabled child they at least get to know whether everything is okay and if there is anything new then it can be diagnosed and they deal with it rather than not knowing what the child's problem.

(iii) *It is exciting for the child*

Furthermore, two (11%) of the respondents said that going for check-ups with their child was quite an exciting experience for the child (*"...it is very exciting for my child..."*). This was more the case for the mothers that had to travel far such as going to Tygerberg hospital, as this was special trip for the child and the child would be excited on seeing different places, as can be seen in the narrative in the table and below:

"it is very exciting for my child, because we go for checkups in Tygerberg so it's a quite a drive then my child gets excited to be on the road and shows me places where she has been during school trips, so am always happy to see her excited like that"

Using this result it can be argued that the even though the mothers live in poverty without enough financial support to use for transportation to take their child for medical check-ups they still sacrificing their own financial needs. They use that little money they have for transportation to take their child for checkups just to make the child happy and excited and also to fulfil their role/identity as a good mother. These findings correspond with views of Koshti-Richman (2009:19) and Spalding, McKeever, 1998:234).

(iv) *It is a waste of time*

It can also be seen in the above table that only one (5%) of the respondent indicated that the check-ups were a waste of time. Her explanation was that her child does not have a severe disability, he is just slow, and therefore going for check-ups does not really make a big difference (*"....it is a waste of time..."*).

(v)   Other/not answered/not sure

The other eight (42%) of the respondents did not have any response with regards to their feelings on them taking their child for the check-up as they felt that it was just a normal process for them to do that *("...a normal thing...").*

Similar to responses to previous questions and discussions, these answers show that the needs of mother and child differ according to specific kind and severity of the disability as confirmed by Savage and Bailey (2004:11). Moreover, as pointed out in Chapter three using literature by Phelps (2009:29), Graungaard and Skov (2006:297) and Leiter, et al. (2004:382), it shows that regular contact with doctors plays an important role in keeping the mothers informed and more capable to properly deal with their child´s disability; it can even be a positive experience for mother and child (Shearn and Todd, 2000:115).

5.5.4.3 Physical care of the disabled child at home

The mothers were asked if they needed any help with the physical care of their child. Table 5.34 and figure 5.27 illustrate their responses.

(a) Need for help with physical care

Table 5.34: Need for help with the physical care of the disabled child (e.g. lifting, transferring, positioning)

Response	Respondents (f)	Percentage (%)
Yes	04	21 %
No	15	79 %
Total	**19**	**100**

n=19
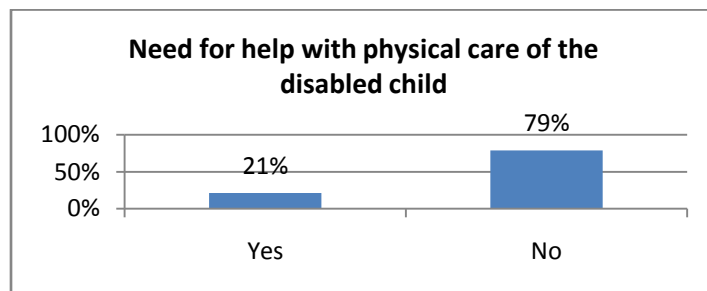
n=19

Figure 5.19: Need for help with the physical care of the disabled child

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From the results above it can be seen that the majority (15 or 79%) of the mothers did not need any help in caring for their disabled child. About four (21%) of the respondents stated that they needed help with the care of their disabled child. For those 79% that indicated that they did not need any help, they stated that it was because they were not sure of the *quality* of care that others would provide for their child so rather they take care of their own child.

Below is one of the narratives from one of the respondents:

"...am very hesitant or not sure whether others would look after my child with the same <u>standard</u> as myself...I guess I have some unknown fears..."

The result above and the narrative supports the literature by Koshti-Richman (2009:19) that states that sometimes mothers can hesitate to have someone look after their child as they may not be sure of the quality of care that the others may provide for their child.

Another reason why the mothers indicated that they did not need any help was because they saw is as their responsibility to look after their disabled child and they felt experienced feeling of guilty and anxiety if they left their child with someone else. Below are two examples of narratives from two respondents in this study:

"...it is my own child and I think I would <u>feel bad</u> if I left her with someone else because I am the mother and it is <u>my responsibility</u> that I look after my child whether she is disabled or not..."

These results support Figley (2000:17) and Shearn and Todd (200:119), where they explain that mothers usually feel that it is their responsibility to care for their disabled child, in order to fulfil the role of the good mother. It should be noted that these mothers should still be provided with support such as counselling because if they become to see that they are not fulfilling their role and responsibility of a good mother it may lead to high anxiety levels and feelings of guilt (Foster et al., 2009:187).

(b) Type of assistance needed

The mothers were asked to indicate what type of assistance they needed. Results are illustrated in table 5.35.

Table 5.35: Type of assistance needed with the physical care of the disabled child

Theme: Help needed with physical care of child		
Subthemes	**Narrative**	**f (%)**
No assistance	*"He is able to feed himself and wash himself, and can walk. So there is <u>no need for help</u> its only his brain that has some-thing going "*	9 (47%)
Someone to look after child after school	*"It would be very helpful to have <u>someone who can look after my child after school</u> so that <u>I can at least go look for work so that I can have enough</u> money for the house and the other children"*	4 (21%)
Other/not answered/not sure	*"am not sure"*	7 (37%)
Total		**20**

n=19

Within the identified the identified theme, several subthemes were also identified, each of these subtheme will be discussed separately.

(i)   No assistance

It can be seen in the table that nearly half (nine or 47%) of the respondents indicated that they did not need any help with the physical care of their mentally or disabled child *("...no need for help....")*. Those mothers that indicated that they did not need any help they stated that their child was not severely disabled as he was able to walk, feed themselves and wash themselves which was a relief to the mothers an example of the respondent narrative may be seen below:

"...He is able to feed himself and wash himself, and can walk. So there is <u>no need for help</u> it's only his brain that has something going ..."

This supports literature by Leiter (2004:382) and Foster, et al. (2009: 187-188) that the severity of the child's disability and needs determines whether the caregiver may need assistance or not. Others indicated that they did not need any help as they thought that no one would want to look after their disabled child. Below is one of the narratives:

"...I don't need any help because I don't think anyone want to look after her, the friend that I have also have their own children to look after so I don't think that they would want to look after my child, they also have their own responsibilities...".

(ii)   Someone to look after the child after school

Using literature by Smith *et al.,* (2009:167) it was explained that mothers that are full time care givers for their disabled child such as Autism Spectrum Disorder may experience a lot more negative experiences and poor well - being as they do not have time for themselves. This is because they have to devote their time to their disabled child. In this study it was found that that four (21%) of those that indicated that they needed assistance/ help with someone coming to look after the child after school hours. This is because these mothers were not able to work as they had to care for their child after school; however they indicated that they would wish to get a job to earn some income.

"...I can at least go look for work so that I can have enough..."

It can be seen that as much as the mother sacrifice their own needs of economic needs they still have a need to go and work as this may also bring some independence rather than relying on the grants/social security benefits that they receive. In their research study Shearn and Todd 2009:19) found that the mothers that had children with disabilities expresses the need to work but they did not express it to others as they feared of being judged by other as well as the professional. This also shows that these mothers are in need of financial support as they are living in poverty (Thyen, Kuhlthau and Perin, 1999: 1235)

(iii)   Other/not answered /not sure

It can also be seen that in the other category about seven (37%) of the respondents did not give a specific answer with regards to the type of assistance they needed *("...am not sure...").* Others just indicated that they did not know or did not respond at all.

5.5.4.4 Assistance for the mothers

   (a) Support systems for mothers to get assistance with caring for their disabled child

Mothers were asked to indicate where they got their assistance in order to care for their disabled child. Results are illustrated in table 5.36 and figure 5.28.

Table 5.36: Support systems for mothers to get assistance with caring for their disabled child

Support systems	Frequency (f)	Percentage (%)
Churches	02	11 %
Nongovernmental Organizations (NGOs)	02	11 %
Community workers	0	0 %
Friends	08	42 %
Family	12	63 %
Social workers	02	11 %
School	06	31 %
Support Groups	01	05 %
Total	**33**	

n=19

With this question mothers were allowed to select more than one option.

Table 5.36 illustrates that over half (12 or 63%) of the respondents which was the highest, indicated that they get their assistance from their family. The second highest assistance eight (42%) comes from friends. Table 5.36 also illustrates that the special school that the children attend also provides a lot of assistance for the mothers in caring for their child with disabilities. Only two (11%) of the respondents indicated that they received assistance from church. Another two (six percent) of the respondents indicated that they received assistance from NGOs in their community. It can also be seen that two (11%) of the respondents indicated that they received assistance from social workers. Only one (5%) of the respondents indicated that they received assistance from support group.

The main finding of this section on the physical needs of mothers caring for their disabled children is that these needs differ greatly according to the kind and severity of disability of the child determines their need. This is supported by Girard (2010:9) and Phelps et al. (2009:27). The effect of the meso- and exo-system, a low-income community, on the needs and perceived needs, an effect on the micro-system, of the mothers in this study became clear in several instances;

most clearly in the choice of clinic due to proximity and not expertise of the medical practioners, as well as the needs named regarding the equipment of the house (Johnson and Yanca, 2007:13).

5.5.5 Social needs of the mothers

Using literature from Savage and Bailey (2004:113), Wickham-Seal (1992:6-9), Judge (1998: 267) and Floyd and Gallagher (1997:359) several social and cultural challenges and resulting needs of mothers caring for their disabled children were identified. Some of these social needs included; the need to socialize with other mothers and friends, need for support informal and formal support. The following questions aimed at exploring the experiences of the mothers with regards to several of these needs, although due to time and space constraints not all could be explored. The mothers were asked to give descriptions of the impact and experiences of having and providing full time care for their disabled child on the aspects identified below.

5.5.5.1 Mother to child relationship and the other children within the family

The first question aimed at establishing in how far the disability of one child had affected the relationship between the mother and other children in the family.

Table 5.37: The mother to child relationship and with the other children within the family

Relationship	Frequency (f)	Percentage (%)
It is fine	8	42 %
Much closer now	6	31 %
Strained	1	05 %
Other/not answered/not sure	6	31 %
Total	**21**	

n=19

The table above illustrates that eight (42%) of the respondents has a *fine relationship* with their disabled child as well as with the other children within the family. It can also be seen that six (31%) of the respondents indicated that the relationship with their child was *much closer* as they were spending a lot of time together. Only one (5%) identified their relationship with their child to be strained as well as that of the other children. Looking at the results above it can therefore be stated that even though caring for a disabled child may bring a lot of challenges and disruption to the family other mothers still manage to experience positivity in their caring role such as becoming more close to the disabled child as well as the other children within the family. These findings are in line with literature by Phelps (2009:29).

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5.5.5.2 Marital relationship

The mothers were asked on how their marital relationship was with regards to caring for the disabled child. Their responses have been divided into subthemes that are identified in table 5.38. Each of the subthemes will be discussed separately.

Table 5.38: The mothers' marital relationship with regards to caring for the disabled child

Theme: Marital relationship		
Subthemes	**Narrative**	**f (%)**
It is fine	*"I am not married but am living with my boyfriend who is very supportive we <u>get on well</u> ..."*	3 (16%)
It has brought us closer to-gether	*"Since we learned about our child's disability, we have <u>become even much closer</u> and we try our best to be the best parent we can to our daughter and make her feel as normal as possible"*	4 (21%)
We divorced	*"After a year we discovered that he had the disability I had to pay a lot of attention to him as I was a new mother and so on.it took my husband very long to accept the fact that our child would never walk, things were just not working out and I became so stress.......then <u>we divorced</u> but he still supports me financially"* *"I am divorced, but the divorce had nothing to do with my child's disability. So this question does not apply to me"*	3 (16%)
No time for dating	*"Am single and don't really have time to date, <u>I feel that my priority is my child</u> maybe in the future I will"*	11 (58%)
Total		**21**

n=19

(a) It is fine

Within this theme three (16%) of the respondents indicated that their marital relationship was fine *("...get on well...")*. These mothers indicated that their marital relationship was *fine* as their partners were very supportive in looking after the disabled child. This supports the literature that if mothers are provided with enough support on their level of need they are more likely to cope better as all their other needs are being met resulting in a state of congruence (Johnson & Yanca, 2007:13).

(b) It has brought us closer

It can also be seen that the child's physical/mental disability brought about four (21%) of the marriages closer together, as they had to learned to support each other in caring for their disabled child *("...we have become even much closer...")*.

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(c) We divorced

Another three (16%) of the respondents indicated that they were divorced *("....we divorced...").* As it can be seen in the narrative above, the respondent indicated that she had to focus her attention to her disabled child and this result in her getting divorced as the husband did not support the mother, below is her narrative:

"...I had to pay a lot of attention to him as I was a new mother and so on...It took my husband very long to accept the fact that our child would never walk, things were just not working out and I became so stress.......then <u>we divorced...</u>"

This result supports Floyd and Gallagher (1997:359) as they extrapolate that having a mentally or physically disabled child impacts and disrupts the family relationship and dynamics, the Paediatrics Nursing News (20004:4) also supports these results. It is therefore necessary that families that have children with disabilities should receive relationship counselling in order to help them with how they can deal with caring for their disabled child at the same time not neglecting their other relationships.

It should be noted the some of the respondents clearly stated that their divorce had nothing to do with the child's disability, below is the respondents' narrative with regard to the divorce:

"I am divorced, but the divorce had nothing to do with my child's disability. So this question does not apply to me"

(d) No time for dating

The 11 (58%) of the respondents did not respond to this question accordingly as they did not have time to be dating or be involved with anyone as they had to focus on their disabled child *("Am single and don't really have time to date, I feel that my priority is my child...")*

This result support the literature by Adams, et al. (1999:962) as they explain that mothers may devote their time to caring for their disabled child as a result their interaction with the other people or forming new relationships may decline. With this result it can be stated that these mothers need both formal and informal social support so that they do not become isolated and withdrawn completely as this would result in poor social as well as emotional well-being (Smith et al., 2009:167).

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5.5.5.3 Relationship with extended family/relatives and friends

The mothers were asked on how their extend family/ relationships were with regards to caring for the disabled child. Their responses have been divided into subthemes that are identified in table 5.39. Each of the subthemes will be discussed separately.

Table 5.39: The mothers' relationships with extended family/relative and friends

Theme: Relationship with extended family, friends and relatives		
Subthemes	**Narrative**	**f (%)**
It is fine	*"We are fine they help sometimes but we not too close"*	5 (26%)
They are supportive and under-standing	*"I live on the same street with my relatives and we are very close. They help me a lot with my daughter if i have to go work, then my mother or aunt come to look after her or take her to their house"* *"My family is very religious so they support me a lot and give me a lot of encouragement."*	11 (58%)
Stressful and unsupportive	*"everything is my fault, they blame me for everything, they are very unsupportive and it is really stressful"*	1 (5%)
No relationship because of long distance	*"My family lives too far away in Joburg so we don´t really have a helping relationship even though i wish i did."*	2 (11%)
Other/not answered/not sure	N/A	5 (26%)
Total		**24**

n=19

(i)   It is fine

Table 5.39 above illustrate that five (26%) of the respondents indicated to have a *fine* relationship with their extended family members relatives and friends even though they were not very close *("we are fine…")*

(ii)   They are supportive and understanding

The 11 (58%) indicated that they had a very good relationship with their extended family members relatives and friends as they were very supportive and understanding *("...they help me a lot …")* the other respondent indicated that her family was supportive and very encouraging ("*…they support me a lot and give me a lot of encouragement").*

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(iii)   Stressful and unsupportive

Only one (5%) of the respondents indicated that their relationship with their extended family members/ relatives and friends was stressful and unsupportive as she was always seen to be the cause of problems ("…*my fault, they blame me for everything...*"). The respondent also indicated that because the family was very unsupportive it was too stressful for her ("*...unsupportive and it is really stressful*")

(iv)   No relationship because of long distance

Only Two (11%) of the respondents indicated that they did not have any relationship with their extended family members relatives and friends as they lived too far from them ("*lives too far away in Joburg so we don't really have a helping relationship*").

(v)   Other

In the "other" category five (26%) of the respondents did not respond much to this questions.

In this whole section based on the theme of *relationships with extended family/relatives and friends* it can be stated that those that had *fine and supportive* relationships seemed to cope better compared to those with strained relationships and of those that had family leaving far from them. This means mothers need to be provided with suitable and high quality social support as this is an important factor in moderating the impact of caring for a child with mental or physical disabilities as explained by Savage and Bailey (2004:14).

Using the ecological perspective it can therefore be stated that the mothers should be provided with social support on all levels namely micro-level, meso level, exosystems (Gregson, 2001:24) and (Bronfenbrenner, 1979:3) and macro systems, if they are to provide effective care for their disabled child and resulting in their own needs also being addressed. This social support should be provided both formally and informally (Judge, 1998:267).

5.5.5.4 Professional and community interaction

The mothers were asked on how their interaction with the professionals and the community. Their responses are outline in table 5.40.

Table 5.40: The mothers' interaction with professionals and the community

Interaction	Frequency (f)	Percentage (%)
It is fine	06	31 %
Supportive and understanding	10	53 %
They are judgmental of me	04	21 %
No interaction	02	11 %
Other/not answered/not sure	01	05 %
Total	**20**	

n=19

From the results above it can be seen that the respondents in the study have a positive relationship with the professionals and community interaction. For example, in table 5.40 it can be seen that six (31%) of the respondents indicated to have a *fine interaction* and relationship with the professionals and community. The results also illustrate that over half (ten or 53%) of the respondents indicated to have a *supportive and understanding* professional and community interaction. The other four (21%) of the respondents indicated they *did not have a good interaction* with the professionals and community as these are very judgmental. Only two (11%) of the respondents indicated that they *did not have any interaction* with the professionals and community.

The results of this section on the mother's social needs and experiences indicate that for the majority of the respondents indicated that the disability did not have negative effects on the relationship with family members, this is also confirmed by literature by Phelps et al. (2009:27) as they explain that the mothers can also experience positivity within their social well-being as a result of providing care for their disabled children. Regarding the marital relationship the majority of mothers even said that they became closer, which supports the possible positive effects highlighted by Phelps et al. (2009:29). However, the negative impact of the child´s disability on some of the relationships (marital and with other family members) was also to be expected according to what was discussed using literature by Floyd and Gallagher (1997:359), Foster et al. (2009:187-188) and Smith et al. (2009:167). The results furthermore indicate that family support

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plays an important role for the mothers and has been found to be the strongest support system (Judge, 1998: 267).

5.5.6 Emotional needs of the mothers

Closely connected to the social needs discussed above are the emotional needs, or the mental well-being described by Girard (2010: 1-12), Dyson (1993) and Floyd and Gallagher (1997), that were described in chapter three will be explored in this section. It was described with support from literature by Figley (1995:10), Burton, Lethbridge & Phipps (2008:361) that caring for a disabled child can have negative effects on the mental well-being of the care-giver, such as stress, stress-related illness, sleep deprivation, feelings of guilt, compassion fatigue and others. According to literature reviewed earlier, the psychological, physical and emotional well-being of these mothers can be positively improved by receiving support from professionals or relatives/friends (informal support) (Kozachek, Stern and Elsea, 2009:187).

5.5.6.1 Assistance in the caring role when worried or unhappy

The mothers were asked to indicate on who assisted them when they were worried or unhappy. Table 5.41 and figure 5.27 illustrate their responses.

It should be noted that in this questions the respondents were allowed to select more than one option.

Table 5.41: Assistance in caring when worried or unhappy

Emotional Support	Family (f)	Percentage (%)	Other persons (f)	Percentage (%)
Listen to your problems	12	63 %	12	63 %
Support you in crisis	11	58 %	09	47 %
Reassure you	09	47 %	10	53 %
Refer you to support services	03	16 %	14	74 %
Other	01	05 %	02	11 %
Subtotal	**36**		**47**	

n=19
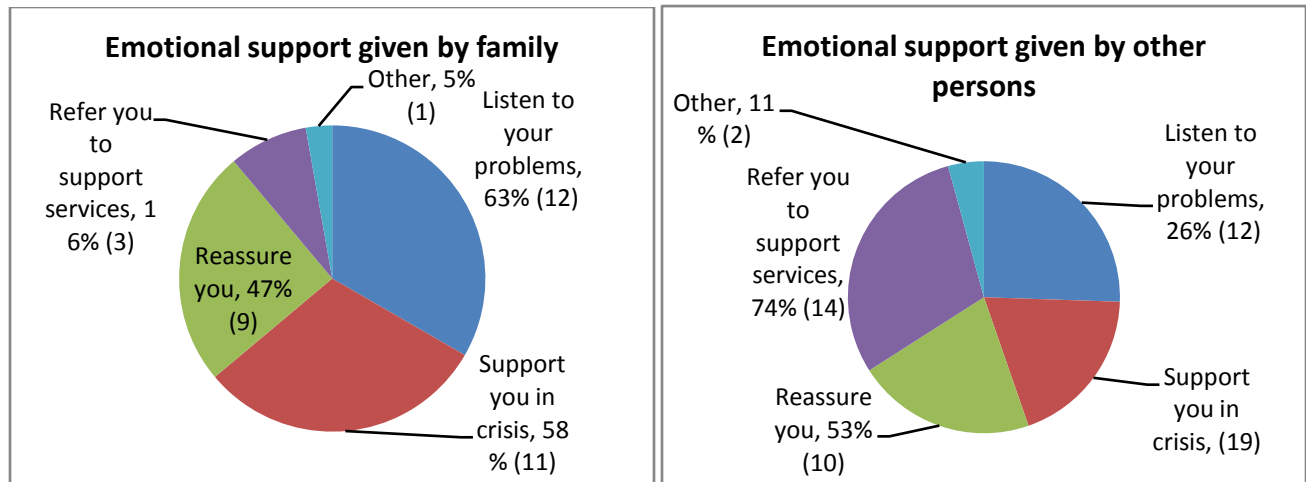
n=19

Figure 5.20: Assistance in caring when worried or unhappy

From the above table 5.41, as well as the figure 5.20, it can other persons provide the majority of the support to the mothers. However, the specific ways in which family members and other persons provide support differs. This is particularly clear in the answer "refer you to support services", where only one (5%) of the respondents said this was done by "other persons" and only three (16%) said this was done by family members. Not only is this a strong difference, this difference also makes up completely for the overall difference between family members and other persons on who provides support. About 12 (63%) of the respondents indicated that their family members, specifically their mother and husband, were always there to listen to their problems whereas only 12 (63%) indicated that other persons listened to their problems. In 11 (58%) of the respondents support in crisis was received support from family, whereas nine (47%) indicated to receive support in times of crises from others. It can be seen that with reassurance, 10 (53%) respondents indicated to receive from family, whereas nine (47%) indicated to receive assurance from other people. Referring to support services only three (16%) the responded indicated to be referred by their family.

These results do not support literature discussed earlier, for example Kristen Harknett (2006:174), who indicated that the family is the main source of support for mothers with children with disabilities.

5.5.6.2 Experience/ feelings of the type of emotional support received

Participants of the study were asked to explain their experiences with the type of emotional support they received. The themes and sub-themes that were derived are discussed in table 5.42

Table 5.42: Experience of emotional support received

Theme: Emotional support received			
Subtheme	**Category**	**Narrative**	**f (%)**
Positive	Very happy about support	*"I am <u>very happy and thankful</u> that my mother is very supportive of me. I don't know what I would do without her* *"I am also <u>very happy that my boyfriend is very suppor-tive and understanding</u> and has learned to be very patient with me and our son..."*	14 (74%)
	Privileged	*"<u>I feel really privileged</u> that my grandmother is still alive and supporting me. She is always there for me. I tell it is such a privilege"*	7 (37%)
Subtotal			*21*
Negative	Could receive more support	*"...am happy that my friend support me but <u>I wish my husband could be more supportive at times</u>...like taking the child out without having me to come all the time..."*	7 (37%)
Subtotal			*7*
Other/not an-swered/not sure		*"my family lives far from me so I don't get much support from them*	3 (16%)
Total			**31**

n=19

(a) Positive experience

Table 5.42 illustrates that within the category for *<u>very happy about the support</u>* the majority (14 or 74%) of the respondents indicated that they were very happy with the support they were re-ceiving *("I am very happy and thankful...")*. The other respondents explained that *"I am also very happy that my boyfriend is very supportive and understanding..."*.

In the second category of the positive subtheme, *<u>privileged,</u>* it can be seen that that seven (37%) indicated that they felt privileged to receive support *("<u>I feel really privileged...")</u>*. This means that in total 68% of the respondents have positive feelings about the emotional support they re-ceive. Families, partners, grandparents and friends were named by the respondents as those pro-viding support, or not. Consequently, these findings support the literature from Kristen Harknett (2006:174) who explains that the social networks and family support are an important source of informal support. In addition, some answers indicate that some of the respondents in the study

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would not cope if they did not have such support from their family, as they are living in poverty and do not have enough money to support themselves. Therefore such support from their family is needed and when it is provided it means a lot to them.

(b) Negative experience

Only seven (37%) of the respondents, had negative feelings about the emotional support they received, they all stated they would need to receive more support *("I wish my husband could be more supportive at times.")*. This finding confirms Shearn and Todd's (2000:16) research results that indicated that sometimes husbands were very unsupportive of the mothers in caring for the disabled children and the mothers stressed that they wished for their husbands to be a little more supportive. It can therefore be stated that fathers/husbands should be provided with training and support to learn how they could help their wives as this would result in a good working relationship and therefore reduce the pressure of providing care by the mother herself.

All the findings in this theme are supported by literature by Lori Walton (2010:3) discussed in Chapter three who emphasized the positive effect of emotional support by family members and social networks on the emotional well-being of the mothers.

(b) Other

Within this subtheme some mothers did not respond at all while only three (16%) of the respondents indicated that they did not receive and experience any emotional support as their family were living far from them *("...my family lives far from me so I don't get much support...")*. These mothers expressed that they would love to receive support from their family as it is very stressful for them living far from family and not having anyone to talk to or to reassure them, as this can be overwhelming for the mothers. Below is one of the narratives from one participant:

"...my family stays in Joburg with my other two daughters am here alone with this one and therefore don't get much support from them. It is very stressful and overwhelming at times as we don't talk much as much as I would want to..."

The findings from these narratives indicate that the participants with no emotional support from relatives or a boyfriend as they live far from them are more likely to experience feelings of stress, loneliness and depression, as they have no one to listen to them and talk to about their problems, leading to the feelings of being overwhelmed and therefore isolation. These results are supported by the findings of Richardson and Schmiege (1993:278), who explain that, because

mothers with school going children are overwhelmed with their problems, they become socially isolated and may even be exposed to mental illness such as depression.

5.5.6.3 Assistance with making important decisions

Participants were asked to identify those who assisted them in their household when it came to making important decisions regarding aspects ranging from family relationship and caring for their disabled child. The data is illustrated in Table 5.43.

Table 5.43: Assistance with making important decisions

Theme: Assistance with important decisions			
Subtheme	**Category**	**Narrative**	**f (%)**
No assistance	Self-help	*"I like making my own decisions you know! At the end of the day yourself is the one that can have a final say about anything"*	8 (42%)
Family assistance	Husband	*"Me and my husband always support each other in the decisions that we make"*	7 (37%)
	Mother	*"I live with my mother and we are very close so usually she's the one that I go to when I wasn't to make important decisions.*	4 (21%)
Subtotal	Sister	*"Me and my sister are very close so before I make any big decision I always ask for her opinion"*	1 (5%)
			11
Professional assistance		*"...there is this counsellor at the clinic that I usually go to when I need clarification with my decisions..."*	2 (11%)
Total			**22**

n=19

(a) No assistance

The above table illustrates that eight (42%) of the interviewed mothers said that they did not get, or did not need assistance and helped themselves *(self-help),* as can be seen in the narrative *(I like making my own decisions"...).* The mothers that stated that they were able to provide self-help stated that they were happy to make these decisions themselves.

(b) Family assistance

About half (11 or 58%) of the respondents indicated that they get assistance with making important decisions from family members, mostly by the *husband* (seven or 37%) if married *(Me and my husband always support each other...").* Only four (21%) of the respondents indicated that they got support in making decisions' from their *mothers ("...my mother... one that I go to when*

I want to make important decisions"). Another family member that was said to provide assistance in making decision was the *sister* of the mother. It can be seen that only one respondent indicated that she got assisted to make important decisions from her sister as they were very close and always asked for the sisters' opinion *("Me and my sister are very close...").*

It can clearly be seen from the results above that even though other mothers indicated that they provided the decision making support decision themselves most of the mothers still received a lot of this type of support from their family members. These results again provide proof that informal support from family is the main source of support for mothers with children with disabilities. This is supported by Stella Tupinamba (2010:1-3) where she emphasizes that, this is because a family is seen as a unit with an inclusive group of people who share close relationship, and are usually the ones to provide emotional support and help each other in times of crisis and making important decisions. Literature also indicates that family members take care and support each other and they are always ready to help even if they have to change their personal plans, (Stella Tupinamba, 2010:1, 3). Mothers with school going children with mental or physical disabilities who have emotional support from their families are therefore much better to cope with emotional problems than those who have no emotional support at all.

(c) Professional assistance

Only two (11%) of the mothers stated that they got *professional assistance*, in these cases, this assistance was provided by a counselor at the clinic, with making important decisions *("... counsellor at the clinic...").* It can therefore be stated that there is not enough support from professionals for mothers with children that have mental or physical disabilities which may lead to the mothers' emotional well-being deteriorating as confirmed by Cichon (2004:43).

5.5.6.4 Experience/feeling with support received to make decisions

Participants were asked to explain their experiences with the support they receive in making decisions in their household. The themes and sub-themes that were derived are discussed in the following section.

Table 5.44: The mothers' experience/feelings with regards to the support received to make decisions.

Theme: Experience with decision-making support		
Subthemes	**Narrative**	**f (%)**
Happy to be able to make own decision	"...*Am very happy to make my own decisions as it make me know that I am strong and can stand on my own...*"	6 (31%)
Happy that family assists	"*I am happy that my mother helps to make decisions as I trust her and I know that she would never lie to me*" "*It is great to have family that are always there to give good advice when making decisions*"	7 (37%)
More assistance desirable	"*I wish my husband could help me more in making decisions than the way he does*"	3 (16%)
Other/not answered/not sure	"*I feel frustrated, I sometimes wish there was someone to help me*"	3 (16%)
Total		**19 (100%)**

n=19

(i)   Happy to be able to make own decisions

From the table above it can be seen that six (31%) of the respondents were happy to make their own decisions *("...very happy to make my own decisions...").* This was because it made them to feel independent and in control within the caring role, according to Lipman (2005:1) this may be a sign of the need to be in control and make important decisions independently.

(ii)   Happy that the family assists in making decisions

About seven (37%) of the respondents indicated that they were happy that there family assisted them in making important decisions as this was seen to be a great privilege as indicated above; *(I am happy that my mother helps to make decisions...")* and *("...It is great to have family that are always there...").*

(iii)   More assistance needed

Table 5.37 also illustrate that even though the mothers were happy to be able to make decisions on their own as well as receiving support to make these decisions from family about three (16%) of them indicated that they wished they could receive more support from their family members

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such as the husband *("...I wish my husband could help me more...")* in caring for their disabled child.

(iv)   Other

Within this category other mothers did not give a response at all as they were not sure of how the experienced and felt assistance in making decisions. However for those three (16%) that responded they indicated that they did not receive any support at all and this was very stressful and frustrating for them and they wished if they had someone to support them in making decisions

"....I feel frustrated... I wish there was someone to help me...").

All the findings in table 5.44, above indicate that the respondents were happy that they were able to make their own decisions as it made them feel independent. However, it can also be seen in their answers that as much as some of the respondents were happy to be independent, some of them felt that it was sometimes overwhelming for them to make decisions on their won without support. These findings support the literature from Quinn and Allen (1989:392), stating that because these mothers may be taking the role of the mother and father, meaning that they have to think of child care, health care and other things regarding their household, without any support in conducting these things one can become overwhelmed, potentially resulting in mental illnesses such as depression or burnout, and isolated.

5.5.7 Psychological needs of the mothers

Literature by Girard (2010:1) and Hu, et al., (2010:30) discussed in chapter three showed that caring for a school going child with mental or physical disability can have a negative effect on the psychological well-being of the caregiver, which is closely related with the emotional well-being. In order to explore the effects of caring for their disabled child had on the psychological well-being of the mothers were asked about their feelings with regard to having a disabled child, caring for that child and the reaction of family members. The results are outlined in the tables and figures below.

5.5.7.1 Feeling experienced with regards to having a disabled child

The mothers were asked to indicate the type feelings they experienced with regards to having a disabled child. The themes and categories that were derived are presented in table 5.45 and discussed in the following section.

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Table 5.45: Feelings experienced with regards to having a disabled child.

Theme: Feelings towards having a disabled child		
Category	**Narrative**	**f (%)**
Punishment	*"I get angry sometimes for no reason as <u>I feel like am being punished</u> for something I don't know...Its tuff sometimes you know."*	1 (5%)
Guilt	*"<u>I sometimes feel guilty</u> wondering whether I have contributed to having a disabled child. But my mother keeps telling me that it is not my fault at all"*	4 (21%)
Anger	" <u>I feel guilty and angry</u> because I know it's my fault	4 (21%)
Initial denial	*"At first I was very sad and I didn't know about this disability until the teacher told me to send him to the special school I was angry with them and <u>I still sent me son to the normal school for</u> the whole of that year* *"because I was not told that my child was going to have down syndrome before she was born when they told me* I was upset and in denial *because all my other children were normal*	3 (16%)
Over-protectiveness	*"....become <u>very protective over him</u>. I see that he is usually left out and the other kids can be mean so I go tell them off and tell their mother"* *"<u>I am very protective over my child</u>, I don't like people to take advantage of him"*	2 (11%)
Acceptance	*"<u>I have accepted</u> that my child is disabled"* *"<u>I love my child I know she is a gift from God</u>*	9 (47%)
Depression / Frustration	*"...<u>am angry and frustrated</u> and am always asking questions why me..."*	5 (26%)
Other/not answered/not sure	*"Initially I had negative feelings, especially when the child would start throwing a serious temper, and was very different everyday...you just didn't know what to expect"*	5 (26%)
Total		**33**

n=19

(i)   Punishment

It can be seen in the above table that only one (5%) of the respondents indicated that she experienced negative feelings such as a feeling of being *punished* for wrong doing, *("...I feel like am being punished...").*

(ii)   Guilt

The other four (21%) of the respondents experienced feelings of *guilt* with regards to having a child with disability *("I sometimes feel guilty...").*

(iii)   Anger

Only four (21%) of the respondents experienced the feeling of *anger* with regards to having a disabled child *("I feel guilty and angry...").*

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(iv)   Initial denial

The results also indicate that three (16%) of the respondents experienced feelings of *initial denial* with regards to having a child with disability *("I was upset and in denial...")* another respondent stated that because she was such in *denial* with the fact that her child was disabled she still sent the child to mainstream school even though the child was supposed to be placed in a special school ("*...I still sent my son to the normal school...").*

(v)   Over protectiveness

Only two (11%) of the respondents' experienced feeling *over-protective* towards the child, *("...very protective over him..."), ("I am very protective over my child...").*

(vi)   Acceptance

Just over a quarter of the interviewed mothers, nine (47%) said that they experienced *acceptance* with regards to having a child with disability, as is illustrated by the narratives above *("I have accepted..."), ("I love my child I know she is a gift from God").*

(vii)   Depression/frustration

About five (26%) of the respondents experienced *depression* and *frustration* with regards to having a child with disability ("*am angry and frustrated...").*

(viii)   Other

Another five (26%) of the respondents said they had mixed feelings with regards to having a child with disability, but could not specifically identify them. ("…*didn't know what to expect").*

If the feelings of the mothers are categorized into positive feelings, acceptance and possibly over-protectiveness, and into negative feelings (excluding "other"), it could said that the majority of respondents, 52% expressed negative feelings towards having a disabled child and only 33% had positive feelings. All the findings in this section correspond with the literature reviewed earlier by Girard (2010:12) and Office (2010:122) concerning the psychological burdens experienced by the mothers, as well as the categories of feelings, e.g. anger, punishment, guilt, identified from the answers of the respondents (Hong, et al. 2009:167).

5.5.7.2 Feeling experienced with providing fulltime care for the disabled child

The mothers were asked to identify the feelings they experienced with regards to caring for their mentally or physically disabled child. The results are illustrated Table 5.46 on the following page.

It can be seen from the table that when the respondents were asked about their experience with regards to the care they have to provide their disabled child, seven (37%) of them indicated that they were *frustrated/emotionally drained* as this was a very tiring job for them as they constantly have to be on the lookout for the child *("emotionally draining because you have to be on alert...").* About eight (42%) stated that they were happy *(Happiness)* to provide care for their disabled child *("I am very happy to care...")* this is because they felt that it was their responsibility and they were able to fulfil the needs of their child.

Table 5.46 also illustrate that, three (16%) of the respondents indicated that they experienced feelings of *withdrawal/isolation, ("I felt very alone and frustrated...")* another respondent in her quote stated that she isolated herself so that she could provide full care for her child and that she avoid them judging her in any way *("I tend to isolate myself form other people...").* The other two (six percent) indicated that they experienced feeling of *anger* having to provide care for their disabled child as no one was there to offer them help in any way, and this was frustrating for the mothers as they also feel blamed for the disabled child *("I feel angry and helpless...").* The other five (26%) of the respondents indicated that they experienced feelings of *grief* to having to provide care to their disables child full time as it means that they did not have time for themselves or knowing that their child would be disabled for the rest of his/her life *("I had so much grief...").* Lastly about eight (42%) respondents expressed *other* feelings, which they could not properly describe as they were not very sure. For example one of the mothers stated that she was okay and just cared for her child as she knew that no else would care for her child, so there were no feelings expressed *("if I don't do it who will...").*

Table 5.46: Feelings experienced with regards to the care that mothers provide for their disabled child

Theme: Feelings regarding own care for child		
Category	**Narrative**	**f (%)**
Emotional draining (Punishment)	*"I have two other small boys on top of this one so it is really tiring and emotionally draining because you have to be on alert the whole time"*	7 (37%)
Happiness	*"it's not a burden at all, I am very happy to care for my daughter as I try my best to make her feel normal just like the other children*	8 (42%)
Isolation/withdrawal	*"At the beginning I felt very alone and frustrated because I was staying far from my family, but now it better"* *"I get frustrated when I cannot help my son with something especially when we are in public. So I tend to isolate myself form other people as I don't want them to be judging me or questioning why my child is like that.*	3 (16%)
Anger	*"I feel angry and helpless a lot because I have to care for my child alone as no one won't help me they say it's my fault that he is like that"*	2 (11%)
Grief	*"I was very emotional as I did not know how I was going to handle the situation of him being like that for the rest of his life. I had so much grief"*	5 (26%)
Other/not answered/not sure	*"Well am okay, if I don't do it who will, it's my child after all.*	8 (42%)
Total		33

n=19

All of these responses confirms literature by Dunn et al. (2001:39) and Hoere et al. (1998:218) that caregivers for children with disabilities may experience negative feelings such as being emotionally drained anger and grief which may lead to isolating/withdrawn from other, this results in increasing levels of stress. This means that these mothers need to receive emotional and psychological in order to overcome these feelings. This can be done through formal support systems where mothers can be taught different coping strategies (Lazars and Folkman, 1984:141).

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5.5.7.3 Family members' reactions on finding out about the child's disability

This question was included to also explore the reaction of the environment, the meso- and exo-system, to the disability and the results are indicated in 5.47 on the following page.

Table 5.47: Family member's reactions on finding out about the child's disability

Theme: Family´s reaction to child´s disability			
Category	**Subtheme**	**Narrative**	**f (%)**
Positive	Accepting	*"They were very <u>understanding and accepting</u>, they love him. They say he is a special little boy"*	6 (31%)
	Supporting	*"My uncle had the same disability so when they found out that my child had it too they were very understanding and <u>supportive</u> especially my mother."* *"my parents were <u>very supportive</u> because they knew what*	7 (37%)
Subtotal			*13*
Negative	Blaming	*"my family was <u>quite rejecting</u>, I think it's because they didn't understand what the disability was in the begin-ning"* *"<u>They blamed me</u> the whole time up to now. They keep asking me why I was drinking when I knew that I was pregnant"*	5 (26%)
	Unsuppor-tive	*"they were <u>very unsupportive</u> because he was always fighting and causing family problems"*	2 (11%)
Subtotal			*7*
	Confusion	*"my boyfriend was really <u>confused he didn't understand</u> what was happening at all"* *"they were so <u>confused, and became anxious</u> for no rea-son*	7 (37%)
Other/not answered/not sure		*"<u>My family and relatives were not here</u> so I just had to survive."*	7 (37%)
Total			**34**

n=19

The open answers of the respondents were divided into categories of positive reactions and nega-tive reactions, in which sub-themes were identified.

(a) *Positive responses*

Tables 5.47 illustrate that 13 of the mothers, the majority, indicated a positive reaction by family members, of which six (31%) said that their family reacted with acceptance towards the disabil-ity of their child *("...understanding and accepting...")* and the other seven (37%) stated that their family supported them ("*...very supportive...").*

(b) Negative responses

It can also be seen in the above table that only seven of the respondents indicated a negative reaction from their family members, out of which five said their family blamed them in some way for the child´s disability and two experienced an unsupportive reaction (*"They blamed..."*).

(c) Other responses

In this category seven (37%) of the respondents said that their family was confused, not sure what to think about the disability and how to react and the other seven (37%) mothers did not answer or experienced no particular reaction, e.g. because their family was not there.

The results presented in the table above indicate that mothers may experience mixed reactions from their family members for having a disabled child. For those that experience positive reactions it is because they feel accepted and supported by their family members who seem to understand the child's disability resulting in positive parental perception for the disabled child as indicated by Judge (1998:267) and (Savage and Bailey, 2004:114).

Whereas those that experience negative feelings it is because their family members may not fully understand the child's disability leading to confusion and blaming the mothers for the child's disability. These findings are in line with literature (Figley, 2000:13). It is therefore necessary that families should receive family counseling if there is a child with disability in the family so that they understand it and learn how to care for the child and help to meet the needs of the mother who is the main giver of the child (Foster et al., 2009:188).

5.5.7.4 The impact of family member's reactions on the mothers with regards to having a disabled child

The mothers were asked to explain how on how their family members reactions affected them. Their responses are outlined in the table on the following page.

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Table 5.48: The impact of family members' reactions on the mothers with regards to having a disabled child

Theme: Feelings toward family´s reaction		
Category	Narrative	f (%)
Sadness	*"I felt really bad and sad for my child* *"It just made me feel sad, I would cry all the time"*	4 (21%)
Rejection	*"I felt rejected and unwanted because all they could talk about was the negativity nothing positive"*	5 (26%)
Happiness	*"I felt really happy and relieved that we were all on the same page and that they were assuring me that they will support me no matter what."* *"It made me feel special as I could see that they loved me which made me give even more love to my disabled child"*	8 (42%)
Other/not an- swered/not sure	*"I just told myself not to worry and be ashamed about the situation"*	5 (26%)
Total		22

n=19

(a) Sadness

It can be seen in the above table that only four (21%) of the respondents indicated that they felt *sad* that their family's reactions were very negative *("I felt really bad and sad...").* This may have added to the stress levels of the mothers

(b) Rejection

The other five (26%), indicated that their family members reactions made them feel *rejected ("I felt rejected and unwanted...")*

(c) Happiness

It can be seen that the eight (42%) of the respondents, the majority, indicated feeling *happy*. Those were also the ones who received a lot of support from their family members and friends *("I felt really happy and relieved...").*

(d) Other

The other five (26%) of the respondents did not give answers, had mixed feelings or, as shown in the in this quote *("I just told myself not to worry...")* did not care.

With these results it can therefore be explained that the reactions that the family members may give to the mothers may have either a positive or negative impact on the mother, this is supported

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by Foster, et al., (2009:188) and Shearn and Todd (2000:117). While most respondents felt happy about their family´s reaction, taken together *sadness* and *rejection*, as negative feelings, are the prevailing category of feelings towards their family´s reaction to the disability of their child. As pointed out by Johnson and Yanca (2007: 13) positive reactions can help in reducing the mother´s stress, having a positive effect on her well-being, resulting in a state of congruence between the mother and her environment. On the other hand if the family´s reactions are of a negative nature they may lead to the state on incongruence.

5.5.7.5 Community and other systems reactions on finding out about the child's disability

The mothers were asked about the reaction of their community and other systems, meaning the meso- and exo-system, to their child´s disability, as it was indicated by Harry (1992:27) under social and cultural needs that a certain cultural and social environment might lead to stigmatiza-tion and isolation within the community. Their responses are presented in Table 5.49.

Table 5.49: Community and other systems reactions on finding out about the child's disability

Theme: Reaction of the community and other systems		
Category	Narrative	f (%)
Acceptance / understanding	*"the people in the community were very understanding and my neighbour also helped me with a lot of stuff for my child*	6 (31%)
Supportive	*"They were very supportive, they sometimes would ask me if I needed them to watch her in case I need to go do something"*	5 (26%)
Blaming	*"They were somehow blaming me that I didn't seek treatment for sometime"*	3 (16%)
Judgmental	*"They were very judging I could see when we walk in the street, they would stare at us weirdly!"* *They are so judging sometimes they call us names"* *They were very judging and critical, especially when they heard that he was going to a special school*	10 (53%)
Discouraging	*"They were so discouraging when i wanted to send her to the special school..."*	1 (5%)
Total		25

n=19

(a) Acceptance/understanding reactions

When asked about the community's and other systems reactions, six (31%) of the participants indicated that the community and other systems seemed to be *accepting/ understanding*. These mothers also stated that the community was very understanding and helped the mothers a lot

with providing the care for their disabled child. Below is one of the narratives from one of the mother's:

"The people in the community were <u>very understanding</u> and my neighbours also helped me with a lot of stuff for my child".

(b) Supportive reactions

Only five (26%) of the respondents found the community to be *supportive.* These mothers indicated that the people in the community were very supportive and they usually they offered to help in looking after the disabled child if the mothers wanted to go out *("...<u>very supportive</u>, they sometimes would ask me if I needed them to watch her in case I need to go do something").*

(c) Blaming reactions

Another three (16%) of the respondents stated that the community was very blaming *("They were somehow blaming...").*

(d) Judgmental reactions

The highest rate of respondents which was over half of the total population (10 or 53%) indicated that the community was very judgmental towards them *("They were very judging...")* as they could observe their reactions at all times.

(e) Discouraging reactions

The other one (5%) respondent stated that the community was very discouraging, especially if the mothers wanted to seek for services for their disabled child *("discouraging when I wanted to send her to the special school...").* This result can be supported by Cichoni (2004:40) who highlights that the other systems reactions of prejudice and stigma is a big barrier for the mothers to seek for support services as they a discouraged.

These results seems to support research results by Kayama (2011:118), Schall (2000: 417) and Office (2011: 4) that disability carries a stigma in the communities as the mothers are judged, discriminated against and blamed in their communities for having a disabled child in which the mothers interviewed for this study also experienced.

5.5.7.6 The impact of community members and other systems´ reaction on the mothers with regards to having a disabled child

The mothers were asked to explain how the community's and other systems reactions affected them. The results are outlined in table 5.50

Table 5.50: The impact of community members' reactions on the mothers with regards to having a disabled child

Theme: Feelings toward community´s reaction		
Category	**Narrative**	**f (%)**
Did not care	*"I don't really care how they people in the community react or act towards my son, only when they try to hurt him then I get upset and deal with them*	8 (42%)
Anger	*"I felt really angry on how they were reacting towards my son because it was just not right and it was not his fault"*	3 (16%)
Rejection	*I felt rejected by my the same people I knew in the community, I have never felt so alone like that time*	3 (16%)
Very happy	*"I was happy with the way that they were treating us the same and not making us to feel out of the group."*	4 (21%)
Other/not answered/not sure	*"I just have enough so there is no point to worry about it*	4 (21%)
Total		**22**

n=19

(i)   Did not care

When the participants were asked on how the community and other systems reactions affected them, eight (42%) of mothers indicated that they *did not care,* of how the people in the community reacted towards them whether their reactions were positive or not *("I don't really care how the people in the community react...").*

(ii)   Anger

The other three (16%) respondents indicated that the community´s and other systems´ reactions made them very angry *("I felt really angry on how they were reacting...")* as this did not only affect them but also the self-esteem of their child leading the mothers to experience more anger and frustrations (Girard, 20104).

(iii)   Rejection

Another three (16%) of the respondents indicated that they felt rejected by the community members reactions *("I felt rejected by the same people I knew in the community...")* and this made

them to experience a lot of stress and were under pressure to try and find ways to eradicate their child's disability which Figley (1995: 10) defines it as compassion fatigue.

(iv)   Very happy

It can be seen in the table that not all the respondents experienced negative feelings as a result of the communities' reactions towards them for having a disabled child. At least four (21%) of the respondents experienced positive feelings and happiness from the interaction with the community and other systems *("I was happy with the way they were treating us...")* this helped in improving the mothers psychological well-being as well as enhancing their role as a good mother (Burton, Lethbridge & Phipps, 2008:361).

(v)   Other

The other four (21%) respondents were not sure or did not answer, for those that responded they indicated that they had already had enough of the community's reactions and it did not affect them anymore so they never worried or bothered about them *("...no point to worry about it").*

These results are a clear confirmation of literature by Gregson (2001:21-24), Klein et al. (1999) and Bronfenbrenner (1973:3) of how the meso- and exo-system influence the micro-system, the feelings of the mother, how a supportive environment can lead to a state of congruity between the individual and the environment (Johnson and Yanca 2007:13). On the other hand, this relationship is also highlighted by the narrative of a mother shown above (Table 5.42) and below wherein a mother felt blame from the community for not seeking treatment for the child:

"They were somehow blaming me that I didn't seek treatment for sometime"

Here it could be said that the mother did not meet the community´s need, or expectations, leading to incongruity in the relationship (Johnson and Yanca 2007:13). This also supports the need to raise awareness about disabilities in the community, as identified by Kayama (2010:119).

5.5.7.7 Role as a mother

The mothers were asked to explain how they felt about their role as a mother having to care for a disabled school going child, which falls within the micro-system, the self-perception of the mothers. Their responses are illustrated in table 5.51 as well as figure 5.28.

Table 5.51: Mothers feelings about their role as a mother having to care for a disabled school going child

Feelings	Respondents	Percentage (%)
Effective	14	74 %
Ineffective	02	10 %
Adequate	03	16 %
Inadequate	0	0 %
Total	**19**	**100%**

n=19
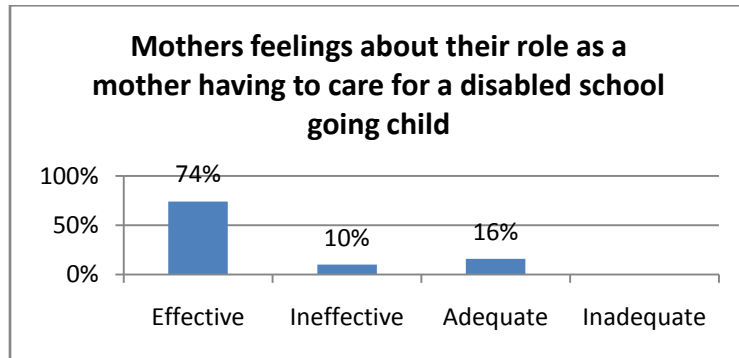
n=19

Figure 5.21: Mothers feelings about their role as a mother having to care for a disabled primary school going child

About 14 (74%) of the mothers thought their role was effective, three (16%) indicated their role to be adequate and only two (10%) thought of their role as ineffective. None on the mothers indicated to be inadequate. This generally positive self-perception of the mothers is, according to the literature discussed by Hanson and Sporakowski (1986:4) which is very important to deal with stress and other psychological burdens associated with caring for a disabled child this is also in line with Shearn and Todd's (2000:119) explanations with regard the way that mothers may view their role of a caregiver.

5.5.7.8 Associations with having a disabled child

Mothers were asked to indicate what they associated having a disabled child with. Their responses are outlined in table 5.52

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Table 5.52: Associations with having a disabled child

Associations	Respondents	Percentage (%)
Natural causes	11	58 %
Punishment	02	11 %
Bad luck	02	11 %
Other	04	21 %
Total	**19**	**100%**

n=19

Just over half (11 or 58%) of the mothers indicated that they associated having a child with disability with *natural causes.* Only two (11%) associated their child's disability with a *punishment* of something bad that they had done. The other two (11%) associated their child's disability with *bad-luck.* The other respondents four (21%) did not associated their child's disability with anything.

With these results it can be seen that the mothers had mixed feelings with regard to having a child with mental or physical disabilities. The results support Office's (2011:129) research findings that mothers may associate different meanings to having a disabled child such as natural causes, bad-luck or punishment.

5.5.7.9 Help needed for mothers in caring for their disabled child

The mothers were asked if they needed any help with caring for their disabled child and indicate why. The results are presented table 5.53 below.

Table 5.53: Need for help in the caring for a disabled child

Response	Respondents (f)	Percentage (%)
Yes	10	53 %
No	09	47 %
Total	**19**	**100%**

n=19

From the table above it can be seen that just over half (10 or 53%) of the mothers indicated to be in need of help whereas nine (47%) indicated to not needing help. These findings corresponds with the results of previous questions regarding their positive self-perception as mothers and the need to feel independent by some as well as literature by Doig, McLennan and Urichuk (2009:234) in which they indicate the need for help and support for mother with school going children with disabilities.

The results for asking the mothers why they needed help or not are shown in the table below, illustrated by several narratives.

Table 5.54: Reasons for the need of help

Theme: Help needed and why			
Subtheme	**Category**	**Narrative**	**f (%)**
positive	Need time for myself	*"I need help so that I can at least have <u>some time to go and visit my friend or for them to come and chat</u>. Because if my child is home all the attention is focused on him"* *"<u>I get very little time for myself</u> because when my daughter goes to school it´s time for me to do all the laundry and chores. By the time she is dropped <u>I have not rested at all and am already exhausted</u>*	7 (37%)
	Need time for other things	*"He is very hyper and too active that's the big problem so I <u>never get time for other things</u> as I have to keep him occupied at all times*	3 (16%)
Subtotal			*10 (53%)*
Negative	No problems looking after the child myself	*"<u>I am very capable to look after my child</u>. <u>I don't need help after all am always home</u>"* *I get a lot of support from my family the comer to stay with her after school when am at work, <u>so I don't need help</u>."*	5 (26%)
	No one else can do it	*"My child has specific needs and <u>I understand her better. Am much comfortable to do it</u>"*	2 (11%)
	No one else would want to help	*"As I explained to you he is too busy and it's to tiring to watch him <u>I don't think anyone else would want to help</u> they would struggle with him"*	2 (11%)
Subtotal			*9 (48%)*
Other/not answered/not sure		*"So that my child can at least be in a <u>positive environment</u>*	6 (31%)
Total			**25**

n=19

(a) Positive responses

The above table illustrates that 10 (53%) of the mothers indicated that they needed help in response to this question. The discrepancy compared to the question before can be explained by the respondents not sure of what specific reasons to give and being included in the "other" category.

Of those mothers that said they needed help, seven (37%) said they needed it because they *needed more time for themselves*, because they never had time e.g. to socialize with friends as they have to look after their disabled child at all times *("...some time to go and visit my friend or for them to come and chat..."),* another aspect is that, three (16%) said they needed to *have time to do other tasks.*, such as house chores or buying groceries *("...never get time for other*

things...") because once the child is back home from school the mothers have to shift their attention to the child *("...I have not rested at all and am already exhausted...")*. This may result in burnout and exhaustion in the mothers.

These results support literature by Shelton, Duerden & Witt (2010:8) and Jeon Brodaty & Chesterson (2005:300) in the sense they explain that mothers that care for children with disabilities face a lot of challenges including having less time for themselves. It is therefore necessary that these mothers are provided with help formally and informally in caring for their child so that they find sometime for themselves while the children are being looked after by someone else or placed in respite care as this would be very valuable for the mothers (Spalding, Mckeever, 1998:234).

(b) Negative response

Of the nine (47%) of respondents who said that they did not need any support, five (26%) stated that this was because they *did not have any problems looking after their child themselves*. These mothers indicated that they were very capable and confident or they already had someone who was helping them to care for their child *("I am very capable to look after my child...")* that is why they did not need any help.

The other two (11%) mothers within this category indicated they did not want any help as they felt that *nobody else would be willing to look after the child*. These mothers felt that the other mothers were already busy with their own children that maybe also had disabilities therefore it would be very unfair to ask them to look after their child most importantly these mothers indicated that their child's needs were too demanding therefore no one would cope to look after that child as indicated in the narrative below:

"As I explained to you he is too busy and it's to tiring to watch him <u>I don't think anyone else would want to help</u> they would struggle with him".

Another two (11%) of the respondents indicated that they were the only ones that knew the needs of their child better compared anyone else *("...I understand her better. Am much comfortable to do it")*.

(c) Other

In this category six (31%) of the mother either did not respond or they gave comments that were neutral. One of the examples was that one mother felt that she needed help as she wanted to have her child in a safe and positive environment such as the respite care facilities *("positive environment").*

All the results in this subtheme support literature by Shearn and Todd (2000:116) in way that they identify the reasons why mothers may not want to receive any support from other, they also indicate that if one has enough support then there is no need for them to ask for more help especially if all their needs on micro, meso, exo and macro level (Gregson, 2001: 22-25).

5.5.8 Coping strategies for mothers

As discussed in the previous chapters mothers caring for their children with disabilities are faced with a number of challenges in their caring role as result they need to be equipped with knowledge on the techniques that they could use (Lundh, 1999:735). With this in mind the respondents were asked to identify the different coping strategies that they used when caring for their disabled child and were faced with the challenges. The results are illustrated in table 5.55 and figure 5.30.

Table 5.55: Coping strategies used by mothers in caring for their disabled child

Strategies	Respondents (f)	Percentage (%)
Good self-esteem/ self-efficacy	05	12 %
Religious beliefs	08	20 %
Relaxation techniques	0	0 %
Face-to-face interaction with professionals	10	24 %
Accessing relevant information	08	20 %
Talking to other mothers about the experiences	10	24 %
Total	**19**	**100%**

n=19

The above results illustrate that higher proportion 10 (24%) of respondents mainly use the technique of talking to the other mothers about the experiences of caring for a disabled child. Here, they can share experiences and support each other if one of them is stressed as a result of the caring process. For example one of the respondents stated that:

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"...when it gets too much I usually speak to one of friends who also has a child with disability, we understand each other better because she knows where I am coming from, compared to if I had to speak to a mother who did not have a child with disability at all."

This result supports literature, for example by Wickman (1992: 14) who explains that mothers tend to benefit positively from talking to other mothers who are in the same situation as them and as a result reduce the stress levels of the mother. Talking to the other mothers is more of an informal support as the professionals may not be involved. It can also be seen that 10 (24%) of the respondents also identified face to face interaction with the professional as a coping strategy.

Table 5.55 also indicates that a higher number of respondents used face to face interaction with the professionals 10 (24%) as a means of coping strategy. The professional provided them with advice, knowledge and support that they needed, helping them to reduce their stress levels. This face to face interaction involves workshops, one of the mothers explained how they sometimes get invited to the workshops by the school to go to Cape Mental health where they are educated about disabilities and how they can deal with children that have disabilities. Below is a narrative form one of the respondents:

"....when I took my child to the clinic, the other day the sister could see that I was not with it at all on that day. So she asked me if I wanted to talk...I agreed and she referred me to the counsellor who was very helpful and up to now when there is anything that is bothering me I go there, I feel better when I talk to the outside people"

The eight (20%) of the respondents indicated that they used their religious beliefs as their coping strategy. Below is one of the narratives from one of the mothers whose child was epileptic:

"When I feel that things are getting out of hand and I just need strength to keep going, I just close my eyes and starts praying, and I feel better afterwards."

"I have had a lot of miscarriages. This is the only child that I have. I feel that he is a gift from God that he wanted me to just focus on one child. So when I find myself getting very stressed with all the things I have to do for him I just call on God, and tell him to have his way. Then I am at piece!"

These narratives show that religion also plays a big role in providing emotional and psychological support in the mothers. This means that if there is congruence between the mothers´ spiritual well-being and her receiving enough spiritual support, it is then likely that this will result in making her caring role to be more positive (Johnson and Yanca, 2007: 13).

These results are in line with the literature from Hu et al. (2010:33), who showed that mothers benefited from face to face interaction with professionals. These results also support literature by Phelps *et al.* (2009:27), who agree with the idea that spirituality may provide valuable means of guidance and purpose throughout the challenging experience of having their children diagnosed with a disability.

The results in the above table also illustrate that accessing relevant information was a technique that eight (20%) of the respondents indicated to use a coping strategy. This means that when mothers are well equipped with the information that is relevant to them it makes things easier for them as they know exactly how to handle the issues when they arise (Graugaard and Skov, 2006:305). Only five (12%) of the mothers indicated that their high self-esteem and or self-efficacy helped them cope. None of the respondents indicated to use relaxation techniques as part of their coping strategy.

5.5.9 Awareness of available resources

This section corresponds, with the need for economic support as explained by Lukemeyer et al., (2004:400-407), the need for knowledge, as well as the need for assistance in caring for their disabled child.

The respondents were asked to indicate if they were aware of the resources that were available in the community to help them in caring for their child with disability. The results are illustrated below.

5.5.9.1 Resources available in the community

Table 5.56: Resources available in the mothers' community

Resources	Frequency (f)	Percentage (%)
Do not know	10	53 %
Special School	02	11 %
Professionals (doctors, nurses)	02	11 %
Other/not answered/not sure	07	37 %
Total	**21**	**100%**

n=19

From the above table it can be seen that the majority 10 (53%) of the respondents indicated that they were not aware of the resources that are available in their community to help them with the

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care of their disabled child as well as to meet their own needs. Only two (11%) indicated that they knew that the special school was the only resource that was available in the community to help them in caring for their disabled child. Another two (11%) indicated that they were aware of the professionals such as doctors and nurses that were in the community to help them in caring for their disabled children. However, in this category the mothers stated that these professionals only help when they were at the clinic. In the category for other seven (37%) of the respondents did not give the applicable answer as they said they were not very sure.

From the results above it can be stated that there is a need in these communities to inform the mothers of the resources that are available to them in the community. Another point that can be made is that the community does really have limited resources for children with disabilities and for their mothers; the school seems to be the only main resource. This supports the literature that low-income communities have very limited resources which again can contribute to the mothers' levels of stress (Wickman–Seal, 1992:9).

5.5.9.2 Mother becoming aware of the resources

For those respondents that indicated that they were aware of the resources available in their community identified in table 5.49, they were asked to indicate how they became aware of these resources. The results are presented in the table below.

Table 5.57: Mothers becoming aware of these resources identified in table 5.56

Resources	Narrative	f (%)
Friends	*"My next door neighbour who is a <u>good friend of mine</u> told me about it, and we agreed to go and see."*	2 (14%)
School	*"at the <u>school meeting</u> we were told about them"*	3 (21%)
Informal ways	*"My <u>children heard about them from their friends</u>, so they came to tell me about it"* *"I have read about them and <u>I pass them</u> when am going to work in the mornings*	9 (65%)
Total		**14 (100%)**

n=14

It can be seen from the above table that two (14%) of the respondents indicated that they became aware of the resources from their communities through their friends. *("…good friend of mine...")*

About three (21%) indicated that they became aware of the resources after they had attended a school meeting where the teachers explained to them about the available resources *("...school meeting...")*

The results from the above table also indicate that over half (nine of 65%), of the respondents became aware of the resources through informal ways such as overhearing about them or seeing them as they walk around the community *("children heard about them from their friends...")* and *("...I pass them...")*

From these results it can be seen that all the systems involved in the mothers lives namely the *micro-, meso-, exos-* and *macrosystems* play a big role in helping the mothers to become aware of the resources that are available (Bronfenbrenner, 1979:3). This means if all the mothers' needs are to be fully met there has to be a mutually beneficial interaction between all the systems in her life and the environment as indicated by Johnson and Yanca (2007: 13).

5.4.9.3 Knowledge of how to access resources

The respondents were asked to indicate whether they had any knowledge with regards to how they could access resources.

Table 5.58: Knowledge of how to access resources

Response	Respondents (f)	Percentage (%)
Yes	7	37 %
No	7	37 %
Other/not answered/not sure	5	26 %
Total	**19**	**100%**

n=19

The results indicated that less than half (seven or 37%) of the respondents were aware of how to access the resources. The other seven (37%) also indicated that they were not aware. Only five (26%) indicated that they were not 100% sure.

Similar to the answers to the previous questions in this section, these responses suggest a need for more information on the availability of resources and how to access them, which corresponds

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to what was found in the literature by Blackburn and Read (2005:507) and Shearn and Todd (2000:115).

5.5.10 Consequences of having a disabled child

As established in the previous chapters, having and caring for a child with mental or physical disability can have a negative effect on the mother's psychological, physical and emotional well-being, depending on the level of the child's disability and the care that they need, (Smith, et al., 2009:167). This section further investigated what the felt consequence was for the mothers interviewed here. The results are illustrated in table 5.59.

5.5.10.1 Physical/emotional condition developing after having a disabled child

The respondents were asked to indicate if they had developed any physical or emotional conditions after they had their physically or disabled child. The results are presented 5.52 below.

Table 5.59: Physical/emotional condition developing after having a disabled child

Response	Respondents (f)	Percentage (%)
Yes	7	37 %
No	8	42 %
Other/not answered/not sure	4	21 %
Total	**19**	**100%**

n=19

The results above indicate that about seven (37%) of the respondents indicated to have developed a condition physical/emotional condition developing after having a disabled child. About eight (42%) indicated that they had not developed any physical/emotional condition after having a disabled child. The other respondents four (21%) did not have any response to this question as they said they did not know or they were just unaware if the condition had actually developed. These results support Lonsdale (1992) and Gulliford and Upton (1992) in the way that they explain that the challenges and demands of caring for a mentally or physically disabled child can be a burden on the mothers which can cause physical and emotional stress.

5.5.10.2 Type of condition developed

For those mothers that had indicated that they had developed physical or emotional conditions after having a disabled child, they were asked to indicate the specific conditions that they had developed. Their responses are outlined in table 5.60

The table below, 5.60, indicates that four (21%) respondents indicated to have developed *stress* since they had their disabled child *("I have become really stressed...")*.

Only two (11%) indicated that they had developed *depression ("I get depressed and moody...")*. The other three (16%) indicated that they had developed *insomnia* since they had their disabled child as a result of the needs and demands that were placed on them by the child's disability (*"I usually struggle to sleep...")*and (*"I just can't go to sleep..."*).

Table 5.60: Type of condition developed

Theme: Kind of condition developed		
Category	**Narrative**	**f (%)**
Stress	*"I have become really stressed, it's not just because of him but the fact that I have other small children and this one is too busy and I have to watch him...so it is hectic"*	4(21%)
Depression	*"They keep changing my mental state, mood swings and then I get so stressed and emotional, but I try to cope."* *"I don't really like to talk about it but I have become isolated from others...I don't want to be around other people as I don't want them to be judging me and I feel that it's best if I stay home with my child and the other kids you know."* *"I get depressed and moody at times especially if the day has been stressful and not having to rest at all as I have to give the kids full attention"*	2(11%)
Insomnia	*"I usually struggle to sleep as when my son was young I had to watch him a lot even in the night having to give him his medication, but now as he is getting older it getting better."* *"I just can't go to sleep, I have to take sleeping tablets sometimes"*	3(16%)
Other/not an-swered/not sure/ high blood pres-sure	*"I never used to have blood pressure until she was born. I now have to be taking high blood pressure medication all the time to...."*	10(53%)
Total		**19 (100%)**

n=19

The rest of the respondents 10 (53%) did not respond to this question as they were unsure. From these results it is confirmed that having a child with mental or physical disability can really have

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a negative effect on the caregivers by increase their stress levels leading to the cause of the conditions. These results correspond with Girard (2010:1) who extrapolate that caring for a disabled child can have lead to health conditions in the care givers such as sleep-deprivation and stress. It can therefore be stated that these mothers need support on all level as in Maslow's hierarchy in order to improve their well-being. These findings are supported by Foster et al. (2009:187), where they extrapolate that the psychological, physical and emotional well-being of the mothers can be improved if they are provided with support.

According Foster, Kozachek, Stern & Elsea (2009:187), the psychological, physical and emotional well-being of these mothers can be positively improved by seeking support from professionals or relatives/friends (informal support). For example, the 87.8% of the mothers who were the sole care givers reported moderate to high levels of anxiety. Therefore formal or informal support may help in improving these mothers well-being. The study by Foster et al. (2009:187) found that mothers who received counselling and support in their caring role reported greater improvement in their well-being. Therefore, support needs to be provided to these mothers on different levels, formal and informal, as one of the most important aspects of care-giving is for the caregiver to take care of herself (Foster et al. 2009:188). All the above cited challenges can not only affect the psychological well-being of the mother, but also negatively affect the physical well-being of the mother.

5.5.11 Involvement with community groups

5.5.11.1 Involvement with the community groups

Mothers were asked if they were involved in any societies/community groups that helped them in meeting some of their needs with regards to the care they provide for their disabled child.

Table 5.61: Involvement with community groups

Theme: Involvement in Community Groups		
Category	**Narrative**	**f (%)**
Positive	*"I am part of a <u>support group at church</u>, where we pray together with the other mothers but not everyone there has disabled child* *"I am on the <u>school committee support</u>, if that count..."*	6 (31%)
Negative	*"no, not really*	13 (69%)
Total		**19 (100%)**

n=19

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It can be seen in the data above that six (31%) of the respondents indicated that they were in-volved in the community groups in the church or in the school as indicated in these brief narra-tives *("...support group at church...)* and *("...school committee support...")*. The results also illustrate that the majority 13 (69%) of the mothers indicated not to be involved in any support groups *("no not really")*. According to Burger (1990), a support group is essential as it makes rehabilitation services accessible to those in need. It is therefore important that the mothers take part in support groups as they can discuss their problems amongst each other (group counsel-ling), share information about services that are available within the surrounding community, dis-cuss their rights and empower each other with knowledge about laws, engage in community ser-vices, and receive professional guidance.

5.5.11.2 Reasons for the involvement with the community groups

The mothers were asked to indicate the reasons why they were either involved or not involved in the community group. Their responses are outlined in table 5.62.

Table 5.62: Reasons for involvement in community groups

Theme: Reasons for involvement or un-involvement in community groups			
Subtheme	**Category**	**Narrative**	**f (%)**
Involved	To socialize with other mothers	*"when am there I at least get some time to talk with the other mothers.....sometimes we pray for each other if one of us is struggling and just needs someone to talk to"* *"I am part of them because they also have other mothers who have children like mine so we get to share ideas"* *"I get to hear the experiences of the other mothers that are more experienced than myself on how they cope with all the caring for their child as am one of the young members there."*	3 (16%)
Not in-volved	No time	*"I don't really have the time to go there. Because when my son is in school I get some time to do the chores and all the house work, and by the time he is back home in the afternoon then I have to watch him."* *"I am working in town, so I would not find time to go to those things"*	6 (31%)
	Not aware of them	*"I just don't know about them*	5 (26%)
Other	Referred & creating op-portunities for others	*"I was referred there as it is a support group for mothers with drinking problems but I have never been there..."* *"I want to create opportunities for children with learning disabilities and their family as the community really needs this.*	6 (31%)
Total			**20**

n=19

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(a) Involved in community groups

It can be seen in the table above that three (16%) of the respondents that indicated to be involved in the community groups said that they were involved because it allowed them to *socialize* with the other mothers, that also had children with disabilities *("... I at least get some time to talk with the other mothers...")* which corresponds to the answers given in the section on coping strategies and what was discussed in Chapter three suing literature by Lazars and Folkman (1984:141) and Turnbull and Turnbull (1993:11).

(b) Not involved in community groups

It can be seen in the table above that six (31%) of the respondents indicated that they were not involved in any community or support groups as they did not have time to do so *("I don't really have the time to go there...")* because they have to look after their disabled child. The five (25%) of the respondents indicated that they were not part of the community group as they were not aware of their existence *(I just don't know about them ...")* and *("I would not find time to go to those things")*. This supports the findings of the literature review and responses to previous questions, which indicated that time is a resource, which is very scarce due to their caring responsibilities and the limitations this inflicts on social activities (Koshti-Richman, 2009:19).

(c) Other responses

The other six (31%) of the respondents that indicated that they were not part of the community or not involved for any reason stated that they had heard about these support group and someone referred them *("I was referred...")* but they never utilised them. The others indicated that they would want to start their own group so that they can create opportunities for others *("...create opportunities...")*.

It can again be seen in the above results that for those that were part of the support groups it was because it helped them to socialize and have contact with other mothers with similar experiences of having and caring for a disabled child. For those that were not involved it was because of lack of time as they were constantly tide up with providing care for their child full time. These results are therefore in line with research findings by Hu, et al., (2010:34).

5.5.12 Non-governmental organizations (NGOs)

5.5.12.1 Awareness of NGOs in the community

Mothers were asked if they were aware of any NGOs available in their communities. Their responses are presented in table 5.63 and figure 5.33.

Table 5.63: Awareness of NGO's in the community

Responses	Respondents (f)	Percentage (%)
Yes	11	58 %
No	08	42 %
Total	**19**	**100%**

n=19

The data illustrated above indicates that the majority 11 (58%) of the participants were aware of the non-governmental organizations that were in their community. Over a quarter (eight or 42%) of the respondents indicated not to have any knowledge of the existence of the NGO's in their communities. These results confirm Kristen Harknett (2006: 172) research that mothers may either be aware or not aware of the resources available to them.

5.5.12.2 The process for mothers in becoming aware of the NGO's in their communities

The respondents were also asked on how they became aware of the non-governmental organizations. The results are illustrated below in table 5.64.

Table 5.64: The process for mothers in becoming aware of the NGO's in their communities

Theme: Reason for knowledge of NGOs in community		
Subthemes	**Narrative**	**f (%)**
Proximity to home	*"One of those is near the taxi stop that I get off when am going home after work"*	2 (12%)
Previous experience	*"....the social workers from there came to my house and I still see them every now and then...."* *"Well am a foster parent for the child care Stellenbosch so I deal with the NGO's a lot"* *"The organization helped me with the completion of forms for the child support grant" "I know about them because they came to see me when my child was young"*	5 (27%)
Reference by others	*"I got to hear about them through the working place"* *"I was referred to them by my friend when I wanted to apply for a child grant"* *"The social workers referred us for support"*	4 (22%)
Other/not answered/not sure	*"I don't know how i came to know them I just know them..."*	8 (39%)
Total		**19 (100%)**

n=19

(a) Proximity to home

When the mothers were asked on how they become aware of the NGO's in their communities it can be seen in table 5.64 that, two (12%) of them indicated that it was because of *proximity to home ("near the taxi stop that I get off when am going home…")*. This meant that the mothers lived near these NGO's or they passed by it at all times.

(b) Previous experience

The results also indicate that five (27%) of the respondents become aware of the services as a result of *previous experience* with these organizations *("social workers from there came to my house)* and *("…came to see me when my child was young")*. These experiences included to have worked with the social workers at that organization or referring someone to those organizations.

(c) Reference by others

Table 5.64 also illustrates that four (22%) of the respondents became aware of these organizations through *reference by others*. For example one of the respondents indicated that when she was in the hospital the doctors and the social worker in the hospital referred her to the child welfare organization in her community which is a non-governmental organization *("…social workers at the clinic referred me…")*.

(d) Other

The eight (39%) of the respondents did not have a specific response to this question as some of them were not aware of the organizations at all and others just indicated that they just knew the organization but could not explain how *("….I just know them...")*

These results indicate that there are different ways of how individuals may become aware of the resources/ organizations that are available in their community. Another point that can be noted from these results is that the NGOs themselves do not publicize themselves to the people in the community which leaves the people not accessing their resources. In line with Borchard, 2011:3-4), it is therefore necessary that NGO's should publicize their organization and services they render to the mothers and the other people in the community.

5.5.12.3 Awareness of the resources rendered by the NGO's

The respondents were also asked to indicate whether they were familiar with the services that these non-governmental organizations render. The results are illustrated in table 5.65 as well as in figure 5.32.

Table 5.65: Awareness of the resources rendered by NGO's in the communities

Responses	Respondents (f)	Percentage (%)
Yes	11	58 %
No	08	42 %
Total	**19**	**100%**

n=19

The results above, indicate that over half (11 or 58%) of the respondents were fully aware of the resources that the NGO's in their communities were rendering. Nearly a quarter (eight or 42%) indicated not to be aware of the services rendered by the organization.

These findings support what was indicated in literature on the subject, for example Kristen Harknett (2006: 172). She argues that there may be a number of organizations/resources that are located in the communities. However, most of the mothers with school going children that have disabilities may not be aware of the support that they can get from these organizations. These organizations may offer support groups for these mothers living in poverty. But, as these re-sources are not publicized most mothers continue to live in poverty and without knowing of the support that may be helpful to them, as these are very important sources of both psycho and socio-economic support, (Kristen Harknett, 2006:174).

From all the results within this category of the NGOs, it can be deducted that most mothers might be aware of the existence of these organizations, but needed to be informed by the organi-zations themselves on the services that they can receive there. It can also be noted that within all the data that has been identified and the respondents´ narratives none of them have mentioned to use the service of an NGO in meeting their own needs, but rather sought economic support. It can therefore be stated that NGOs need to make an effort in also trying to focus on providing services to meet the mother´s own needs and not only those of the child (South African, Disabili-ties, 2011:2).

5.6. Conclusion

In general, the results of this empirical study support most of the findings made in the literature review in the previous chapters.

Regarding the disabilities of the children in this study, the most significant finding of this study has been that the majority of them have a learning disability. This reflects on many of the other aspects explored here: the children´s needs (e.g. equipment); the mother´s needs; and expectations and experiences of the services provided by the school.

Furthermore, as expected in a low-income environment in which the school and the respondents are located, the mothers have a very low income. Moreover, the majority of the care-givers are single mothers. The low-income communities in this study also had limited resources available for the mothers; from having only one special school to choose from, to limited alternatives for medical care, lack of information, and a lack of formal support or knowledge as to how to access these. Additionally, negative reactions of the community, from stigmatisation to blame, which emerged in this study, were also to be expected, according to the literature.

Regarding the consequences of the child´s disability and having to care for it – the same economic challenges, psychological and emotional consequences and feelings, such as stress, anger, guilt, lack of time, depression and isolation, emerged in the interviews conducted, as were to be expected.

The importance of informal support networks, especially the family, was also clearly confirmed by the experiences expressed in the mothers´ responses.

The biggest discrepancy between the results to be expected, according to the literature, and this empirical study, was the high degree of positive experiences and expressed feelings, such as that of independence, self-sufficiency, and being an efficient and good mother; although, the possibility of positive experiences was emphasised at the beginning of Chapter III.

The following chapter of this thesis will provide an overall conclusion, bringing together the research objective, analysing whether it has been met by this study, and it will give certain recommendations, based on these findings, for possible future research on this subject as well as on

necessary improvements to the situation of mothers caring for their disabled children in low-income communities in South Africa.

CHAPTER VI: CONCLUSIONS AND RECOMMENDATIONS

6.1 INTRODUCTION

The aim of this final chapter is to present conclusions based on the findings of this study and, where possible, give recommendations concerning possible improvements of the situation of mothers caring for their disabled children, as well as recommendations for possible future research. The recommendations will serve as a guideline for the service providers as well as the government to raise awareness of the experiences of mothers caring for their school-going children in terms of identifying the challenges that they face as well as the resulting needs (physical, emotional, psychological and social needs), and therefore provide them with the necessary support within an ecological perspective in order to make their caring role more effective, resulting in a positive well-being and a state of congruency. In doing so, this chapter meets the final objective of the study, which was to offer guidelines for service providers and the government to improve and provide support for mothers caring for their school-going children with mental or physical disabilities in the low-income communities.

6.2 CONCLUSIONS AND RECOMMENDATIONS

6.2.1 Outline of the study

The aim of this study was to develop an understanding of the experiences of mothers caring for their school-going children with physical or mental disabilities in low-income communities using the ecological perspective. The rationale for this research was a gap in the existing literature regarding the experiences of mothers caring for their school-going children with mental or physical disabilities in low-income communities in South Africa, which was identified in the preliminary and main literature review. The literature review further indicated that these mothers have to struggle with several challenges, particularly in low-income communities.

In order to achieve the aim of this study, four research objectives were formulated:

- To give an overview of the nature of physical and mental disabilities of school-going children and the care they need.

- To explain the challenges and resulting needs of mothers caring for their primary school going children with physical and mental disabilities.

- To describe how the needs of mothers caring for primary school-going children with physical or mental disabilities can(are) be met in South Africa within an ecological perspective.

- To conduct an empirical study in order to investigate the experiences of mothers caring for their physically or mentally disabled school-going children in low income communities and what impact these experiences have on their psycho-social well-being, as well as investigating the actual support that these mothers need in order to make their caring work more effective.

As outlined in the research approach (1.4), the researcher used both qualitative and quantitative research approaches to collect the data for the research, as combining features of these two approaches allows a greater insight into the experiences of mothers. While the quantitative part provides measurable and statistically comparable data, the qualitative data provides a more detailed and open insight into the experiences of the mothers from the respondents´ perspective. Additionally, due to the identified gap in the literature, the research design was also exploratory and descriptive in nature.

The research methodology, outlined under 1.4.3, included two main parts: firstly, a literature study of all relevant literature on the subject matter, in order to gain the necessary in-depth understanding of the field; and secondly, data-collection, using a semi-structured questionnaire.

The population of this study consisted of biological mothers of children with physical or mental disabilities, who attend a special school in Cloetesville, Stellenbosch; a low-income community. The researcher used a non-probability sampling method, to select twenty respondents, of whom only nineteen could be interviewed due to limitations described earlier.

6.2.2 Progress of the study

The research objectives were achieved in several stages. Chapters II, III and IV formed part of the literature study, while the data-collection in form of the questionnaire was presented in Chapter V.

Chapter II provided, in line with the first objective, an overview of the disabilities of school-going children and the care they need. These were divided into physical disabilities – epilepsy and cerebral palsy – and mental disabilities – mental retardation, learning disabilities, autism spectrum disorders, Down-syndrome and fetal alcohol syndrome.

The second objective of this research study was met in Chapter III, where the challenges and resulting needs of mothers caring for their school-going children with mental or physical disabilities in low-income communities were identified. This was done from an ecological perspective, which emphasizes the importance of taking into account the relationship between the individual and his/her environment and the effects they have on each other, on several systemic levels. The needs identified in this chapter were divided into five categories: access needs, economic needs, social and cultural needs, and mental/psychological needs. Furthermore, Chapter III explored how a low-income environment can affect these needs.

Chapter IV focused on how the different needs of these mothers can be met in general, as well as within the South African context, thus fulfilling the third objective of this research study. Firstly, the prevalence of poverty and disability in South Africa was discussed, in order to provide the necessary background on the socio-economic situation in the country. Secondly, different kinds of support – formal, informal support and other coping strategies – to help mothers of disabled children meet their needs were discussed, and, where possible from available literature, their availability in South Africa.

The fourth objective of this research study was achieved in Chapter V, with the empirical study, using the questionnaire and its analysis to explore the respondents´ experiences regarding their care for their school-going disabled children in low-income communities.

6.2.3 Findings, conclusions and recommendations

6.2.3.1 Literature study

The research conducted in Chapter II, using available literature, with the purpose of providing the necessary background information on the disabilities of school-going children, most importantly found how complicated and diverse a single disability can be and, consequently, how complicated and diverse the needs of the affected children can be.

The literature study in Chapter III firstly allows the conclusion that mothers who care for their mentally or physically disabled school-going children face a number of challenges, ranging from the danger of sliding into poverty, due to high financial costs and lowered employment chances, to physical and psychological health problems, resulting from exhaustion or self-blame. It was further found that these challenges can be interrelated and have an aggravating effect on each other. Consequently, it was found that these challenges can be translated into certain needs the mothers have. The ecological perspective taken during the course of the chapter, illustrated how the relationship, or interaction, between the environment and the individual on different systemic levels, affects in how far the needs of the mother, e.g. for economic support, and the needs of the environment, e.g. the needs of the child, or other family members, are met, resulting in a state of congruity or incongruity. Finally, the last section of the chapter explored the effects of a low-income environment on the needs of the mothers and found that not only can the disability of a child lead to or worsen existing poverty; according to statistics disabled children are more likely to be born into a low-income environment. This might be due lack of access to medical services, or generally an unhealthy environment for mothers, among other factors.

In Chapter IV it was found, firstly, that South Africa, while classified as a middle-income developing country, has one of the most unequal societies in the world, and despite its relative wealth, the experience of most South African households is of outright poverty or of continuing vulnerability to becoming poor. Hardly any reliable data regarding the prevalence of disability in South Africa was found in the literature. Statistics vary between 5.9 per cent and 12 per cent of the population.

Regarding the formal support options available in South Africa, it can be concluded that while South Africa, through its constitution, policies and grant system has provided a very positive environment. In particular, the South African social security system is very advanced compared to similar countries. However, it was found that practical implementation of policies often lags far behind these policies, due to a lack of financial resources or lack of coordination. Additionally, private medical insurance and care, which is highly developed in South Africa, remains unaffordable for the majority of the population.

Aside from formal support, for example, through legislation and grants, several informal support options for mothers caring for their disabled children were identified and discussed in Chapter IV, as it was indicated that particularly in an environment where there is a lack of formal support, informal support becomes very important. The informal support options identified were: emotional support, e.g. from family, friends, support groups or professionals; and social support, by formal and especially informal social networks, which can help to alleviate stress caused by a lack of time, social isolation and other related challenges described earlier.

6.2.3.2 Empirical study

The empirical study which was conducted and then presented and analysed in Chapter V represents the second main part of this thesis. As stated before, all the respondents to the semi-structured questionnaire were the biological mothers of the school-going children with either physical or mental disabilities in the low-income communities around the Stellenbosch area, namely Cloetesville and Kayamandi. The results of the empirical study were discussed in Chapter V in several thematic areas corresponding with the categories of challenges and needs identified in the previous chapters and in the questionnaire: The role of the special school in meeting the needs of the mother; economic needs; physical needs; social needs; emotional needs; psychological needs; coping strategies; awareness of availability of resources; consequences of having a disabled child; involvement with the community; and non-governmental organisations.

Overall, most of the assumptions made, based on the literature reviewed in the previous chapters, were confirmed. Several of the main findings presented in Chapter V will be briefly summarised below following the same outline as in the questionnaire.

(i)   Identifying details

All the respondents who participated in the study were the biological mothers of the school-going children with either physical or mental disabilities in the low-income communities around the Stellenbosch area namely Cloetesville and Kayamandi. Their ages ranged from twenty-one to forty years and their marital status was balanced, 26% indicating that they were married. The other 26% indicated that they were single and the other 26% were divorced. Only 11% indicated that they were living with either their partners or boyfriends. The majority of the respondents were Afrikaans speaking and only a quarter were Xhosa speaking. With regards to education all

the respondents had low level of education, not higher than Grade 11, and the majority of about 69% could only do unschooled work and earned very little income.

Basically in the identifying details category, it was found that the majority of the respondents came from a low-income environment and had low levels of education, qualifying them mostly for only unschooled work. Additionally, over half of the mothers were unemployed.

Conclusion

From these findings it can be concluded that the mothers caring for their school-going children with mental or physical disabilities in the low income communities are of different ages and all come from the low-income communities and they have very low level of education which has resulted them to having to do unschooled work where the wages are very low or not to be employed at all.

Recommendation

With the results explained above it is recommended that the service providers such as the social workers, teachers and nurses always assess the mother's situation on all levels in a holistic manner. This can be done by finding out about their level of education, income level as well as employment status, so that the challenges that they are facing and the resulting needs are fully assessed and applicable intervention for the mother as well as her disabled child can be planned.

Another recommendation is that the government should work together with service providers to reach out to these mothers to meet their level of need. This can be done by providing training programmes that can help to generate income for them in order to help them improve their economic situation and upgrade their education level so that they can at least get employment on a professional level.

(ii)   Definition of the child's disability

During the study most of the mothers were not sure of the actual medical definition of their child's disability; as a result they focused on giving the symptoms and characteristics of their child's disability. These characteristics included aspects such as the child being slow, having seizures as well as abnormal body coordination problems and being unable to walk.

When they were asked how they came to define their child's disability most of the mothers indicated that the specialists/ doctors had informed them that their child had such a disability. In terms of the special needs for the child the mothers were different in the needs that they identified. The needs of the child varied with the level of the disability: those with a severe level of disability indicated that their child needed extra care and attention as well as having to see the therapist and specialists on a regular basis. Nearly 70% of the respondents indicated that their child needed to take medication on a regular basis. The other quarter indicated that their child's specific special need was to attend special education. Only a small percentage of the respondents indicated that their child needed to use a wheelchair.

Conclusion

From these findings it can be concluded that mothers in a low-income community may not understand the definitions of their child's disability. The first reason that might contribute to this is their low level of education; secondly, they may be in denial. Thirdly, as a result of limited access to resources or specialists, the children may end up receiving an inaccurate diagnosis of their disability. This may result in the mothers' only focusing on the symptoms or characteristics of that child's disability as indicated above. In the end this may lead to leaving the child with limited proper care as the mothers may not be familiar with how to care for the child or not know what resources/services to access. In the end this can be stressful for the mothers as they are unable to meet their child's needs, making caring ineffective.

It can further be concluded that their inability to give the actual definition of their child's mental or physical disability is the avoidance of being labelled in the community by other people and so avoid being stigmatised or discriminated against.

Another conclusion that can be drawn from this with regard to the special needs of the child is that, children with mental or physical disabilities may need structured and long term care that places huge demands on their carers as a result of their disability. It should be noted that the level and severity of their disability will determine the special care that they may need. Therefore they need to be assessed and diagnosed appropriately and their needs should identified so that they receive the care that they need either by being placed in a special care environment or receiving special education.

Recommendations

Based on the finding above it can firstly be recommended that the service providers and specialists (health professionals i.e. doctors, nurses and counsellors) need to help mothers to understand the actual definition of their child's disability. This should be done so that the mother can access the appropriate support services to help them with dealing with the actual definition and also be able to learn how they can support their child and provide appropriate care. This can be done by health professionals organising workshops around the community to reach out to these mothers and explaining to them about the different disabilities and their actual definitions and the care that the child with that specific disability may need.

It is also recommended that special schools in low-income communities be equipped with the resources to meet the different needs of the child. Mothers need to be provided with special support from welfare organisations and health professionals as they experience a lot of strain on different levels; therefore providing them support based on their level of needs may help in reducing the negative experiences from their caring role.

(iii)   Special education for the disabled child

It was found that the special education system educates the disabled children at their level of understanding and depending on their level of disability. This means that they do not educate the children using the class grade systems rather they use the class level system. Therefore even if the child is older, such as sixteen years old and they are at a development level of an eight year old child then they are placed in the low level class. When the mothers were asked what class level their child was in, the majority indicated that they did not know at all what level the child was in as they were not familiar with how the special school system functions.

Most of the mothers in the study also indicated that it was very easy to get their child into the special school as they were referred by the mainstream teachers or other professionals such as doctors or nurses. A quarter of the respondents indicated that it was difficult for them to get their child into the special school for several reasons such as; initial denial, unaware of the process to get the child into the school.

In terms of school selection for the disabled child to up to 74% of the respondents indicated that this special school selected for this study was their first school choice as a result of proximity,

the other respondents that stated that this was their not their first choice explained that it was either they were in denial that their child was disabled and that he/she has to attend special school. The other reasons were that they did not want to be judged, looked down on by the other people in the community for having a mentally or disabled child and having that child attend to special school as they did not want to be stigmatised.

When the mothers were asked if they were aware of the available resources at the special school to meet the needs of their child, the majority of the mothers indicated that the school had specially trained teachers to educate their child based on the level of disability. Only a small number of 13% of the mothers indicated that they were not aware of the resources available in the school to meet the needs of their child and what the school does.

In terms of contact with the school educators, the majority of the respondents indicated that they met their child's educator at least once a month, and others indicated that they met with the educators only if the school had invited them for a meeting.

When asked about what the educators said about the mother's child's progress, the majority of the mothers indicated that the teachers stated that there was tremendous progress in the child's work, and that most of the children had special skills but worked very well under supervision. A large percentage of the participants seemed not to remember much of what the educators had said about their child or did not answer the question at all as they did not see their child's educators that regular.

In terms of meeting the needs of the child, the majority of the mothers indicated that their child's main need that the school was meeting was the educational need as the child received more attention as a result of being educated in small groups compared to how they would be educated in the mainstream education. Most importantly the school was meeting the needs of the child to socialise with peers.

Conclusion

It can be concluded that the mothers are fully aware that their child is attending the special school, however, they are not fully informed of how the special school education system works. This reflects that there is no clear communication or partnership between the school and the

mothers, as they are not well informed of the process that the special school follows. As much as the mothers get to meet the educators of their disabled child at the school it can be concluded that their needs are not usually addressed as the school mainly focuses on the disabled child's progress rather than assessing how the mothers are coping in their caring role.

Another conclusion that can be drawn is that for those mothers who have been fully informed about their child's disability and understand the definition of the disability may find it easy to access the special school as they may not have initial denial. It can also be concluded that the proximity of the special school determines how easily the mothers access the school to send their child there.

The final conclusion is that the other people's attitudes in the community towards mothers with mentally or physically disabled child may influence the mothers' decisions to send their child to a special school.

Recommendation

The recommendation that can be made with regard to the results that have been explained is that the school needs to provide information sessions to all the mothers that have children with disabilities attending the school. Understanding special education laws and systems as well as the special school's guidelines for services will help the mothers to get the best support for their child at school. This is because the child may be eligible for support services, but the school might not provide services unless the mothers ask for them.

The school also needs to build a positive working relationship with the mothers, where the mothers are free to discuss their child's progress with the teachers and also be informed on the role that the mothers can play in order to enhance their child's education performance.

In order for the mothers to fully understand their child's disability and the education system the education department, social workers and the schools should render one-on-one service to the mothers where they can be educated about their child's specific disability at their own pace, in order to identify how the disability affects the child's functioning and their work.

(iv) **Special education meeting the needs of the caregivers (mothers) of school going children with mental or physical disabilities.**

The majority of the mothers indicated that the school did not meet their needs resulting from being full-time carers of their disabled child. On the other hand, it was found that the school helped the majority of the mothers with the child's tuition fees as well as transportation which was a relief for the mothers as they were already struggling financially, so this was a burden reduced.

Conclusion

From this it can be concluded that while the mothers appreciated and needed the help provided by the school, it was not enough.

Recommendation

Consequently, it is recommended that services provided by the school to meet more of the mothers´ needs be increased or supported by other welfare organisations and social development e.g. accessing the Disability Dependence Grant.

(v) **Economic needs of the mother**

It was found that, as most of the mothers were unemployed as they stayed home to look after their children, their main source of income was the Child Support Grant as well as the Disability Dependence Grant. The majority of them were very aware of their rights with regard to financial support for the disabilities and the carers, as the school informed them about them very well and others indicated that they had read at the clinic about their rights to access social security benefits such as grants.

Conclusion

This indicates that the availability of a Child Support Grant and Disability Dependence Grant is vital for mothers caring for their disabled children in low-income communities, which is possibly why they are so well informed about these grants.

Recommendation

There is no specific recommendation from the results of this question, other than the importance of maintaining a working grant system to support these mothers.

(vi)   Physical needs of the mothers

The majority of the mothers indicated that their houses were adequately equipped for them to be able to care for their disabled child. For those who indicated that their house was not equipped they stated that their house was not in the safe neighbourhood, a lot of crime exists as well as a culture of drugs so they felt that this was not a positive influence and environment for their child.

In terms of medical check-ups for the child only a small number of participants found their child's check-ups to be a waste of time whereas the small total number indicated not to feel anything about the check-ups. The highest total of the mothers found the check-ups to be very helpful.

When asked if they needed any help with the physical care of the child, the majority of the mother indicated that they did not want any help as they thought that they were the only ones that would be able to provide the best care for their child. Secondly, the mothers indicated that they did not think that anyone else would want to look after their disabled child apart from sending the child to the special school.

For those who indicated that they needed help, they stated that they needed someone to come and help looking after the child after school so that the mother could at least have some alone time to socialise with others for at least few hours or just to relax.

The highest number of the participants indicated that they received a lot of assistance from family members in caring for the child and to deal with the challenges that rise from their caring role. The main family members that provided support was the maternal grandmother and the also the husband. Another support came from friends of these mothers.

Conclusion

It can be concluded that a safe environment within the community and in their homes is the main concern for the mothers with the children with disabilities in the low-income communities. This is very important for the mothers as they want to protect their children from dangers happening within their communities.

It can also be concluded that mothers with children with disabilities are very sceptical about leaving their child with other people. As indicated above, this is because they feel that no one can care for their child as well as the mothers themselves. Secondly, they feel that no one would want to help in caring for the disabled child.

It can also be concluded that mothers value the medical check-ups that the children have to attend as it gives them peace realising that their child is in good health and the disability is under control. Again, it can be concluded that informal support is the main source of assistance in meeting the mother's physical needs.

Recommendation

It is recommended that the government (health care department and the social development) introduce the respite care system where mothers can have someone to care for their child for few hours in a safe environment so that the mothers can have some alone time to socialise with others, so that they are not always isolated and withdrawn, in the end leading to stress or depression.

(vii)   Social needs of the mothers

It was found that all the mothers indicated that having a mentally and physically disabled child had a great implication on their social well-being and relationships with the different systems in their lives. The mothers indicated that they experienced both positive and negative experiences from their caring role. The mothers indicated that even though it was difficult at times to communicate with their disabled child they still found their relationship to be good and that they became much closer to the child. On the other hand, the mothers experienced negative experiences with the other normal children in the house as they did not pay much attention to them because they had to devote all their attention to the disabled child and that it was very hectic. The other relationships with the other family and extended family were seen to be supportive and understanding.

In terms of the marital relationships the mothers indicated that having a disabled child had brought them very close to their husband, whereas the other mothers indicated that their husbands were not very supportive in caring for the child and that they were getting frustrated with all the time the mothers had to spend with their disabled child.

In terms of the interaction with the community and professional people, it was found that the mothers found them to be supportive and understanding.

Conclusion

It can therefore be concluded having a child with disabilities affects not only the mothers providing the care for the child, but also siblings and the relationships among the family members. This means that having a mentally or physically disabled child can negatively influence the mothers' family relationships and the other system by disrupting and causing strain between the systems as a result of the care demands from the disabled child. It can also be concluded that if the mothers have a good support system that helps in the care of the disabled child and meet the mothers other needs, it is likely that the mother will experience positivity in her role resulting in improved mental well-being.

Recommendation

It is recommended that mothers should be provided with a lot of social support by the social welfare organisations, social worker and counsellors in their caring role. This social support should include information from professional counsellors and social workers on how the mothers can balance their mother to child relationship with their disabled child as well as the other children in the house, so that they all get equal attention. This support should be provided both formally professionals and informally by family and support groups. This means that all family members should be supportive of the mother´s caring role, for example, by sharing responsibilities.

(viii)   Emotional needs of the mothers

The mothers indicated that caring for their mentally or disabled child impacted on their emotional well-being. When asked to indicate who gave the greatest support in their lives on a regular basis with regards to the caring of their disabled child within certain categories such as listening to problems, support in crisis, reassurance and referral to support services. Within all these categories the family was the ranked as the highest in providing support and especially emotional support in nearly half of the categories. A highlight was seen in the referral to the other services; where over a quarter of the respondents indicated that they were referred to the services by professionals. These professionals included doctors, teachers, as well as nurses, however, the sup-

port that the professionals provided mainly focused on the child rather than dealing with the mothers' experiences that resulted from the care that they provided for their child.

It was also found that the over half of the mothers seemed to be very happy and contented with the all the emotional support that they received from their family. Only a small number indicated that they were not happy with the support from family members such as husbands as they felt that, they could have provided more support for the mothers than what they were providing.

Conclusion

It can therefore be concluded that family is the many source of emotional support for the mothers as they are there to listen to the problems that the mothers have with regard to the care of the disabled child, as well as being there all the time and in time of crisis and providing reassurance. This also shows that the family has a very positive impact on the mothers' emotional well-being meaning that it may help in reducing their stress levels if they continue to provide this support to the mothers which may explain why the mothers appeared to be very happy with the support they received from their family system.

Another conclusion that can be made is that there is a lack of professional emotional support for the mothers apart from referring them to the relevant services to meet the disabled child's needs. This indicates that the professionals such as teachers, doctors, nurses and psychologists focus on the needs of the disabled child and ignore the mothers caring for that child's needs giving her caring role challenges which impact on the mothers' emotional well-being negatively. This may also indicate there is no strong relationship between the mothers and these professionals and they do not consider the mothers experiences or challenges that result from the care that they have to provide on the regular basis.

Recommendation

It is therefore recommended that service providers/professional (teachers, doctors, nurses and psychologists) need to provide awareness programmes on the different challenges that carers of disabled children face and their negative experiences, so that they educate the people and the family members on how to help these mothers overcome these challenges and provide appropriate support for the mothers.

Another recommendation is that the service providers/professionals (welfare organisations, social development and the health care department) need to educate their employees on how they could reach out to the mothers with the children with disabilities. This can be done by helping them to identify the needs of these mothers and their experiences as a result being able to help the mothers meet their needs and therefore eradicating the problems or challenges that resulted from having to care for their disabled child and also build a trusting professional working relationship.

(ix)   Making important decisions

When the mothers were asked who assisted them in making important decision with regard to caring for the disabled child, most of the mothers indicated that they received no support at all in making decisions and they made these decisions on their own. Some of the mothers who indicated that they did not receive any support at all with regard to making decision stated that they were happy that they were able to make their own decisions as this gave them a sense of independence. On the other hand, those mothers who indicated that they received this support from their family, stated that they were very happy that their family was there to assist them in making important decisions. This type of support usually came from their family, namely, husbands and mothers.

Conclusions

It can therefore be concluded that being able to make own decisions had a positive impact on the mothers in the sense that it improved their self-esteem by knowing that they were capable of making important decisions on their own making, them to feel independent. This is good for their emotional well-being in the sense that if the mothers feel confident of their abilities then they are likely to have a positive attitude towards the care that they have to provide for their disabled child.

It can again be concluded that the family is the always the main source in providing different types of support for the mothers.

Recommendation

From the results above, it is recommended that the social worker and the educators empower the mothers who are not able to make important decisions on their own, using the principles of social

work such as client self-determination, to practice making decisions using different steps. These steps may include identifying the pros and consequences of each decision.

(x) Psychological needs of the mothers

The mothers had different experiences in their feelings with regard to having a disabled child. A very small number indicated that they felt it as if they were being punished for something they had done; others indicated that their feelings were more of guilt, thinking that they had contributed to their child having a disability. Others basically experienced feelings of initial denial. In was also found that the other mothers experienced a feeling of over-protectiveness and nearly a quarter of them experienced a feeling of acceptance at having a disabled child.

With regard to providing full-time care for the child it was found that mothers had different feelings, those with a greater support system indicated that they were happy to provide support for their child. Those with less support system indicated that they experienced feelings of frustration and they were usually emotionally drained as a result of all the tasks that they have to perform in caring for the their mentally or disabled child. In this regard it was also found that those mothers with children with severe disability such as cerebral palsy were the ones who expressed that they were emotionally drained and they experienced withdrawal and isolation, compared with the mothers whose children only had learning disability.

It was also found that the other systems had different reactions to finding out about the mothers having a disabled child. Some family systems were very supportive and understanding where as some were very confused as they did not understand the disabilities and did not know how to help. Others were very judgemental.

Conclusion

From the findings above it can be concluded that the impact of having and caring for a children with mental or physical disabilities is large and long-term. This is because the mothers may experience feelings of anger, guilt and frustration, leading to stress and depression. In addition to the financial challenges and all the tasks that they have to perform, mothers are faced with an emotional burden of dealing with the stigma of having a disabled child as well as the disappointment of knowing their children will not achieve normal adult milestones. Another aspect is

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that the mothers who receive more support to meet their different needs tend to experience positivity in their caring role.

Another conclusion is that mothers may experience stress as a result of the daily care demands: emotional distress (e.g., maternal depression), interpersonal difficulties (e.g., parental discord), financial problems and adverse social consequences (for example, social isolation).

Lastly, it can be concluded that providing full-time care for a mentally or disabled child can take a heavy toll if the mothers do not have adequate support. This is because care-giving involves many stressors: changes in the family dynamic, household disruption, financial pressure, and the sheer amount of work involved.

Recommendations

It is therefore recommended that mothers with children with mental or physical disabilities be provided with psychological support. This can be done by service providers/organisation (psychologists, counsellors and social workers) providing counselling services for the mothers as well as training sessions where the mothers can be educated on how they can cope in times of stress or frustration. These coping strategies may include helping the mothers to set achievable goals and engaging in problem-focused coping in order to achieve them. This may lead to feelings of control and mastery in the care that they have to provide and dealing with the stigma that causes them stress.

In these training sessions the mothers should be provided with information which includes strategies for gathering information, making decisions, planning, and resolving conflicts. It also includes efforts directed at acquiring resources to help deal with the underlying problems, and situation-specific, task-oriented actions. Mothers could also be taught to keep a record of how to deal with negative experiences and the steps they followed to deal with those experiences. This can help them to deal with future stress as they can read their journal to look at the steps and goals that they followed in order to reduce their stress levels and negative experiences.

It is also recommended that welfare organisations, churches and social workers implement programmes that empower the mothers to take control to deal with their challenges and resulting

needs on their own instead of totally depending on external service providers for support, mothers should be encouraged to take charge of the situation and educate and train themselves again.

(xi)   Knowledge and awareness of available resources and how to access them

Nearly half of the respondents indicated that they were not aware of the resources available in their community to help them with the care of their child and meet the mother's own needs. The special school was the only resource that the mothers were very aware of as meeting their child's educational needs.

Conclusion

It can therefore be concluded that mothers are not very well informed of the resources that are available in their communities. The reason for this may be the fact that these resources are not available in the community at all, or the organisations have not raised awareness of the resources that they offer.

It can also be concluded that there may be a number of organisations/resources that are located in the communities in which the mothers live. However, most of these mothers with school-going child with mental or physical disabilities may not be aware of the support that they can get from these organisations, as these organisation are not visible enough to the mothers. These organisations may offer support groups for the mothers with children with disabilities living in poverty. But, as these resources are not publicized most mothers continue to live in poverty and without knowing of the support that may be helpful to them, as these are very important sources of both psychological and socio-economic support.

Recommendation

From the findings and conclusions indicated above it can be recommended that welfare organisations need to make their services available to the mothers and explain to them what help is available to assist them to access these resources. In terms of lacking resources in these low-income communities, the government needs to take initiative in placing and establishing services such as centres for counselling, respite care services, venues for support groups, in these communities for the mothers, in order to help them to care for their disabled child.

The final recommendation is that welfare organisations need to publicise the services that they offer to the mothers with pre-school children and how these single mothers can access these services. These services may include counselling, life skills training, adult education as well as support groups for the mothers who have children with mental or physical disabilities. This is because most of these mothers are not aware of the resources and services they can get from their community welfare organisations.

It can also be recommended that social workers, educators, and health professionals should promote the social welfare services available to the community and explain their roles within the community and their organizations. Mothers with children with disabilities should be educated during the workshops or home visits offered by the service providers indicated above, about services that are available and how they can be of assistance during stressful life events, and particularly when they cannot cope in their caring role.

(xii)   Physical and emotional conditions developed after having a disabled child

It was found that the mothers indicated that they had developed some physical and emotional conditions after having their disabled child. These conditions included stress, depression and insomnia. This was due to the fact that long-term care demands can be a burden which can cause physical and psychological stress in the long term resulting in the emotional conditions indicated above.

Conclusion

It can therefore be concluded that there is a need for support for mothers who care for their children with disability in order to prevent them from developing physical or emotional conditions as a result of having to care for a disabled child.

Recommendation

It is recommended that right at the beginning when the mother's child has been diagnosed with a specific disability, doctors, psychologists and social workers assess the mother's situation holistically in order to find out the systems that can provide support for her and also offer her support at her level of need. These professionals (doctors, psychologists and social workers) can liaise and co-operate among themselves and the other welfare organisations to offer services such as home visits that can monitor the mother's progress and the needs that are developing, so that

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they can prevent the mothers from developing these physical or emotional conditions resulting from having to provide care for the disabled child.

(xiii)   Involvement with community/support groups

Over half of the respondents indicated that they were not aware of or involved in any community/support groups. The reasons for not being part of support groups were that the participants had no knowledge of what a support group was or of any in the community. In addition to lacking knowledge, the other important reasons in the majority of the participants was that they were not involved as they did not have any time at all to be part a support group as they had to devote their time to providing care for their disabled child and there was no one to help in looking after the child if they were to attend the support group. For those mothers who were a part of the support group the majority of them stated that they were there as it gave them the opportunity to at least socialise with other mothers and share experiences.

Conclusion

It can be concluded that mothers with school-going children with disabilities lack knowledge of community/support groups. They do not understand the purpose of support groups and have very limited knowledge of groups in their community. It can be seen that the respondents' communities lack support services for mothers with children with disabilities.

It can also be concluded that if the mothers were provided with assistance in caring for their disabled child they would definitely be able join a support group if one is available and they are informed about them, as one of the many barriers is lack of time and having someone to come and help look after the child when they are out.

Recommendations

From the findings above is it can be recommended that the social workers, churches and other welfare organisations should facilitate and promote support groups for mothers who are providing full-time care for their mentally or physically disabled child. Secondly, the government (health care department, the education department and non-governmental organisations) should liaise with one another in providing respite care in the low income communities where mothers could drop off their children for some time and others to look after the child so that the mother

get to have some time to take part in a support group on the regular basis. The mothers could also socialise and share experiences with other mothers and learn different coping strategies in caring for their disabled child, and in return enhance their emotional, physical and psychological well-being.

Lastly, it is recommended that welfare organisations in the community should inform the mothers about the existence of support groups in the community. Furthermore, these mothers should be educated about the benefits of support groups.

6.3 OVERALL CONCLUSION AND RECOMMENDATION

6.3.1 Final conclusion

Overall, this study can be seen as a success in providing much-needed insight into the experiences of mothers caring for their mentally or physically disabled school-going children in South African low-income communities. Most of the assumptions based on the international literature reviewed in the earlier chapter were confirmed by the data collected using the questionnaire. Moreover, several valuable recommendations for welfare organisations and the government (department of health, education department and non-governmental), could be deduced from the findings of this research, which could help to improve the often precarious situation of mothers caring for their disabled child, helping them to better meet their needs.

6.3.2 Recommendations for further research

As pointed out in the problem statement for this thesis, there is a gap in the literature regarding the experiences of mothers caring for their mentally or physically disabled school-going children in South African low-income communities. While it can be seen as a successful first step towards filling this gap, its delimitations, such as the small sample, time and space constraints, necessitate further extensive research on this topic in South Africa, in order to further validate and complement the findings. Further research is also needed on how welfare services coordinate their services in order to identify the needs of mothers caring for their children with mental or physical disabilities. Moreover, the role of social workers in helping these mothers with their caring demands could benefit from further research. Additional research is also needed on how the gov-

ernment can improve the access to assistance for families that have children with mental or physical disabilities to all the services that the child needs without being marginalized because of costs or stigmatisation. Lastly, research is needed on how the government can develop and implement policies that focus on meeting the different needs of families caring for their disabled children.

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APPENDIX

APPENDIX A: SEMI-STRUCTURED QUESTIONNAIRE

UNIVERSITY OF STELLENBOSCH

DEPARTMENT OF SOCIAL WORK

SEMI-STRUCTURED QUESTIONNAIRE

RESEARCH TITLE: **The experiences of mothers caring for their primary school going children with mental or physical disabilities in low income communities: An ecological perspective.**

Researcher: Masters Student (L. Chirwa)

1. **IDENTIFYING THE PARTICULARS OF THE RESPONDENTS**
   a)

1.1 Marital status of the respondent:

Married	
Single	
Cohabiting	
Divorced	
Widowed	

1.2 Age of respondent

21-25 year		26-30 year		31-35 year		36-40 year	

1.3 Home language..

1.4 What is your highest qualification?

School standard	
None	
Sub A – St.2/Grade 1-4	
St. 3 – 5/ Grade 5 - 7	
St. 6 – 7/ Grade 8 – 9	
St. 8 – 9/ Grade 10- 11	
St. 10/ Grade 12	
After school training (specify)	

1.   THE DISABLED CHILD

2.1 Identifying information of the disabled child

2.1.1 Age.......................

2.2 Type of disability

Physical disability

....
......

Mental disability

....
......

2.3 Definition of the child's disability

2.3.1 How would you define your child's disability?

....
....
....
....

2.3.2 Explain how you came to define your child to have that disability?

....
....

....

....

2.4 The special needs of the disabled child

2.4.1 What are the special needs of your child based on his/her disability?

....

....

....

....

2.5 Education (primary school)

2.5.1 What class level is your child in?

Level	Tick accordingly
R-1	
2-3	
4-5	

2.5.2 How old was your child when she/he started school?

....

2.6 Admittance of child to the special school

2.6.1 What was the process to get your child into this school?

....

....

....

2.7 School selection for the disabled child

2.7.1 Was this your first school choice? Yes/No

2.8 Awareness of resources available from the school

2.8.1 Which facilities/resources are available at the school to meet the needs of your child disabled child?

....

....

....
....

2.9 Contact with the school educators

2.9.1 How often do you meet your child's educators to discuss your child's progress?

Everyday	
Once a week	
Once a month	
Every six month	
Never	
Other (specify)	

2.9.2 What do the educators say about your child's disability and progress

....
....
....
....

2.10 Meeting the needs of the disabled child

2.10.1. How do you think your child's needs are met when he/she is at school?

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....
....

2.10.2. Explain how helpful the special school is to your child

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....
....

2.11 Barriers at the school

2.11.1. Which barriers are at the school that impact on your child's schooling?

....
....

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....

2.12 Meeting the needs of the mother

2.12.1. How does the school meet your own (physical, emotional, psychological and economic needs) as a fulltime care giver for your disabled child?

 Please explain

....
....
....
....
....

1. **ECONOMIC NEEDS**

    3.1 Please indicate your <u>occupation</u> with regards to the information provided in the table

Status	Before the birth of your disabled child	After the birth of your disabled child	When the disabled child started school
Employed			
Unemployed			

3.2 What type of work can you do? (Mark all applicable categories)

Type of work	(tick)
Unschooled	
Schooled	
Professional	
Other. (please specify)	

3.3 What is the income group of your household?

R0-1000	
R1001-R2000	
R2001-R3000	
R3001-R4000	
R4001-R5000	
R5000+	

3.4 Knowledge of the support that is available

Are you aware of the rights that you and your disabled child have with regards to financial support? Yes/No

If yes how did you become aware of them?

....

....

....

....

1. **PHYSICAL NEEDS OF THE MOTHER**

4.1 HOUSING

4.1.1 How equipped is your house to meet the special needs of your child?

....

....

....

....

4.2 Special equipment for the disabled child

4.2.1 Does your disabled child have any special equipment as a result of his/her disability? Yes/No
If yes, what type of special equipment?
....

4.2.2 How did you obtain the equipment?
....
....
....

4.3 Medical checkups for the disabled child

4.3.1 How often does your child need to go for medical checkups?

Daily	
Once a week	
Once a month	
Once a year	
Never	
Other. Specify....	

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4.3.2 Where does the disabled child go to for medical checkups?

....

4.3.3 How far is the place where you go for checkups from your home?

....

4.3.4 Do you need transport to get there? Yes/No

4.3.5 How do you feel about your child's checkups?

....

....

....

4.4 Physical care of the disabled child at home

4.4.1 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? Yes/No

If yes, what kind of assistance?

....

....

....

....

4.5 Assistance for the mothers

4.5.1 Where do you get assistance with caring for your disabled child?

Churches	
Non- governmental organizations (NGO's)	
Community workers	
Friends	
Family	
Social workers	
Schools	
Support groups	

5. SOCIAL NEEDS OF THE MOTHER

5.1. Social needs of the mother

Please describe the impact and experience of having and providing full time care for your disabled child on the following social aspects of your life

5.1.1 How is your relationship with your disabled child, and the other children within the family?

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....
....
....

5.1.2 How is your marital relationship with regards to the caring of your disabled child?

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....

5.1.3 How is your relationship with your extended family members, relatives and friends?

....
....
....
....

5.1.4 How is your interaction with the community and the professionals?

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....
....
....

6. EMOTIONAL NEEDS OF THE MOTHER

6.1 Who assists you in your caring role when you are worried or unhappy?

Emotional support	Family	Other persons(please indicate who)
Listen to your problems		
Support you in crisis		
Reassure you		
Refer you to support services		

Other (specify)		

6.2 Please explain your experience in general of the type of emotional support that you receive

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....
....
....
....
....

6.3 Who assists you when you want to make important decisions?

....
....
....

 6.4 What is your experience of the support you receive in making decisions?

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....
....

7.   <u>PSYCHOLOGICAL NEEDS</u>

7.1. Please indicate the type of feelings you experience with regards to having a disabled child

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....
....
....

7.2. Which feelings do you experience with regards to the care that you provide for your disabled child?

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7.3. What was your family member's reaction on finding out that your child had a physical/mental disability?

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....

7.4. How did these reactions affect you?

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....
....

7.3. What was the communities' and the other systems reaction on finding out that you had a child with mental/physical disability?

....
....
....

7.4. How did these reactions affect you?

....
....
....
....
....

Role as a mother	
Effective	
Ineffective	
Adequate	

Inadequate	

7.5. How do you feel about your role as a mother having to care for a disabled primary school going child?

7.6. What do you associate having a disabled child with?

....

......

7.7. Do you need any help in the caring of your disabled child? Yes/No

Please indicate why?

....

....

....

....

....

7.8 Coping strategies:

7.8.1. What coping strategies do you use in caring for your disabled child?

Coping strategies	
Good self-esteem/self-efficacy	
Religious beliefs	
Relaxation techniques	
Face-to face interaction with professionals	
Accessing relevant information	
Talking to other mothers about the experiences	

7.9 Awareness of the available resources

7.9.1. Which resources are available in your community to help you in caring for your disabled child?

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....

............Please explain how you got to know about these resources

....

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....

....

....

7.10 Knowledge of how to access resources

7.10.1. Are you aware of how you can access to the resources that can help you to care for your child as well as meeting your own needs as a care giver? Yes/No

Please indicate why?

....

....

....

....

7.11 Consequences of having a disabled child

7.11.1. Do you have any physical or emotional conditions that developed after having your disabled child?

....

....

....

7.11.2.   Please explain the kind of condition?

....

....

....

....

7.12 Involvement community groups

7.12.1. Are you involved in any societies/communities groups that help you in meeting some of your needs with regards to the care of your disabled child? Yes/No

Why?

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....
....
....

7.13 Non- governmental organizations

7.13.1. Are you aware of the Non-government organizations that are available in your community? Yes/No

If yes how did you come to know about them?

....
....
....
....

7.13.2. Are you aware of the services that they render? Yes/ No

<div align="center">

THANK YOU

INFORMED CONSENT FORM

</div>

UNIVERSITY OF STELLENBOSCH

DEPARTMENT OF SOCIAL WORK

RESEARCH TITLE:

The experiences of mothers caring for their primary school going children with mental or physical disabilities in low income communities: An ecological perspective

The aim of this research study is to develop an understanding of the experiences of mothers caring for their primary school going children with physical or mental disabilities in low income communities.

Please respond to the questions and statements as fully and objectively as you can. Please give your answers by ticking the box that applies to you or writing in the spaces provided.

All the information that you will give will be dealt with confidentiality, and would not be made known to any persons or organizations without the written approval of the respondents. This means that all the respondents' personal information will not be made known.

Participation is voluntary and no force will be used to gain participation.

I, _____ , the undersigned, declare that the research has been explained to me. I also understand that the information that I will provide will not be given to other persons and organizations without my written approval. I participate voluntarily in this research

        Signature: _____

        Date: _____

        Witness: _____

        Date: _____

APPENDIX B: LETTER TO PARENTS FROM THE SCHOOL ABOUT RESEARCH PARTICIPATION (ENGLISH)

Dear Mothers,

You are invited to take part in a research project conducted by a Social Work Masters student from Stellenbosch University. The research focuses on finding out about your experiences and feelings as a mother providing full time care for your disabled child.

You can choose whether you would like to participate in this study or not. Whichever decision you will make will be respected.

If you would like to volunteer to take part in this research study please indicate in the table below of which day you would like to come to the school and the time that you wish to participate.

APPENDIX C: BRIEF VAN SKOOL AAN OUERS AANGAANDE DEELNAME IN NAVORSIG

Geagte Moeders,

U word genooi om deel te neem aan 'n navorsingsprojek wat gevoer gaan word deur 'n Magister student van Stellenbosch Universiteit. Die navorsing fokus daarop om uit te vind omtrent U ervaringe en gevoelens as 'n moeder wat voltyds sorg vir 'n gestremde kind.

Deelname is nie verpligtend nie so U kan kies of U wil deelneem of nie. U besluit sal gerespekteer word, ongeag wat U besluit.

As U vrywillig wil deelneem aan die navorsing studie, dui asseblief in die onderstaande tabel aan op watter dag U na die skool kan kom en die tyd wat U wil deelneem.

DATUMS: 2011	TYE	NAME
Donderdag - 1ste Sept	09:00 – 09:45 09:45 – 10:15 10:15 - 10:45 10:45 - 11:15 11:15 - 11:45 11:45 - 12:15 12:15 – 12:45 12- 45 – 13:15	
Vrydag - 2de Sept	09:00 – 09:45 09:45 – 10:15 10:15 - 10:45 10:45 - 11:15 11:15 - 11:45 11:45 - 12:15	
Maandag – 5de Sept	09:00 – 09:45 09:45 – 10:15 10:15 - 10:45 10:45 - 11:15 11:15 - 11:45 11:45 - 12:15 12:15 – 12:45	

	12- 45 – 13:15	
Dinsdag- 6de Sept	09:00 – 09:45	
	09:45 – 10:15	
	10:15 - 10:45	
	10:45 - 11:15	
	11:15 - 11:45	
	11:45 - 12:15	
	12:15 – 12:45	
	12- 45 – 13:15	
Woensdag – 7de Sept	09:00 – 09:45	
	09:45 – 10:15	
	10:15 - 10:45	
	10:45 - 11:15	
	11:15 - 11:45	
	11:45 - 12:15	
	12:15 – 12:45	
	12- 45 – 13:15	
Donderdag – 8ste Sept	09:00 – 09:45	
	09:45 – 10:15	
	10:15 - 10:45	
	10:45 - 11:15	
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	11:45 - 12:15	
	12:15 – 12:45	
	12- 45 – 13:15	
Vrydag – 9de Sept	09:00 – 09:45	
	09:45 – 10:15	
	10:15 - 10:45	
	10:45 - 11:15	
	11:15 - 11:45	
	11:45 - 12:15	
Maandag – 12de Sept	09:00 – 09:45	
	09:45 – 10:15	

	10:15 - 10:45	
	10:45 - 11:15	
	11:15 - 11:45	
	11:45 - 12:15	
	12:15 – 12:45	
	12- 45 – 13:15	
Dinsdag – 13de Sept	09:00 – 09:45	
	09:45 – 10:15	
	10:15 - 10:45	
	10:45 - 11:15	
	11:15 - 11:45	
	11:45 - 12:15	
	12:15 – 12:45	
	12- 45 – 13:15	
Woensdag – 14de Sept	09:00 – 09:45	
	09:45 – 10:15	
	10:15 - 10:45	
	10:45 - 11:15	
	11:15 - 11:45	
	11:45 - 12:15	
	12:15 – 12:45	
	12- 45 – 13:15	

THANK YOU!!!!!