

**THE IMPACT OF SOCIO-ECONOMIC FACTORS IN RAISING A CHILD WITH A
MENTAL DISABILITY IN THE NORTH WEST OF PRETORIA**

by

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DECLARATION

I hereby declare that: “The impact of socio-economic factors on raising a child with a mental disability in the North West of Pretoria” is my own work, that all the sources used or quoted have been indicated and acknowledged by means of complete references, and that this dissertation was not previously submitted by me for a degree at another University.

Anna Magdalena Elizabeth Trollope

Signature:.....

Date:.....

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SUMMARY

The impact of socio-economic factors on raising a child with mental disability in the North West of Pretoria

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In this study the impact of socio economic factors in raising a child with mental disability was discussed and explored. There is limited research done on this topic in the world and in South Africa.

Studies show that there is a direct link between poverty and mental disability. There are multiple factors that have an influence on a family that have a child that suffers from mental disability. These factors include stress and unresolved emotions regarding the child that suffers from mental disability, financial burdens, dealing with the child's problematic behaviour and the social stigma associated with disabilities. It was found that there is little support available for families that have to deal with all these factors.

Different aspects of mental disability have been discussed in this study in order to create a better understanding of mentally disability and to provide all the necessary information surrounding mental disability. Aspects that were discussed are: a) What is mental disability, b) Levels of mental disability, c) The link between poverty and mental disability, d) Socio-economic and psychosocial factors that have an impact on the family, e) Causes of mental disability, f) Role of the social worker, and g) Services provided to families. These aspects have been discussed through literature and in the empirical study.

Findings from this study show that families that have a child with mental disability also have to contend with a lot of socio-economic factors that play a role in the family. Having a child with a mental disability in the house has an influence on all members of the family. Children with a mental disability have serious emotional and behavioural problems. Parents of mentally challenged children commonly experience different emotions. Raising a child with a mental disability may be more expensive than raising a typical child.

It was thus concluded that there is a need to explore the impact of socio-economic factors in raising a child with a mental disability.

Key words: Mental disability, Moderate mental disability, Mild mental disability, Socio-economic factors, Child.

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CHAPTER ONE

GENERAL ORIENTATION TO THE RESEARCH METHODOLOGY

1.1 Introduction

Multiple socio-economic factors have an influence on raising a child that suffers from a mental disability (Lloyd & Rosman, 2005:186). Lloyd and Rosman (2005:186) state that multiple factors contribute to the fact that childhood disability is overrepresented among children living in poverty. The National Health Interview survey, cited in Lloyd and Rosman (2005:186), found that among children whose families live in poverty there was a prevalence of 21.5% of chronic illness; and among those families it was reported that, while receiving Temporary Assistance to Needy Families (TANF), there was a prevalence rate of 25.6% for mental retardation, autism and attention deficit disorder. Internationally 16% of American children, that's almost 12 million, are living in poverty. Poverty impacts children's health in a myriad of ways. When families do not have enough income, fundamental perquisites for good health are often difficult to obtain.

According to an article entitled 'World facts and Statistics on Disabilities and Disability Issues' (2011:1), the two-way link between poverty and disability creates a vicious circle. Poor people are more at risk of acquiring a disability because of a lack of access to good nutrition, health care, sanitation, as well as safe living and working conditions. Once this occurs, people face barriers to education, employment and public services that can help them escape poverty.

In South Africa three nationwide studies have attempted to describe the epidemiology of mental disability. In 1999, the first National Disability Survey yielded a prevalence for all disabilities of 5.9%, and that of intellectual disability of 1.1%. A second study was conducted as part of the national census survey in 2001. The prevalence of mental disability was 0.5% and the overall disability prevalence was 5%. Of the population with

disabilities surveyed, only 30% had any formal education. The census did not include persons in institutional care, therefore excluding a large population of persons with disabilities. In 2007, a further national survey, which examined severe mental or learning disabilities, yielded a prevalence of 0.27%. The methodology in all these studies involved regional household surveys on the existence and experience of disability (Adnams, 2010:436-437). In this study, the impact of socio-economic factors in raising a child with a mental disability will be studied.

The following key concepts are important in this study:

In the literature different terms are used for **mental disability**, but the meaning is the same for all. The terms that are used are: learning disability, intellectual disability, mental handicap or mental retardation (Burke & Cigno, 1996:5). The term used in this study will be mental disability and will be defined as follows: “when a person has certain limitations in mental functioning and in skills, such as communicating, taking care of him or herself, and social skills” (National Dissemination Centre for Children with Disabilities, 2011:1).

Mild mental disability is not identified until a child enters school and sometimes not until the second or third grade, when more difficult academic work is required. Children with mild mental disability can master academic skills up to about the sixth-grade level and are able to learn job skills well enough to support themselves independently or semi-independently (Heward, 2006:1).

Mild mental disability: IQ score: 50 – 55 to approximately 70 – 75. Intermittent supports are provided on an as-needed basis. Students do not necessarily require continuous or daily support (Raver, 2009:1).

Moderate mental disability: IQ score: 35 – 40 to 50 – 55. Limited supports are provided over a prescribed period of time. Intermittent and extensive supports may be necessary for some students as well (Raver, 2009:1). Children with a **moderate mental disability** show significant delays in development during their preschool years. As they

grow older, the gap in overall intellectual development and adaptive functioning generally grow wider between these children and their age mates without disabilities (Heward, 2006).

Socio-economic factors can be defined as “the field of study that examines social and economic factors to better understand how the combination of both influences something” (Business Dictionary, 2012).

The New Children’s Act 38 of 2005 identifies a **child** as “a person under the age of 18” (Children’s Act 2005:20).

1.2 Literature Review

1.2.1. Different levels of mental disability

Mental retardation may be defined as mild, moderate, severe, or profound, depending on a child's IQ scores and functioning. In schools, intermittent or limited supports are commonly provided for students with mild mental disability (Raver, 2009:1).

Mild mental disability

Mild mental disability comprises of an IQ score of 50 – 69 and slightly impaired motor coordination. This often does not get diagnosed until a later age. Children will be able to develop communication skills and learn appropriate social skills (Sulkes, 2009:1). Children with a mild mental disability are not identified until they enter school and sometimes not until the second or third grade, when more difficult academic work is required. Most students with a mild mental disability master academic skills up to about the sixth grade level and are able to learn job skills well enough to support themselves independently or semi-independently. Some adults who have been identified with mild mental disability develop excellent social and communication skills, and once they leave school are no longer recognised as having a disability (Heward, 2006:1).

Both Sulkes (2009:1) and Heward (2006:1) agree that children with mild mental disability are often only diagnosed at a later stage. According to them these children will also be able to learn appropriate social and communication skills. These children will be

able to support themselves independently. The information will help the researcher to know on what level the children function and what they are able to do.

Moderate mental disability

Children with a moderate mental disability show significant delays in development during their preschool years. As they grow older, the gap in overall intellectual development and adaptive functioning generally grows wider between these children and their age mates without disabilities. People with a moderate mental disability are more likely to have health and behaviour problems than are individuals with a mild mental disability (Heward, 2006:1). Moderate mental disability comprises of an IQ score of 36 – 51, poor social awareness and fair motor coordination. They can profit from training in self-help activities. They can talk or learn to communicate and will be able to progress to elementary school level. They will be able to learn to travel alone in familiar places. Social and occupational skills can be learned by them. They will need supervision and guidance when under mild social or economic stress (Sulkes, 2009:1).

Heward (2006:1) and Sulkes (2009:1) agree that children with moderate mental disability will be able to learn some social and occupational skills. The difference between children with moderate mental disability and their peers without disability will grow wider the older they get. These children need help to function at social events and will not be able to handle stress. They tend to have more health and behavioural problems than someone without disability.

Severe mental disability

IQ score: 20 – 25 to 35 – 40. Extensive support has to be provided to children suffering from severe mental disability; this includes assistance on a daily basis in a number of settings. Profound mental disability: IQ score below 20 – 25. Pervasive supports must be provided to these children. This usually involves constant assistance, often of high intensity and may include life-sustaining measures (Raver, 2009:1). Individuals with severe and profound mental disability are almost always identified at birth or shortly afterward. Most of these infants have significant central nervous system damage, and

many have additional disabilities and/or health conditions. Although IQ scores can serve as the basis for differentiating severe and profound mental disabilities from each other, the difference is primarily one of functional impairment (Heward, 2006:1). Both Raver (2009:1) and Heward (2006:1) concur that children with severe and profound mental disability need support and assistance on a daily basis. They will not be able to function independently.

These are the different levels of mental disability that have been explored in this study, especially mild mental disability and moderate mental disability. The researcher has conducted her research with families that have children in Suiderberg High School. Children attending this school suffer from mild or moderate mental disability. These children have been tested by psychologists and occupational therapists at the school. Each child needs to be evaluated before being admitted to the school.

1.2.2 Link between poverty and mental disability

Researchers have begun to investigate the largely ignored proposition that poverty and socio-economic position may be an important determinant of the psychopathology of both children with mental disabilities and their parents (Emerson & Hatton, 2009:434). Studies have consistently reported a significant association between poverty and the commonness of mental disabilities. The available evidence suggests that this association reflects two distinct processes.

Emerson (2007:107,113) indicated three links of poverty to mental disability. Firstly, poverty causes mental disabilities, an effect mediated through the association between poverty and exposure to a range of environmental and psychosocial hazards. Secondly, families supporting a child with mental disabilities are at increased risk of experiencing poverty due to the financial and social impact of caring for a child with mental disabilities and the exclusion of people with mental disabilities from the workforce. It is likely that the association between poverty and mental disabilities accounts in part for the health and social inequalities experienced by people with mental disabilities and their families. Elwan (1999: iii) adds that poverty and disability seem to be inextricably linked. It is

often noted that people with disabilities are poorer, as a group, than the general population, and that people living in poverty are more likely than others to be disabled. Well-being is associated with the ability to work and fulfil various roles in society.

Authors are in agreement that there is a definite link between poverty and disability; seeing that people with disability are often noted as being poorer (Emerson & Hatton, 2009; Emerson, 2007; Elwan, 1999). The researcher is in agreement with the above authors about the link between poverty and disability which can be seen in the community where the research has been conducted. The authors stated that disability has an effect on people's work environment. People with disability often are not able to work and are therefore dependent on others or on a State pension. This contributes to their poverty. This information helps to show what the socio-economic factors are that the parents are dealing with, especially the poverty that goes hand in hand with mental disability.

The White Paper for Social Welfare (1997) indicates that the majority of people with disabilities in South Africa have been excluded from the mainstream of society and have thus been prevented from accessing fundamental social, political and economic rights. The exclusion experienced by people with disabilities and their families is the result of a range of factors, for example:

- the political and economic inequalities of the apartheid system;
- social attitudes which have perpetuated stereotypes of disabled people as dependent and in need of care; and
- a discriminatory and weak legislative framework which has sanctioned and reinforced exclusionary barriers (Republic of South Africa (RSA), Ministry for Welfare and Population Development, 1997):

The key forms of exclusion responsible for the cumulative disadvantage of people with disabilities are poverty, unemployment and social isolation. It is commonly considered that the specific needs of people with severe mental/intellectual disabilities fall outside

the range of development. Such people are likely to be regarded as ill and in need of constant care. They are not, therefore, provided with opportunities to participate in society to the best of their abilities.

People with severe intellectual disabilities living in rural areas often have a low life expectancy, due to lack of care, support and access even to the most basic services. Families can seldom meet the additional financial burden of regular visits to hospitals, additional expenses for equipment and assistive devices, and other necessities (Republic of South Africa (RSA), Ministry for Welfare and Population Development, 1997).

Elwan (1999:24) indicates that studies have identified three types of factors which can make disabled people, or families with disabled people, worse off: (i) loss of income; (ii) additional costs resulting from the disability; and (iii) marginalization or exclusion from services and/or social and community activities. The extra costs directly related to the disability include such things as medical expenses, equipment (crutches, wheelchairs, etc.), adaptations to housing and specialized services. Disabled people have lower education and income levels than the rest of the population. They are more likely to have incomes below the poverty level than the non-disabled population, and they are less likely to have savings and other assets. These findings are applicable to both developing and developed countries.

Elwan (1999:34) also indicates that poverty and disability are interlinked – not only does disability add to the risk of poverty, but conditions of poverty add to the risk of disability. He further states that poor households do not have adequate food, basic sanitation or access to preventive health care. They live in lower quality housing, and work in more dangerous occupations.

As seen above, the researcher is of the opinion that mental disability is a problem in many of the communities in South Africa, especially in the poor communities where people have little resources to help them deal with these problems. Families are

affected by this on a daily basis. Families in Daspoort sometimes struggle to cope with more than one child that is suffering from a mental disability. It has been observed that in some cases the parents also seem to be suffering from a mental disability.

1.2.3. Socio-economic factors

Caring for a child with a disability brings multiple challenges to parents, such as additional financial burdens for treating their child's condition, dealing with the child's problematic behaviour, and the social stigma associated with disabilities. Consequently, parents of a child with a disability often experience more physical health symptoms, negative effects, and poorer psychological well-being than parents with a child without a disability (Ha, Greenberg & Seltzer, 2011:405). Boyd (2010:1) also confirms that raising a child who is mentally challenged requires emotional strength and flexibility. He further asserts that the child has special needs in addition to the regular needs of all children, and parents can find themselves overwhelmed by various medical, care giving and educational responsibilities. He also adds that whether the special needs of the child are minimal or complex, the parents are affected and support from family, friends, the community or paid caregivers is critical to maintaining balance in the home.

Furthermore, families living with low income have no financial support or resources that can help them to cope with a child suffering from mental disability. Ha et al. (2011:405) concur with Boyd that raising a child with a mental disability has multiple challenges for the parents. These challenges include difficult behaviour, financial concerns and emotional concerns. The researcher observed that parents will have to face many challenges in raising a child with a mental disability.

Reynolds (2012:1) agrees with Ha et al. (2011:405) that a child's mental disability is difficult to face and overcome. These authors further state that learning disabilities encompass a wide range of problems, including trouble with speaking, reading and writing, Maths, memory and physical coordination. Furthermore, parents of children with learning difficulties face a wide range of emotions and problems. It is further asserted that having a child with a disability poses a significant risk to parents' physical and

emotional well-being. However, this risk may differ across different racial and ethnic groups, given diverse cultural norms, resources, and support available to these parents. Within each minority population, different factors may account for the variability in the extent to which having a child with a disability leads to negative health and mental health consequences for the parents.

Boyd (2011:1) has identified emotional issues, physical exhaustion and stress, school related issues and financial concerns as issues that can be experienced by low income families with children with mental disabilities. Each one of these issues will be discussed below.

Firstly, emotional issues: Parents of mentally challenged children commonly experience different emotions over the years. They often struggle with guilt. One or both parents may feel as though they caused the child to be disabled, whether from genetics, alcohol use, stress, accidents or other logical or illogical reasons. This guilt can harm the parent's emotional health if it is not dealt with. Some parents struggle with "why" and experience a spiritual crisis or blame the other parent (Boyd, 2011:1).

It is confirmed by Gohel, Mukherjee and Choudhary, (2011:64) that parents of a child with a mental disability can face enormous emotional challenges, such as repeated physical and emotional crises, interactive family issues, ruined schedules, and additional expenses; which can create financial burdens for a family. It may be during these times of physical and emotional stress that parents will act out their frustrations on each other, the other children or even the child with the disability or illness.

Boyd (2011:1) further asserts that most parents have aspirations for their child from the time of their birth and can experience severe disappointment that they will not be president, a physician, an actor or whatever they had in mind. He states that these parents must deal with the "death" of the perfect child who existed in their minds and learn to love and accept the child they have. Occasionally, parents feel embarrassed or ashamed that their child is mentally disabled.

Secondly, physical exhaustion and stress: Physical exhaustion can take a toll on the parents of a mentally challenged child. They may also need to be watched to avoid inadvertent self-harm, such as falling down stairs or walking into the street (Boyd, 2011:1). The degree of this is usually relative to the amount of care needed. Feeding, bathing, moving, clothing and diapering an infant is much easier physically than doing the same tasks for someone who weighs 80 kilograms. The child may have more medical and other health-care appointments than other children and may also need close medical monitoring. These additional responsibilities can take a physical toll on a parent, leading to exhaustion. The American Academy of Family Physicians relates that these issues can cause significant caregiver stress (Boyd, 2011:1). Parents need to help these children with day to day tasks. Low income families cannot afford to pay helpers to assist them with these children. The future of these children also causes the parents stress (Boyd, 2011:1). Parents of mentally disabled children are more vulnerable to stress than parents of normal children. The high level of stress experienced by parents of mentally disabled children could be related to subjective factors, such as a feeling of being restricted, social isolation and dissatisfaction, and these factors might pave the way for the manifestation of anxiety symptoms. Gohel et al. (2011:64) concur by stating that parents of mentally disabled children require mutual support from a spouse, family and other members of society.

Gohel et al. (2011) also state that managing such problems requires much effort and skill in handling them, and hence such support would be considered an important factor. Furthermore these authors stated that behavioural problems in children with mental disabilities cause stress. Boyd (2011:1) agrees by saying these children constantly need to be watched and need supervision. Parents need to learn skills in how to deal with these problems and they need support from their spouse, family and community.

Thirdly, school-related issues: The parent of a child with developmental disabilities may have to deal with complex issues related to education. Parents often have to advocate for their child to receive a quality education at a private or public educational institution

that will enrich them. This often requires close parental knowledge of available specialised schools or training centres (Boyd, 2011:1). In this regard, Adnams (2010:439) states that in each province in South Africa, special schools provide for school-aged learners with a range of developmental disabilities. He states that education policies have not been implemented for those with severe and profound intellectual disabilities, and in practice this group is excluded from governmental educational benefits. Within the mainstream education system, although national policy provides for learners' special needs, those with mild intellectual disability in general do not have their learning needs adequately met within a system still struggling with a legacy of inequity inherited from the apartheid era.

Furthermore, throughout the country, there are major service gaps for adolescents and adults with mental disabilities. This author further states that policies in South Africa provide each province with special education schools. As Boyd (2011:1) mentioned, some children need to attend private schools, but finances and transportation is a problem as well as parents who are not involved with their children's development. Adnams (2010:439) also states that there are still major service gaps in rendering services to people with mental disabilities. Hence, the researcher has conducted the study at a government school.

Boyd (2011:1) also asserts that the parent must monitor the child's interactions with others to ensure they are not being bullied. Furthermore, transportation to and from school may require specialised transport, and children with severe disabilities may need to be schooled at home or in special education schools. He states that this is a major problem for families with a low income and they need to make use of public schools. Furthermore, these schools are sometimes far away from their homes and children need to make use of alternative transport and this is again an extra expense for the family.

Lastly, financial concerns: Raising a child with a mental disability may be more expensive than raising a typical child. These expenses can arise from medical

equipment and supplies, medical care, care giving expenses, private education, tutoring, adaptive learning equipment or specialised transportation. The care of the child may last a lifetime instead of 18 years. Parents may have to set aside money in a trust fund for the child's care when they pass away (Boyd, 2011:1). Parents with a low income will not be able to provide for all the financial care that a child with a mental disability may need. They will not be able to pay for private education, they will need to make use of public medical facilities and public transport, and they will not be able to put money away in a trust fund for the child (Boyd, 2011:1). Having a child with an intellectual disability can impose financial, social and physical stress on the family. Research done by Lopez, Clifford, Minnes and Ouellette-Kuntz (2008:99) has shown that caregivers of children with disabilities experience greater stress than caregivers of children without disabilities. Parents of young children with developmental delays report experiencing greater stress than parents of children without delays.

The researcher has observed that raising a child with a mental disability has a socio-economic and psychosocial impact on the family. Raising a child with special needs tends to be more expensive because of their disability. A child with a mental disability will need to attend a special education school. This child might need to use chronic medication that would cost a lot of money. This will have a major impact on the financial situation of the family.

1.3 Theoretical Framework

The theoretical framework that was used in this study is the bio-psycho-social model. Models are systems used to facilitate the understanding of concepts (Knouff, 2011). This study will be focused on families that are confronted with mental disabilities. The bio-psycho-social model was used to explain the physical, psychological and socio-cultural aspects of mental disabilities in families.

This model is based on the systems approach and the family can be seen as the system that was studied (Kaplan, [Sa] 18-19):

The Bio-Psycho-Social model is a comprehensive, integrative, and elegant model that allows us to address all major areas of the presenting issue across three spheres: physical, psychological, and socio-cultural. It allows (and actually encourages) us to holistically examine the interactive and reciprocal effects of environment, genetics, and behaviour.

Saylor (2003:1) agrees with Kaplan; the bio-psycho-social model is a method of understanding health and illness through biological, psychological, and social factors. The principle of the bio-psycho-social model states that all issues relating to health are products of a complex interplay of these three factors. Biological influence plays a key role in the bio-psycho-social model. In this aspect of the model, the physiological causes of an illness are identified and studied.

The theories behind the bio-psycho-social model, however, view biological factors as only one part of illness and that no illness manifests itself based solely on physiological grounds. It must work in conjunction with other deciding features. Psychological influence is another of these chief features. Under this aspect of the model, a healthcare provider will look for underlying psychological issues that contributed to the development of the patient's condition. There are a variety of psychological influences that can contribute to an illness, including depression, negative thought patterns, and a lack of self-control. The social influence aspect of the bio-psycho-social model examines the illness from a sociological perspective. Considerations such as economic standing, religion, and even technology can play pivotal roles in the creation of disease. Personal belief systems are also thought to be of significant importance in the development of illness (Saylor, 2003:1).

This model was relevant to this research because it focused on the medical condition of the child as well as on the psychological and social factors of the family. The bio-

psycho-social model was utilised as a theoretical framework for exploring the impact of socio-economic factors in raising a child with a mental disability.

1.4 Rationale and Problem Formulation

In terms of environmental factors, there is evidence of an association between poverty and mental disability. As in other developing countries, there is little data in South Africa on the effect of poverty and disability on each other (Adnams, 2010:437). The researcher works as a social worker in Daspoort. Daspoort and its surrounding areas is a low income community situated in the west of Pretoria. It came under the attention of the researcher that so many children are diagnosed with mental disabilities that a school for these children has been established in the area. The researcher is interested in exploring the impact of socio-economic factors in raising a child with a mental disability. Identifying the role played by socio-economic factors in families raising a child with a mental disability will help the health professionals that work with these families on a daily basis. Poverty plays a big role in these families. Enhanced insight and understanding might empower these professionals while delivering services to these children.

The researcher had access to these families through Suiderberg High School. All the children attending Suiderberg High School have already been diagnosed with mild to moderate mental disability, as each child needs to be evaluated before being admitted to the school. The Principal gave the researcher permission to do the research at Suiderberg High School. Exploring and highlighting the impact of socio-economic factors in raising a child with a mental disability might lead to an improved understanding; which might in turn empower health professionals in service rendering.

1.5 Goal and Objectives

1.5.1 Goal

The goal of this study was to explore the impact of socio-economic factors in raising a child with a mental disability.

1.5.2 Objectives

The objectives of this study were the following:

- To describe the socio-economic factors that has an impact on a child with a mental disability.
- To explore the role of socio-economic factors in raising a child with a mental disability.
- To make recommendations on strategies that may improve services to families with children with mental disabilities.

1.6 Research Question of the Study

Research has begun to investigate the largely ignored proposition that poverty and socio-economic position may be an important determinant of the psychopathology of both children with mental disabilities and their parents (Hatton & Emerson, 2009:434). Elwan (1999:8) agrees with Hatton & Emmerson (2009:434), that poverty and disability seem to be inextricably linked. It is often noted that disabled people are poorer, as a group, than the general population, and that people living in poverty are more likely than others to be disabled. Well-being is associated with the ability to work and fulfill various roles in society. But the links between poverty and disability do not appear to have been systematically examined, even in developed countries.

Therefore, the researcher decided to study the impact of socio-economic factors in raising a child with a mental disability.

The research question for this study was: **“What is the impact of socio-economic factors in raising a child with a mental disability?”**

1.7 Research Design and Methodology

In this study the research approach used is the qualitative approach. The research type used is applied research. The research design is case study and the subtype, collective case study. The population of the study was white Afrikaans speaking parents that have children in Suiderberg High School. Semi-structured interviews were conducted. A more detailed description of the research methodology as well as ethical aspects applicable to the study will be discussed in chapter three.

1.8 Limitations of the Study

Although all the objectives of the study were reached there were some unavoidable limitations in the study. 1). Participants were very unreliable and did not come for the interviews. Although the researcher phoned them and sent them text messages to remind them they still did not come. 2). The researcher was only able to conduct interviews with nine people and not ten as was mentioned in the research proposal. This was caused because people are unreliable and did not come for the interviews. In future the researcher will schedule more interviews than needed to ensure that the correct amount of interviews will be conducted.

1.9 Outline of the Research report

The final product of this research is a report with the following structure.

Chapter 1: General introduction to the research study

- Introduction
- Literature review
- Theoretical framework
- Rationale and problem statement

- Goal and objectives
- Research design and methodology
- Limitations of the study
- Outline of the research report

Chapter 2: Literature study

- Introduction
- Theoretical framework of the study: Bio-psychosocial model
- What is mental disability
- Levels of mental disability
- Causes of mental disability
- Link between poverty and mental disability
- Socio-economic and psychosocial factors
- Role of the social worker
- Services provided to families with children with mental disability
- Conclusion

Chapter 3: Research methodology and empirical findings

- Introduction
- Research methodology
- Ethical aspects
- Empirical findings / results of the study
- Summary

Chapter 4: Conclusions and recommendations

- Introduction
- Goal and objectives of the study
- Key findings of the study
- Conclusions
- Recommendations

CHAPTER TWO

Literature review on the role of socio-economic factors in raising a child with mental disability

2.1 Introduction

Mental disability is a disability that occurs before the age of 18 years. Persons suffering from mental disability experience difficulty in two main areas: 1) intellectual functioning and 2) adaptive behaviour (the use of everyday social and practical skills). Mental disability can be diagnosed through the use of standardized tests of intelligence and adaptive behaviour (and cannot be determined by IQ alone). People with intellectual disabilities who are provided appropriate personalized supports over a sustained period generally have improved life outcomes. People suffering from mental disability will be able to live on their own with the right amount of support (The Arc, 2011).

2.1.1 Theoretical framework

The theoretical framework that will be used in this study is the bio-psycho-social model. Models are systems used to facilitate the understanding of concepts (Knouff, 2011). This study will be focused on families that are confronted with mental disabilities. The bio-psycho-social model will be used to explain the physical, psychological and socio-cultural aspects of mental disabilities in families.

The bio-psycho-social approach was developed at Rochester decades ago by Dr George Engel and Dr John Romano. While traditional biomedical models of clinical medicine focus on pathophysiology and other biological approaches to disease, the bio-psycho-social approach emphasizes the importance of understanding human health and illness in their fullest contexts. The bio-psycho-social approach systematically considers biological, psychological, and social factors and their complex interactions in

the understanding of health, illness, and health care delivery (The Biopsychosocial approach, 2014:1).

The bio-psycho-social model focuses on both disease and illness, with illness being viewed as the complex interaction between biological, psychological, and social factors. Disease is defined as an objective biological event involving the disruption of specific body structures or organ systems caused by either anatomical, pathological, or physiological changes. In contrast, illness refers to a subjective experience or self-attribution that a disease is present. Thus, illness refers to how a sick person and members of his or her family who live with them respond to symptoms of disability (Fuchs, Gatchel, Peng, Peters & Turk, 2007:582).

The psychosocial factors involve both emotion and cognition. Emotion is the more immediate reaction to nociception and is more midbrain based. Cognitions then attach meaning to the emotional experience and can then trigger additional emotional reactions and thereby amplify the experience of pain, thus perpetuating a vicious circle of nociception, pain, distress, and disability. We then review the implications of the new insights for better understanding the etiology, assessment, treatment, and prevention of chronic disability (Fuchs, Gatchel Peng, Peters & Turk, 2007:582).

Barrel-Carrio, Epstein and Suchman, (2004:576) agree with Fuchs that the bio-psycho-social model is both a philosophy of clinical care and a practical clinical guide. Philosophically, it is a way of understanding how suffering, disease and illness are affected by multiple levels of organization, from the societal to the molecular. At the practical level, it is a way of understanding the patient's subjective experience as an essential contributor to accurate diagnosis, health outcomes and humane care. Defending the bio-psycho-social model as a necessary contribution to the scientific clinical method, three clarifications are suggested: (1) the relationship between the mental and physical aspects of health is a complex—subjective experience which depends on but is not reducible to laws of physiology; (2) models of circular causality

must be tempered by linear approximations when considering treatment options; and (3) promoting a more participatory clinician patient relationship is in keeping with current Western cultural tendencies, but may not be universally accepted.

As discussed above by different authors, the Bio-psycho-social Model focuses on the biological, psychological, and social factors; as well as on their complex interactions in understanding health and illness. This model is ideal for this study. It focuses on the socio-economic factors as well as on mental disability. By focusing on the socio-economic factors and mental disability the situation as a whole will be understood. This model not only focuses on the disease but also on the psychological and emotional factors. This study wants to understand the impact of socio-economic factors in raising a child with mental disability. And this is only possible if you look at the biological, psychological and social factors, as well as at the disease.

2.1.2 Internationally

Mental disability is a descriptive term for sub average intelligence and impaired adaptive functioning arising in the developmental period (< 18 years). Mental disability and other neuro-developmental disabilities are seen often in a general pediatric practice. Approximately 10% of children have some learning impairment; while as many as 3% manifest some degree of mental disability (Zeldin, 2012:1). Gohel, Mukherjee & Choudhary, (2011:64) agree with Zeldin (2012:1) that the prevalence of mental retardation is 3% all over the world. However, 75% of mental retardation cases fall into the mild mental retardation category, while the remaining 25% have IQ's (Intelligence Quotient) of below 50 and are classified as moderately, severely or profoundly retarded. Severe mental retardation is uncommon.

The World Health Organization (2011) estimates that around 10% of the world's population that being around 700 million people, live with some kind of disability. That's the world's largest minority. But what about mental disability? There are no solid statistics, only rough estimates on the global prevalence of mental disability (Ball, 2013:1). According to Ball (2013:1), there are no solid statistics on the global

prevalence of mental disability. This makes it difficult to determine the exact amount of people suffering from mental disability. The researcher could only find statistics that were estimated.

The Canadian estimate varies from about 0.7% to 2.5% of the Canadian population. That's somewhere between 245,000 and 875,000 people. The estimate most often used is that of 2% or 700,000 Canadians that have some type of mental disability, ranging from very mild to profound. We can be more accurate about the numbers of people with moderate to profound intellectual disabilities because they almost all use services of some kind. They are thought to represent 0.35% of the total population, or about 125,000 people (Ball, 2013:1).

2.1.3 Sub-Saharan Africa

An estimated 10 to 15 million people in Africa have some form of intellectual disability. Because of the stigma and associated discrimination attached to intellectual disability in Africa, the majority of those affected live in poverty and isolation. Even in developed countries, people with an intellectual disability and their families are much more likely to be poor than the general population (Questions and Answers about Intellectual Disability, 2010:1). According to Paving a way out of poverty for people with intellectual disability, (2010:1) there are 130 million people with intellectual disabilities and their families around the world, according to Inclusion International. In Africa, some 10 to 15 million people – from a population of over 800 million – have a mental disability. Paving a way out of poverty for people with intellectual disability (2010:1) agrees with Questions and Answers about Intellectual disability, (2010:1) because of stigma and discrimination, the majority of those affected live in poverty and isolation.

Efforts to promote inclusion and opportunity in all aspects of community life for people with intellectual disabilities have met many barriers, some quite resistant to change. Globally, more than any other group including people with other forms of disability, people with mental disabilities experience higher unemployment rates and are excluded from education, employment, health care and other general services, and from

“belonging” in their communities (Paving a way out of poverty for people with intellectual disability, 2010:1).

People with mental disability do not have access to resources, and communities tend to isolate these people. People suffering from mental disabilities struggle to get work and therefore are isolated in poor conditions with little resources.

2.1.4 South Africa

In the National Youth Development Agency NYDA’s report, Statistics South Africa provided the following information on disability in South Africa in 2005:

- 780 623 persons between the ages of 0 and 29 were classed as people with a disability. The total number of persons with a disability in SA in 2005 was 2 255 982, meaning that a substantial number of disabled persons were young people.

- In terms of the types of disabilities (age 10-34):
 - 199 565 people had sight disabilities (all ages 724 169 people)
 - 157 243 people had hearing disabilities (all ages 543 104 people)
 - 62 417 people had communication disabilities (all ages 146 164 people)
 - 168 944 people had physical disabilities (all ages 668 082 people)
 - 140 812 people had mental disabilities (all ages 279 094 people)
 - 137 703 people had emotional disabilities (all ages 354 495 people)

As seen above, the total figure (for all ages) for mental disabilities was 279 094, whilst the total figure for emotional disabilities was 354 495, meaning that a very substantial proportion of persons with mental and emotional disabilities in SA were in fact young people, where young people with other disabilities made up a notably smaller percentage of the overall figures (SA Federation for mental health, 2012:2).

The data collected in the South African Census of 2001 indicates that there were 2 255 982 people with various forms of disability. This number constituted 5% of the total

population enumerated in this census. Of this number, 1 854 376 were African, 168 678 coloured, 41 235 Indian/Asian and 191 693 white. The number of females affected was 1 173 939, compared to 1 082 043 males (Statistics South Africa Census 2001).

The table below provides the percentage of persons who were affected by the various types of disabilities. The prevalence of sight disability was the highest (32%), followed by physical disability (30%), hearing (20%), emotional disability (16%), intellectual disability (12%) and lastly communication disability (7%). However, although the ranking of disabilities by gender is very similar to the above general ranking, a higher percentage of disabled males (31%) suffered from physical disabilities while, 36% of disabled females suffered from problems related to sight (Statistics South Africa Census 2001).

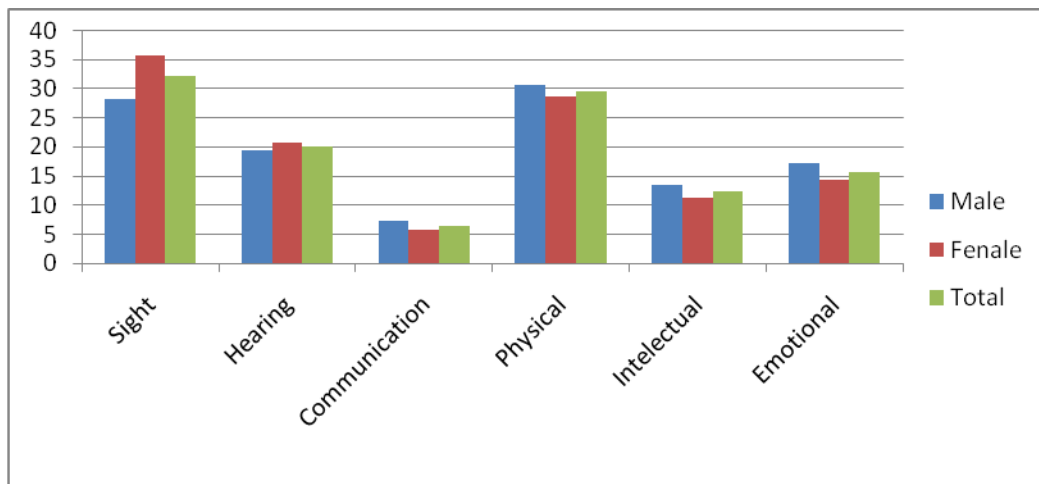


Figure 1: Provides the percentage of persons affected by various disabilities

With these statistics it is clear that intellectual (Mental) disability is a problem that needs to be addressed. Many people are affected by it and have to overcome the challenges regarding their disability. Mental disability occurs worldwide. Many parents have to deal with the problems and challenges of raising a child with a mental disability. In this study the researcher will explain some factors that play a role in raising a child with mental disability.

2.2 What is mental disability

Mental disability is characterized by a below-average intelligence or mental ability and a lack of skills necessary for day-to-day living. People with mental disabilities can and do learn new skills, but they learn them more slowly. There are varying degrees of mental disability from mild to profound (Chang, 2011:1).

According to Chang (2011:1) someone with mental disability has limitations in two areas. These areas are:

Intellectual functioning. Also known as IQ, this refers to a person's ability to learn, reason, make decisions, and solve problems.

Adaptive behaviors. These are skills necessary for day-to-day life, such as being able to communicate effectively, interact with others, and take care of oneself.

IQ (intelligence quotient) is measured by an IQ test. The average IQ is 100. A person is considered mentally disabled if he or she has an IQ of less than 70 to 75 (Chang, 2011:1).

To measure a child's adaptive behaviors, a specialist will observe the child's skills and compare them to other children of the same age. Things that may be observed include how well the child can feed or dress himself or herself; how well the child is able to communicate with and understand others; and how the child interacts with family, friends, and other children of the same age (Chang, 2011:1).

Mental disability is thought to affect about 1% of the population. Of those affected, 85% have mild mental disability. This means they are just a little slower than average to learn new information or skills. With the right support, most will be able to live independently as adults (Chang, 2011:1).

According to Krucik, (2005:1), mental disability exists in children whose brains do not develop properly or function within the normal range. There are four levels of retardation: mild, moderate, severe, and profound. Sometimes, mental disability may be classified as *other* or *unspecified*. Krucik (2005:1) agrees with Chang (2011:1) that mental disability involves both a low IQ and problems adjusting to everyday life. Mental disability can result in learning, speech, physical, and social disabilities. Severe cases are diagnosed at birth. However, milder forms might not be noticed until a child fails to meet a common developmental goal. Almost all cases of mental disability are diagnosed by the time a child reaches 18 years of age.

Logson ([sa]), described mental disability as "significantly sub-average intellectual functioning, existing concurrently with deficits in adaptive behavior and manifesting during the developmental period that adversely affects a child's educational performance." The American Association on Intellectual and Developmental Disabilities, formerly called the American Association of Mental Retardation, established criteria for the diagnosis of mental disability:

- Severe delays in development of cognitive, communication, social, adaptive, physical, fine and gross motor development, and behavioral skills typically beginning in infancy and early childhood;
- Significantly below average scores on academic, communication, and intelligence assessments, typically two standard deviations below the mean or average on standardized, norm-referenced assessments;
- Test scores at or below the 2nd percentile compared to same age peers; and
- Significant limitations in two or more adaptive skill areas (Logsdon, [sa]).

Different authors defined mental disability and explained what it is. Understanding what mental disability is will help the researcher to understand what the parents are dealing with. The researcher understands mental disability as a person with a below average IQ that is able to learn certain behaviour just slower than the average person. A person

with mental disability struggles to reason, solve problems, communicate and make decisions.

2.3 Levels of mental disability

According to Raver, (2009:1) mental disability may be defined as mild, moderate, severe, or profound, depending on a child's IQ scores and functioning. Children with mild mental disability are not identified until they enter school and sometimes not until the second or third grade, when more difficult academic work is required. Most students with mild mental disability master academic skills up to about the sixth-grade level and are able to learn job skills well enough to support themselves independently or semi-independently. Some adults who have been identified with mild mental disability develop excellent social and communication skills, and once they leave school are no longer recognized as having a disability (Heward, 2006:1).

Krucik (2005:1) defines Mild Mental Disability as a person that takes longer to learn to talk, but can communicate well once he or she knows how, fully independent in self-care, has problems with reading and writing, is socially immature, is unable to deal with the responsibilities of marriage or parenting, may benefit from specialized education plans, has an IQ range of 50 to 69 and may have associated conditions, including autism, epilepsy, or physical disability. Krucik (2005:1) and Heward (2006:1) agree that people with mild mental disability can learn good social and communication skills and will be able to live independently.

Children with moderate mental disability show significant delays in development during their preschool years. As they grow older, discrepancies in overall intellectual development and adaptive functioning generally grow wider between these children and their age mates without disabilities. People with moderate mental retardation are more likely to have health and behaviour problems than are individuals with mild mental disability (Heward, 2006:1).

Krucik, (2005:1) further defines moderate mental disability as: a person who is slow in understanding and in using language, has only a limited ability to communicate, can learn basic reading, writing, counting skills, is a slow learner, is unable to live alone, can get around on their own, can take part in simple social activities and has an IQ range of 35 to 49.

Individuals with severe and profound mental disability are almost always identified at birth or shortly afterward. Most of these infants have significant central nervous system damage, and many have additional disabilities and/or health conditions. Although IQ scores can serve as the basis for differentiating severe and profound mental disability from one another, the difference is primarily one of functional impairment (Heward, 2006:1). Krucik (2005:1) agrees with Heward (2006:1) that a person suffering from severe mental disability has noticeable motor impairment, has severe damage to and/or abnormal development of the central nervous system and has an IQ range of 20 to 34.

Krucik (2005:1) and Heward (2006:1) agree that a person suffering from profound mental disability is a person that is unable to understand or comply with requests or instructions, is immobile, must wear adult diapers, uses very basic nonverbal communication, cannot care for own needs, requires constant help and supervision and has an IQ of less than 20.

Levels of Mental / Intellectual disability (Sulkes, 2009)

Level	Intelligence Quotient (IQ) Range	Ability at Preschool Age (Birth to 6 years)	Ability at school Age (6 to 20 years)	Ability at Adult Age (21 years and older)
Mild	52-69	<ul style="list-style-type: none"> • Slightly impaired motor coordination • Often not diagnosed until later age • Can develop social and communication 	<ul style="list-style-type: none"> • Can be expected to learn appropriate social skills • Can learn up to about the 6th-grade level by 	<ul style="list-style-type: none"> • May need guidance and assistance during times of unusual social or economic stress

		skills	late teens	<ul style="list-style-type: none"> • Can usually achieve enough social and vocational skills for self-support
Moderate	36-51	<ul style="list-style-type: none"> • Poor social awareness • Fair motor coordination • Can profit from training in self-help • Can talk or learn to communicate 	<ul style="list-style-type: none"> • Can progress to elementary school level in schoolwork • May learn to travel alone in familiar places • Can learn some social and occupational skills 	<ul style="list-style-type: none"> • Needs supervision and guidance when under mild social or economic stress • May achieve self-support by doing unskilled or semiskilled work under sheltered conditions
Severe	20-35	<ul style="list-style-type: none"> • Able to learn some self-help skills • Has limited speech skills • Poor motor coordination • Can say a few words 	<ul style="list-style-type: none"> • Can learn simple health habits • Benefits from habit training • Can talk or learn to communicate 	<ul style="list-style-type: none"> • Can develop some useful self-protection skills in controlled environment • May contribute partially to self-care under complete supervision

Profound	19 or below	<ul style="list-style-type: none"> • Little motor coordination • May need nursing care • Extreme cognitive limitation 	<ul style="list-style-type: none"> • Limited communication skills • Some motor coordination 	<ul style="list-style-type: none"> • Usually needs nursing care • May achieve very limited self-care
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Different levels of mental disability were explained in the above paragraphs. The study will focus on children with mild and moderate mental disability. In order to know what the researcher is talking about it is important to know all the levels and understand all the levels. The researcher understands mild mental disability as children with an IQ of between 52-69. These children can learn social skills and will be able to support themselves independently or semi-independently. They will be able to attend school up to Grade 6 and would then need to be placed in a school for children with special needs. The researcher understands moderate mental disability as children with an IQ between 36-51. Children with moderate mental disability show significant delays in development during their preschool years. They will be able to learn skills but will need support in looking after themselves.

2.4 Causes of mental disability

Mental disability affects about 1 - 3% of the population. There are many causes of mental disability, but doctors find a specific reason in only 25% of cases. A family may suspect mental disability if the child's motor skills, language skills, and self-help skills do not seem to be developing, or are developing at a far slower rate than the child's peers. Failure to adapt (adjust to new situations) normally and grow intellectually may become apparent early in a child's life. In the case of mild retardation, these failures may not become recognizable until school-going age or later (Kaneshiro, 2011:1).

No reliable data on the cause of intellectual disability in South Africa exists. Clinically derived reports suggest that a number of causes of intellectual disability in South Africa are similarly prevalent in developed countries. A few studies have examined causes in small population samples. Studies reported a congenital cause in 20.6% of affected children, an acquired cause in 6.3%, and in 73.1% the cause was undetermined. In terms of environmental factors, there is evidence for an association of poverty and intellectual disability, including in the world's richer countries, but, as in other developing countries, in South Africa there is little data on the mechanisms through which poverty and disability affect each other (Adnams, 2010:437).

High prevalence rates in South Africa for conditions that are associated with the onset of mental disability in the prenatal and developmental period would suggest a higher total prevalence of mental disability than in developed countries. Most of these conditions are preventable, and this fact underscores the need for accurate epidemiological data in order to address effective interventions to reduce the prevalence of conditions that contribute to mental disabilities in South Africa (Adnams, 2010:437). The degree of cognitive impairment from mental disability varies widely, from profoundly impaired to mild or borderline disability. Less emphasis is now placed on the degree of disability and more on the amount of intervention and care needed for daily life (Kaneshiro, 2011:1).

The causes of mental disability can be categorized as follows according to The Arc (2011):

Genetic condition – This can be seen as abnormalities of genes inherited from parents, errors when genes combine, or from other disorders of the genes caused during pregnancy by infections, overexposure to x-rays and other factors. There are many genetic diseases associated with mental disability.

Problems during pregnancy: – When a pregnant mother uses alcohol or drugs it can cause mental disability. In fact, alcohol is known to be the leading preventable cause of mental disability. Smoking increases the risk of mental disability. Other risk factors that

the mother can expose the unborn fetus to are: malnutrition, certain environmental toxins, and illnesses of the mother during pregnancy, such as toxoplasmosis, cytomegalovirus, rubella and syphilis (The Arc, 2011).

Problems at birth - Prematurity and low birth weight predict serious problems more often than any other conditions. Problems during the birth process can also cause intellectual disability, such as temporary oxygen deprivation or birth injuries may cause mental disabilities (The Arc, 2011).

Problems after birth - Childhood diseases, such as whooping cough, chicken pox, measles, and Hib (HaemophilusInfluenzae Type b) disease that may lead to meningitis and encephalitis can damage the brain, as can injuries such as a blow to the head or near drowning (The Arc, 2011) .

Poverty and cultural deprivation - Children that are exposed to poverty are at a higher risk for malnutrition, childhood diseases and exposure to environmental health hazards. These children often receive inadequate health care. These risk factors increase the risk of mental disability. Children in disadvantaged areas may be deprived of many common cultural and educational experiences provided to other youngsters. These children are under-stimulated and this can result in irreversible damage and can serve as a cause of mental disability (The Arc, 2011).

Adnams (2010: 437) agrees with The Arc (2011) concerning conditions that have an impact on the burden of disability through either high prevalence or severity, and include nutritional deficiencies, infectious diseases, mother-to-child transmitted HIV/AIDS and tuberculosis, meningitis (TBM), foetal alcohol spectrum disorder (FASD) and violence and injury.

Understanding the causes of mental disability will help the researcher to understand where mental disability comes from and the causes of mental disability. There are many causes but doctors can find a specific cause in only one in four people. There are different causes of mental disability and the family's circumstances and history also play a role. Genetic conditions, problems at birth, accidents where brain damage occurs,

poverty and childhood diseases are all some of the causes of mental disability. This is necessary to understand in order to understand what the families deal with on a daily basis and where it comes from. It is also important to remember that in most cases, the doctors were not able to find the cause (The Arc, 2011).

2.5 Link between poverty and mental disability

Research has begun to investigate the largely ignored proposition that poverty and socio-economic position may be an important determinant of the psychopathology of both children with mental disabilities and their parents (Hatton & Emerson, 2009:434). Elwan (1999:8) agrees with Hatton & Emmerson (2009:434) that poverty and disability seem to be inextricably linked. It is often noted that disabled people are poorer, as a group, than the general population, and that people living in poverty are more likely than others to be disabled. Well-being is associated with the ability to work and fulfill various roles in society. But the links between poverty and disability do not appear to have been systematically examined, even in developed countries.

Socio-economic position is not an inherent property of individuals or families, but the result of the interaction between the impact of powerful social institutions in stratifying the social order and people's active involvement in recreating and maintaining the social hierarchy through cultural and social practices. People occupying lower socio-economic positions may have difficulty accessing resources that are necessary to enable them to live lives that are considered appropriate or decent within their society (Hatton & Emerson, 2009:434).

Recent research has begun to investigate the proposition that differences in socio-economic position between families with a child with mental disabilities and families with a child without mental disabilities may partly account for the higher rates of psychopathology reported in children with mental disabilities and their parents (Hatton & Emerson, 2009:434). People with disabilities have lower education and income levels than the rest of the population. They are more likely to have incomes below the poverty

level, and are less likely to have savings and other assets than the non-disabled population. These findings hold for both developing and developed countries. In developed countries, official programs do not appear to result in incomes for the disabled commensurate with non-disabled peers; even with substantial transfer and employment programs, the disabled still face a higher risk of poverty. Analysis of case studies in some developing countries shows that higher disability rates are associated with higher illiteracy, poorer nutritional status, lower inoculation and immunization coverage, lower birth weight, higher unemployment and underemployment rates, and lower occupational mobility (Elwan, 1999:iv).

Families often provide the main support for persons with intellectual disabilities, whether they are adults, children, or adolescents. Care of family members with intellectual disabilities by productive adults means that one or more parents are not able to access paid work or must work fewer hours or give up on job advancement. This contributes to a vicious cycle of poverty and exclusion (Paving a way out of poverty....2010:1).

The general lack of attention paid to family poverty as an important construct in its own right (rather than as a confounding variable to be controlled) is particularly surprising given that families supporting a child with mental or developmental disabilities are in general significantly more likely than other families to be located in lower socio-economic positions and to experience poverty (Hatton & Emerson, 2009:434). Disabled people have lower education and income levels than the rest of the population. They are more likely to have incomes below poverty level than the non-disabled population, and they are less likely to have savings and other assets. These findings hold for both developing and developed countries. The links between poverty and disability go two ways – not only does disability add to the risk of poverty, but conditions of poverty add to the risk of disability. Poor households do not have adequate food, basic sanitation, and access to preventive health care. They live in lower quality housing, and work in more dangerous occupations (Elwan, 1999:34).

The link between poverty and mental disability is an important factor in this study. The families that will take part in this study will be seen as living in a poor community. The researcher wants to show that there is a direct link between poverty and mental disability. Families living in poor communities do not have access to resources to help them with their mentally disabled children. Clinics are far away, they do not have access to occupational therapists or speech therapists to help them in supporting their children. Therefore children with mental disability living in poverty will not have the chance to improve their circumstances.

2.6 Socio-economic and psychosocial factors

The research with representative samples of children with mental disabilities and their parents has consistently demonstrated much higher levels of psychopathology and poorer well-being amongst both children with mental disabilities and their parents compared with those without mental disabilities. Although these differences in psychopathology are often assumed to be an inevitable consequence of the child's mental disability and therefore result in a naturally stressful parenting role, namely that poverty and socio-economic position may play an important part in the development and maintenance of psychopathology in both children with mental disabilities and their parents. Families with a child with mental disabilities are more likely to be living in poverty, differences in socio-economic position between families with a child with or without mental disabilities can substantially account for differences in child and parent psychopathology (Hatton & Emerson, 2009:433).

Caring for a child with a disability brings multiple challenges to parents, such as additional financial burdens for treating their child's condition, dealing with the child's problematic behaviour, and the social stigma associated with disabilities. Consequently, parents of a child with a disability often experience more physical health symptoms, negative effects, and poorer psychological well-being than parents with a child without a disability (Ha, Greenberg, Seltzer, 2011:405).

Reynolds (2012:1) agrees with Ha, Greenberg and Seltzer (2011:405) that a child's mental disability is a difficult thing to face and overcome. Learning disabilities encompass a wide range of problems, including trouble with speaking, reading, writing, math, memory and physical coordination. Parents of children with learning difficulties face a wide range of emotions and problems. Raising a child who is mentally challenged requires emotional strength and flexibility. The child has special needs in addition to the regular needs of all children. Parents can find themselves overwhelmed by various medical, care giving and educational responsibilities (Boyd, 2011:1).

Whether the special needs of the child are minimal or complex, the parents are affected. Support from family, friends, the community or paid caregivers is critical to maintaining balance in the home. Families living with low income have no financial support or resources that can help them to cope with a child suffering from mental disability (Boyd, 2011: 1). Gohel, Mukherjee & Choudhary (2011:64) agree with Boyd (2011:1) that a family who has a child with a mental retardation will experience many challenges, such as repeated physical and emotional crises, interactive family issues, ruined schedules, and additional expenses, which can create financial burdens for a family. It may be during these times of physical and emotional stress that parents will take out their frustrations on each other, the other children or even the child with the disability or illness.

Parents having children with mental retardation require mutual support from spouse, family and other members of society. The presence of behavioural problems in children is known to produce greater stress for parents. Managing such problems requires more effort and skill in handling them, and hence such support would be considered an important factor (Gohel, Mukherjee & Choudhary, 2011:64). The impact of children with mental retardation on parents and other family members has long been of interest to professionals. Consequently, an understanding of relationships within the family has grown considerably over time. (Gohel, Mukherjee & Choudhary, 2011:65).

The more dependent the child, the more adverse his effect on his siblings. In other words, the more responsibility required by the normal siblings (particularly girls), the less likely the handicapped child would be welcomed into the family by his brothers and sisters. The parents require devotion of more time to mentally retarded child than to the normal child, and this might have a negative impact on the siblings (Gohel, Mukherjee & Choudhary, 2011:65).

Research found that the parents of children with mental retardation experience more psychological problems in aspects of aggression, depression, obsession, anxiety, physical complaints and psychosis than parents of normal children. It is also found that the parents of mentally retarded children are more vulnerable to stress than parents of normal children. The high level of stress experienced by parents of mentally retarded children could be related to subjective factors, such as a feeling of being restricted, social isolation and dissatisfaction, and might have paved the way for the manifestation of anxiety symptoms (Gohel, Mukherjee & Choudhary, 2011:65).

Chandrashekar (2011:1) indicated that there are some challenges that parents face when raising a child with mental disability:

Acceptance – When a doctor gives the parents the news that their child is mentally disabled and will never be completely normal, it is too painful for most parents to face. Many parents spend years in denial, trying to find some solution or cure to this problem. They might go from one hospital to another, trying alternative forms of medicine or looking to religion for a miracle. But mental disability is not a disease and there are no medicines to cure it. It is a syndrome which is caused by genetic factors (chromosomal abnormalities like in Down's Syndrome), hereditary causes (due to marriage between close relatives, previous incidences of mental disability in the family) or due to brain damage of some sort. As hard as it is to accept, once parents realize that their child has a mental disability and will always remain so, their expectations of the child will readjust accordingly. They can move on to taking the necessary steps to help the child make the

most of their potential by addressing their special needs through special education, vocational training etc.

Self-blame – The parents wonder if they did something wrong, during the course of the pregnancy or after birth, while taking care of the child. They wonder if God is punishing them for their sins.

Stigma – Many parents might feel that a child with mental disability is something to be ashamed of and cannot be allowed out of the house. Neighbours, relatives or others might make cruel remarks about the child and parents might feel isolated and without support.

Helplessness- Many parents do not know how to get help for their child once he or she has been diagnosed with mental disability. The sense of helplessness comes both from a lack of understanding about mental disability and a lack of information about the resources available for mentally disabled individuals. It might also arise from insensitive handling of the case by the mental health professional, who might not have enough time to talk to each family at length about their experience.

Behaviour problems- Many parents find it difficult to handle behaviour problems like screaming, crying, inability to concentrate, aggressiveness and stubbornness that a child with mental disability might have. For parents, especially mothers, who have to take care of household tasks and work apart from taking care of the child, patience can wear thin. Getting angry with the child or hitting him/her also does not help very much. Often, the child might not understand how disruptive his/her behaviour is to others and why they get angry.

Unrealistic expectations- Many times, parents of children with a mental disability are dissatisfied with the slow progress their child is making in learning new things. They push harder to force the child to learn quicker and try to be on par with other children. However, the child can only learn to the best of his or her ability and no more. If he or she has the mental age of an 8 year old, he or she cannot be expected to undertake a

normal vocation which requires complicated mental processes. When parents have unrealistic expectations of what their child can achieve, it leads to disappointment not only for them but also in the child who does not understand what he or she is doing wrong.

Worry about the future- One of the main concerns of parents with children with a mental disability is about how their children will be taken care of when they die. They feel that no one else can take care of their child with the same love and care that they have and they are scared about how their child will manage to survive in the world.

Marital/family problems- Having a child with a mental disability places greater strain on a family than otherwise. Due to the extra tasks that have to be done to take care of the child, parents feel overworked, stressed out and unhappy. The marital relationship can become strained if the parents have different approaches in dealing with the child or if one parent has to take care of the child all the time. Sometimes, mothers might feel they are not getting enough support from their husband in taking care of the child. Fathers might feel that the mothers are unnecessarily worried and overprotective of the child. Other family members can complicate matters depending on how they react to the child.

Raising a child with mental disability has a lot of socio-economic and psychosocial factors in the family. A child with special needs tends to be more expensive because of their disability. A child with mental disability will need to attend a special education school. This child will need to use chronic medication that would cost a lot of money. This will have a major impact on the financial situation of the family (Chandrashekar, 2011:1).

Psychologically raising a child with a mental disability can be emotionally exhausting for the parents as well as for the siblings. The siblings may feel that they are not important and that the brother or sister gets all the attention. Parents will also stress about the future of this child. Who would look after him or her when the parents are not there anymore? Most of the time a child suffering from mental disability has difficult

behaviour and parents dealing with this will need specific parenting skills to know how to deal with it (Chandrashekar, 2011:1).

2.7 Role of the social worker

Social workers in disability work have both the opportunity and the obligation to engage in a wide range of research efforts, from the simplest single subject design in a neighborhood agency, to program evaluation, to policy analysis, and to secondary analysis of governmental data. As our communities are continuously enhanced by the participation of children and adults with disabilities, social workers will continue to direct their research toward making the lives of those who experience disabilities more just and fulfilling (Bellin, Dewees....., 2007).

Social workers are an important part of a service team supporting people with a disability and their families. As a social worker you will provide information, advocacy, social support, practical help, and counselling to people with a disability and their families. Social workers will work with people to assess their needs, help them set goals, work out strategies to achieve those goals and help people to develop the skills they need to manage their own lives. You may work with people with a disability of all ages. Social workers negotiate, on behalf of people with a disability and their families, with government officials and organisations providing services (ACT, 2011).

One of the roles of the researcher in this study is to create a better understanding of where the social worker as a professional fits in. The social worker in the community can help the family by linking them to resources that would be able to help them. The social worker can help the parents to get the child into a special education school. The social worker would be able to advise the parents surrounding parenting skills to help them deal with the child's disability as well as the child's behaviour. The social worker can support the family in helping them deal with the socio-economic factors surrounding raising a child with mental disability.

2.8 Services provided to families with children with mental disability

The Cape Mental Health offers a range of services for people with intellectual disability and their families – including counselling and support, education and care centres for children and adults, and training and employment opportunities for those who are able to work. Many of their services are offered free to those that are in need, and they depend on concerned individuals and businesses for the funds they need to continue (Cape Mental Health, 2013:1). Cape Mental Health is an organisation that offers services to children with mental disability. The researcher was not able to find such an organisation in the community of North-west Pretoria. It would be very helpful if all the communities had access to organisations like this that would be able to render services to these families.

There is little national evidence available on access to early learning for pre-school children with disabilities. A 2006 study found that only a quarter of children aged 0-6 years, who were recipients of the Care Dependency Grant (CDG), attended a crèche or child-minding group. Where children with disabilities do have access to early learning, it often takes place within informal community settings, with individuals (such as mothers of disabled children) running stimulation programmes (Children with disabilities in South Africa, 2012).

The country's inclusive education programme has enabled expansion of facilities for children with disabilities in public ordinary (mainstream) schools. The number of full-service schools (FSSs), i.e. schools that are equipped to support a range of disabilities, has grown from 30 in 2008/09 to 513 in 2010/11. Currently, some 110 300 learners with disabilities are attending ordinary public schools. In addition, 423 special needs schools nationwide are catering for approximately 105 000 learners. Nonetheless, evidence from surveys suggests that children with disabilities are substantially less likely to attend school than their non-disabled peers. Furthermore, among those children with

disabilities who do get access to schooling, drop-out rates are higher than for those who are not disabled (Children with disabilities in South Africa, 2012).

In line with policies, a range of services for people with intellectual disability (PWID) are outlined by government sectors, but a comprehensive and integrated approach is often hampered by a lack of prioritization of resources. In many areas, basic and other services are provided by the private sector. Services tend to be concentrated in larger centers and many PWID's in rural areas have no meaningful access to services at all (Adnams, 2010:439).

Inadequate alignment of policies to plans of Departments continues to undermine the pace of service provision. There are numerous policies in place that are intended to fulfil government's constitutional and legal obligations towards children with disabilities. However, these have not been consistently linked to national and provincial planning processes. For example, despite the clear statement of priorities in White Paper 6 on Inclusive Education, a review of strategic plans of the Department of Basic Education at the national and provincial levels reveals inadequate provisions to support children with disabilities. Again, although the National Rehabilitation Policy is in place, the Department of Health's strategic plans reviewed as part of this study (at the national and provincial levels) make little reference to this policy or to the Policy on Standardisation of Assistive Devices. The Strategy for the Integration of Services for Children with Disabilities cites the Department of Social Development as one of the lead departments in the provision of habilitation and rehabilitation services for children with disabilities, but neither national nor provincial strategic plans reviewed make clear provisions for implementation (Children with disabilities in South Africa, 2012).

In each province, special schools provide for school-aged learners with a range of developmental disabilities. Education policies have not been implemented for those with severe and profound intellectual disabilities, and in practice, this group is excluded from governmental educational benefits. Within the mainstream education system, although national policy provides for learners' special needs, those with mild intellectual disability

in general do not have their learning needs adequately met within a system still struggling with a legacy of inequity inherited from the apartheid era. Specialized health services, including mental health services for PWID, are few and largely focused in secondary and tertiary centers in towns and cities. In all regions, in spite of policy for rehabilitation, there is inadequate provision for multidisciplinary health services for PWID (Adnams, 2010:439).

Throughout the country, there are major service gaps for adolescents and adults with mental disability. The gap extends to published literature on services for PWID's other than organizational reports (Adnams, 2010:439).

According to the policy of disability in South Africa, people with disability have the right to support systems. These include family, disabled people's organisations, non-governmental organisations that work with issues of disability and social services, community based organisations, social workers and medical and psychological health practitioners (Policy on Disability, [Sa]:18). But this is not always the case in all the communities. Most communities have access to clinics. But these clinics do not always have all the necessary staff that would be able to help children with mental disabilities. These children must have access to an occupational therapist and a speech therapist. Few of the clinics can provide these services.

2.9 SUMMARY

In conclusion, according to statistics South Africa 2005, 140812 people between the ages 10-34 suffer from mental disability. Mental disability is characterized by below-average intelligence or mental ability and a lack of skills necessary for day-to-day living. People with mental disabilities can and do learn new skills, but they learn them more slowly. There are varying degrees of mental disability from mild to profound (Chang, 2011:1). According to Raver, (2009:1) mental disability may be defined as mild, moderate, severe, or profound, depending on a child's IQ scores and functioning. Krucik

(2005:1) defines Mild Mental Disability as a condition in a person that causes them to take longer to learn to talk, but the mildly mentally disabled can communicate well once they know how, they become fully independent in self-care, have problems with reading and writing, are socially immature, are unable to deal with the responsibilities of marriage or parenting, may benefit from specialized education plans, have an IQ range of 50 to 69 and may have associated conditions, including autism, epilepsy, or physical disability.

Children with moderate mental disability show significant delays in development during their preschool years. As they grow older, discrepancies in overall intellectual development and adaptive functioning generally grow wider between these children and their age mates without disabilities. Individuals with severe and profound mental disability are almost always identified at birth or shortly afterward. Most of these infants have significant central nervous system damage, and many have additional disabilities and/or health conditions.

The causes of mental disability can be categorised as follows: genetic conditions, problems during pregnancy, problems at birth, problems after birth (childhood diseases), poverty and cultural deprivation. Research has begun to investigate the largely ignored proposition that poverty and socio-economic position may be an important determinant of the psychopathology of both children with mental disabilities and their parents (Hatton & Emerson, 2009:434). People with disabilities have lower education and income levels compared with the rest of the population. They are more likely to have incomes below poverty level, and are less likely to have savings and other assets than the non-disabled population. These findings hold true for both developing and developed countries. The link between poverty and mental disability is an important factor in this study. The families that will take part in this study will be seen as living in a poor community. The researcher wants to show that there is a direct link between poverty and mental disability.

Caring for a child with a disability holds multiple challenges for the parents, such as additional financial burdens for treating their child's condition, dealing with the child's problematic behaviour, and the social stigma associated with disabilities. Consequently,

parents of a child with a disability often experience more physical health problems, negative effects, and poorer psychological well-being than parents with a child without a disability (Ha, Greenberg, Seltzer, 2011:405). Raising a child who is mentally challenged requires emotional strength and flexibility. The child has special needs in addition to the regular needs of all children. Parents can find themselves overwhelmed by various medical, care giving and educational responsibilities (Boyd, 2011:1).

Social workers are an important part of the service team supporting people with a disability and their families. As a social worker you will provide information, advocacy, social support, practical help, and counselling to people with a disability and their families. Social workers will work with people to assess their needs, help them set goals, work out strategies to achieve those goals and help people to develop the skills they need to manage their own lives. According to the policy of disability in South Africa, people with disability have the right to support systems. These include family, disabled people's organisations, non-governmental organisations that work with issues of disability and social services, community based organisations, social workers and medical and psychological health practitioners (Policy on Disability, [Sa]:18). But this is not always the case in practice in all the communities.

CHAPTER THREE

Research methodology and empirical findings

3.1 Introduction

In this chapter the researcher focused on the research methodology regarding the study. Furthermore, the empirical findings were collected, studied and put together into themes and subthemes to form conclusions. The information that was collected through semi-structured interviews from nine participants will be used in this chapter to form specific themes and subthemes. These themes will be discussed and supported by literature where necessary. This study was guided by the following research question: **“What is the impact of socio-economic factors on raising a child with a mental disability?”**

The research methodology and ethical aspects of the study will firstly be presented, followed by the empirical findings of the study.

3.2 Research Approach

For the purpose of this study the researcher used the qualitative research approach. This approach will help the researcher to determine the impact of socio-economic factors on raising a child with a mental disability.

The researcher chose to use the qualitative research methodology based on the theory which describes the qualitative approach as understanding phenomena by using naturalistic observation in order to understand the subjective perspective of the subject's inside world. Creswell (1998:15) defines the qualitative approach as an inquiry process that explores a social human problem. In the case of this study the impact of socio-economic factors in raising a child with a mental disability is the social human problem in question, which makes this research methodology appropriate for this study.

Furthermore, it assists the researcher in building a complex, holistic picture; in analysing words, reports, detailed views of participants; and conducting the study in the natural setting.

With this research approach the researcher was able to explore the issue of mental disability of children in families residing in low income communities. This study was in-depth and in detail. The phenomena of mental disability was studied as a whole in a real-world situation (Durrheim, Terre Blance & Painter, 2006:47).

3.3 Type of Research

In this study, applied research was used as a type of research in order to address a specific need/situation that had been identified. Applied research is designed to offer practical solutions to a concrete problem or to address the immediate and specific needs of practitioners (Neuman, 2006:25). In this study a specific problem, namely the impact of socio-economic factors in raising a child with a mental disability, was researched and recommendations were made to help families. The researcher therefore found a way to help these families (De Vos & Fouché, 2005:105).

In this study a specific need was identified; namely to explore the role of socio-economic factors in raising a child with a mental disability. The socio-economic factors were identified and described in this study. Therefore, applied research was the ideal research type to use.

3.4 Research Design

Mouton (2001:5) states that the research design is the plan or blueprint of how one is planning to conduct the research. The research design focuses on the end product and on the logic of the research. The most appropriate research design for this study was the case study and the subtype collective case study. Cases were studied on the impact of socio-economic factors on raising a child with a mental disability. Comparisons were

made between the cases and concepts. In this way theories can be extended and validated (Fouché & Schurink, 2011:322).

3.5 Research Methods

3.5.1 Study population

Bless and Higson-Smith (2005:85) state that a population is a set of elements on which the researcher focuses from which generalisations are made. Powers, Meenaghan and Toomey (1985:235) in Strydom (2005:193) define a population as a set of entities in which all the measurements of interest to the practitioner or researcher are represented. The population in this study are Afrikaans-speaking families that have children in Suiderberg High School. Suiderberg High School is a school for children with special needs.

Each child must undergo an assessment at the school before being admitted to the school. These assessments are done by psychologists and occupational therapists. Only learners with special educational needs and to whom LSEN-numbers (Learners with special education needs) have been issued by the Department of Education, may be admitted. Children may be admitted from the year in which they turn 13. The school caters for children with mild to moderate mental disability.

3.5.2 Sampling

The Suiderberg High School has 300 Afrikaans-speaking children that attend the school. The names and telephone numbers of these families were given to the researcher. The researcher utilised non-probability purposive sampling because a particular case was chosen that was of interest for this particular study. Typical cases were selected that contained the most characteristics, representative or typical, of the population that serve the purpose of the study best (Strydom & Delport, 2011:392). The researcher selected the cases that represent the characteristics of the study, namely a low income family with a child with a mental disability that attends Suiderberg High School. The researcher selected ten families that met the criteria.

3.5.3 Data collection

For the purpose of this study, the researcher used semi-structured interviews as the data collection method. The interview notes guided the researcher and did not dictate it. It was a guideline to follow during the interview. With this method, deep, rich information was collected. The participants were also able to share more information regarding the questions and the researcher explored when the answer was not clear. This method gave the researcher and the participants more flexibility (Greeff, 2011:351-352). The data was collected through long interviews with nine families. All the participants were parents of children attending Suiderberg High School.

The researcher conducted semi-structured interviews with families that have a child attending Suiderberg High School. The researcher made use of an interview schedule, this provided the researcher with a set of predetermined questions that were used as an appropriate instrument to engage the participant and designate the narrative terrain (Greeff, 2011:352). With an interview schedule the researcher focused on what she hoped to cover in the interview beforehand and to focus on difficulties like the wording of the questions and the sensitivity of the topic.

3.5.4 Data analysis

After data collection and checking was completed, the researcher began the process of analysing the data. The analysis was conducted in order for the researcher to detect consistent patterns within the data, such as the consistent covariance of two or more variables. When one started to analyse the data that was collected, patterns came to the fore which could prove a hypothesis to be either true or false or to answer the research question (Bless & Higson-Smith, 2005:137).

According to Creswell (1998) in De Vos (2005:334) there are six steps in the process of data analysis. They are the following:

- **Planning for recording of data:** The researcher used semi-structured interviews that were recorded with the consent of the participants. The researcher also made use of field notes in order to gather information which was observed.

- **Managing or organising the data:** The researcher sorted and divided the data into two different files, namely the relevant data and the irrelevant data. Data was managed into physical files and computer files.
- **Reading and writing memos of data:** This helped the researcher to get a feeling of the whole data base. The researcher read through the transcripts a couple of times in order to understand the information and to make sure that she interpreted it correctly. Memos were written in the form of field notes and then transcribed. The memos and transcripts were used as information data to conclude the research report.
- **Generating categories, themes and patterns:** When categories with meaning came to the fore, the researcher had to look for categories with internal convergence and external divergence. The data was reduced into small manageable themes so that the final report could be written. The researcher gave each discrete incident, idea or event a name, something that stands for or represents a phenomenon. As the researcher was breaking down the data, categories and subcategories were formed.
- **Testing the emergent understandings:** The researcher evaluated the usefulness of the data. This was done by searching through the data during which one challenged the understanding, searched for negative instances of the patterns and incorporated these into larger constructs, as necessary.
- **Representing, visualising (writing the report):** The researcher analysed the data into a written format. The researcher clarified how the data and concepts fitted together. Through writing, organising and contemplating, the data was fitted together and was put into a written report.

3.5.5 Ensuring trustworthiness of the data

The researcher made sure that the measurement procedure and instrument were credible, transferable, dependable and conformable. To establish the credibility the researcher made sure that the inquiry was conducted in such a manner so as to ensure that the subject had been accurately identified and described. The researcher made use of the following strategies to ensure the credibility of the qualitative research: 1)

Prolonged engagement: the researcher made sure that she understood the concepts of mental disability and familiarised herself with the medical terms. The researcher engaged in prolonged observations of mental disability. 2) Peer debriefing: the researcher was in contact with other researchers that have done research on mental disability to share problems. 3) Member checks: this is done in order to ensure that the findings of the research reflect the reality of participants' experiences. The researcher did member checks to ensure that credible data was collected (Schurink, Fouché & de Vos, 2011:419-420).

To establish transferability the researcher made sure that the findings or the research could be transferred from a specific situation or case to another. To ensure dependability the researcher made sure that the data was logical, well documented and audited. To ensure conformability the researcher made sure that research provided evidence that corroborates the findings and interpretations by means of auditing (Schurink, Fouché & de Vos, 2011:420-421).

3.5.6 Pilot study

The purpose of the pilot study was to determine whether the relevant data could be obtained from the respondents. The pilot study helped to improve the success and effectiveness of the investigation. Possible flaws in the measurement procedure were detected and unclear or ambiguously formulated items were identified (Welman, Kruger & Mitchell, 2005:148). Testing of the interview schedule was done with a family that has a child that attends Suiderberg High School in order to determine whether the schedule was without any loopholes. The family that was interviewed did not form part of the main study.

3.6 Ethical Considerations

Research ethics is a set of moral principles which is suggested by an individual or group, is subsequently widely accepted, and which offers rules and behavioural expectations about the most correct conduct towards experimental subjects and

respondents, employers, sponsors, other researchers, assistants and students (Strydom, 2011b:114). Hereunder follows a discussion of the ethical guidelines that were followed during this study.

3.6.1 Avoidance of harm

Possible harm would have been mainly be of an emotional nature, therefore physical injury could be ruled out. Emotional harm to subjects is often more difficult to predict and to determine than physical discomfort, but often has more far-reaching consequences for respondents (Strydom, 2011b:115).

The researcher was well aware of the emotional harm that participants might suffer due to participating in research. To avoid emotional harm, the participants were informed that participation was voluntary and that they would the right to withdraw at any time, if they should feel any discomfort. The researcher also informed them what the reason for the study was and the possible impact it could have on them. The researcher would arrange with her colleagues Nadia van der Merwe and Lynette van Wyk at CMR Daspoort, to interview these families if they needed counselling.

3.6.2 Voluntary participation

Participation was at all times voluntary and no one was forced to participate in the project (Rubin & Babbie, 2005:71). The researcher made it clear to them that they could choose to be part of the study and that they could withdraw at any time. The researcher did not let them feel obligated to be part of the study.

3.6.3 Informed consent

Obtaining informed consent implies that all possible and adequate information on the goal of the investigation; the procedures which will be followed during the investigation; the possible advantages, disadvantages and dangers to which respondents may be exposed; as well as the credibility of the researcher be rendered to potential subjects or their legal representatives (Strydom, 2011b:117). The researcher shared this information with the participants. Participants were legally and psychologically competent to give consent and they were informed that participation was voluntary.

The participants all received informed consent letters to sign, explaining the goal of the research as well as their rights and the advantages of taking part in the study. Participants were informed that the data will be kept for 15 years at the University of Pretoria (See informed consent letter attached as Appendix B).

3.6.4 Debriefing

Participants contacted the researcher for debriefing after the interview. The researcher debriefed participants who indicated that they want to discuss the interview. The researcher spoke to the participants afterward if there was anything that they wanted to discuss. The researcher also provided the participants with her phone number as well as with the phone number of a social worker working in the area that would be able to help them with counselling.

3.6.5 Violation of privacy/ anonymity/ confidentiality.

Privacy implies the element of personal privacy, while confidentiality indicates the handling of information in a confidential manner. Information given anonymously ensures the privacy of subjects (Strydom, 2011b:119). The interviews were conducted in a private place and all the respondents' names have been kept anonymous. The names of the participants are also not mentioned in the research report, and the data gathered is being kept in safe storage at the Social Work and Criminology Department of the University of Pretoria. Information given by the respondents has and will only be used for the purpose of this study and not for any other purposes.

3.6.6 Release or publication of the findings

The findings of the study have been introduced to the reading public in written form, failing which even a highly scientific investigation would mean very little and would not be viewed as research. The researcher has compiled the report on the role of socio-economic factors in raising a child with a mental disability in the North West of Pretoria, as accurately and objectively as possible (Strydom, 2011b:126). The researcher made sure that the final written report was accurate, objective, clear and unambiguous, and

contained the necessary information. The researcher made sure that the goal of the study was reached and that all concepts were understandable.

A written format of the findings of the study was published as a mini-dissertation and was submitted to the University of Pretoria in order to give the general public as well as professionals in the field access. The research data will be stored at the University of Pretoria for a period of 15 years. Furthermore, an article was written and submitted for possible publication.

3.7 SECTION 1: Empirical Findings

In this section, research findings will be presented and discussed. Biographical data of participants followed by the discussions of themes and sub-themes will be presented. Research findings will be substantiated by literature. Nine parents were interviewed and therefore, nine participants took part in the study.

3.7.1 Biographical information

The study focused on parents that have a child that suffers from a mild mental disability and that attend Suiderberg High School. Biographical information in this study includes:

- Age of the participant
- Gender of the participant
- Relationship status
- Relationship to the child
- Age of the child
- Gender of the child
- Summary of participants

Gender and age of the participants

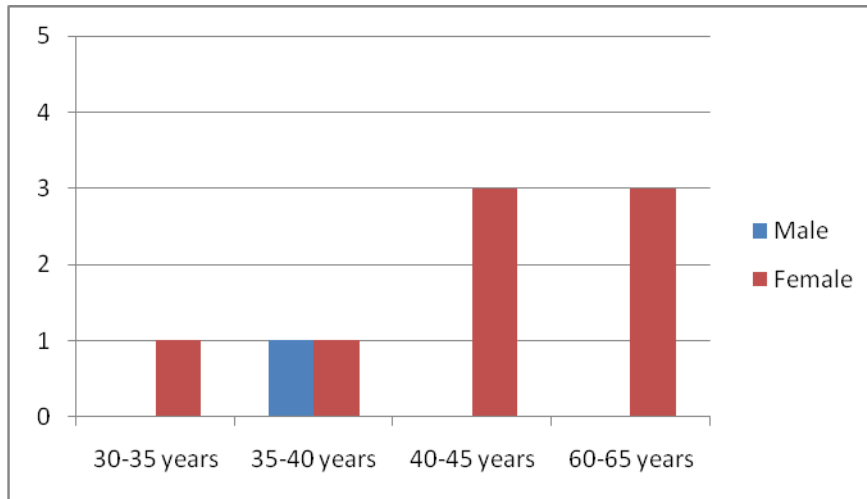


Figure 1: Gender and age of participants

In **Figure 1** the gender and the age of the participants are demonstrated. There were a total of nine participants. One of them was male and eight were female. One female was between 30-35 years old, one was between 35-40 years old, three were between 40-45 years and three were between 60-65 years old. The male was between 35-40 years.

Relation to the child

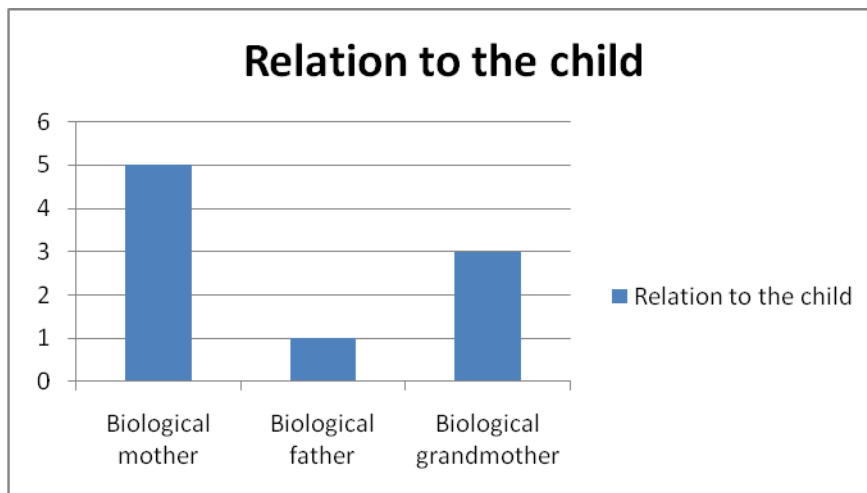


Figure 2: Relation to the child

In **Figure 2** the relation to the child is demonstrated. Five of the participants were the biological mother, one was the biological father and three were the biological grandmothers. These were the primary care givers of the children.

Relationship status of the participant

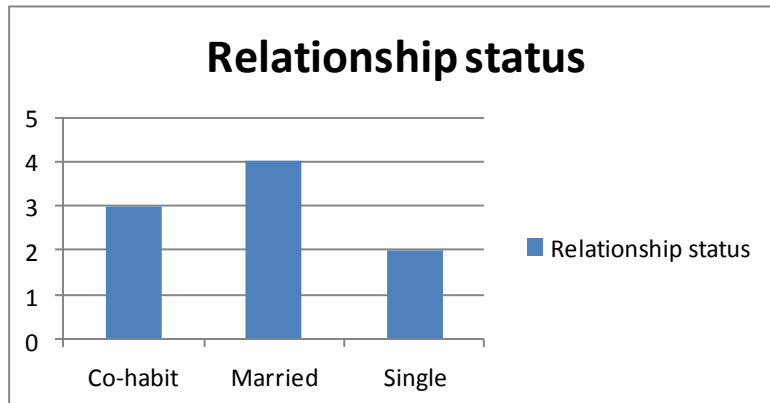


Figure 3: Relationship status

In **Figure 3** the relationship status of the participants is demonstrated. Three of them are in a co-habiting relationships, four of them are married and two are single.

Gender and age of the child attending Suiderberg High School

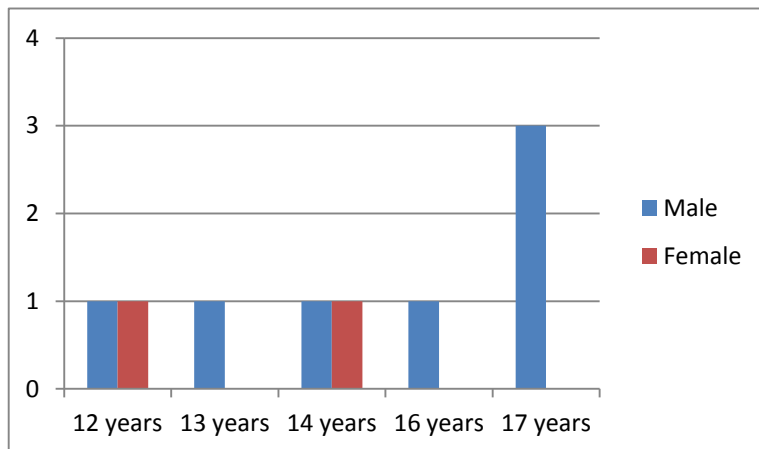


Figure 4: Gender and age of the child attending Suiderberg High School

In **Figure 4** the gender and age of the child attending Suiderberg High School is demonstrated. There was one boy and one girl of 12 years, one boy of 13 years, one boy and one girl of 14 years, one boy of 16 years and three boys of 17 years.

Summary of participants:

	Gender:	Relationship status:	Children in household:	Finances:
Participant 1:	Female	Divorced	3	Depend on her fiancé. She is unemployed.
Participant 2:	Female	Married	2	State pension. Husband works.
Participant 3:	Female	Married	2	Child care grants.
Participant 4:	Female	Co-habit relationship	3	She is unemployed. Husband works. Receives child care grant.
Participant 5:	Female	Divorced	3	Child care grant.
Participant 6:	Female	Widow	2	Mine pension from husband.
Participant 7:	Female	Widow	2	State pension. Foster care grant.
Participant 8:	Male	Married	2	Disability grant.
Participant 9:	Female	Married	1	She is unemployed depends on her husband.

3.8 SECTION 2: Empirical Findings

There were various themes and sub-themes that were generated from the data during the data analysis. A thematic analysis of the themes will follow. Each theme will subsequently be discussed using verbatim quotes from the interviews to support the themes and literature to substantiate the findings. The following are the themes and subthemes:

THEME:	SUB-THEME
School related issues	<ul style="list-style-type: none"> • Reason for the child attending a special needs school. • Problems with reading, writing and maths.
Emotions regarding the child with special needs.	<ul style="list-style-type: none"> • Influence on the family. • Behavioural problems of the child. • Concerns regarding a child with special needs.
Financial aspects	<ul style="list-style-type: none"> • Finances regarding the child • Financial support from the Government.
Medication	<ul style="list-style-type: none"> • Medication that the child is using • Access to medication.
Resources	

3.8.1 Theme 1: School related issues

All the children of the participants are attending Suiderberg High School. Suiderberg High School offers prevocational education for learners with mild intellectual disability. Children need to go through a selection process before being admitted to the school. Each child must have a LSEN (Learner with special education needs) number from the Department of Education allocated to them.

According to the participants the following were the reasons for their children attending Suiderberg High School:

- *“Sy kon nie saam met die stroom gaan van die laerskool in standard 4 gaan nie.”*

“She couldn’t cope in the main stream in the primary school in Grade 6”

- *“Hy het n leer probleem, hy gebruik Ritalin en Respadol medikasie. Hy kan nie in ‘n gewone skool funksioneer nie, hy is te stadig.”*

“He has a learning problem, he uses Ritalin and Respadol medication. He can’t function in a normal school, he is too slow.”

- *“Hy was eers in Nicolas Smith maar hy het nie vordering gemaak nie. Hy was 2 jaar in Graad 0 en toe sit hulle hom oor na Graad 1 maar toe vorder hy nie.”*

“He was first in Nicolas Smith but he didn’t make progress. He was in Graad 0 for two years, they then put him through to Graad 1 but he didn’t show any improvement.”

None of the participant’s children could develop according to their age and grade. All of the children repeated a grade in the main stream school and were then referred to the special education school. It is confirmed by Gavin (2014:3) that someone who has an intellectual disability will have trouble learning and functioning in everyday life. This person could be ten years old, but might not talk or write as well as a typical ten-year-old. He or she also is usually slower to learn other skills, like how to get dressed or how to act around other people. During school, a child with a mental disability will probably need help. They may be in special classes or get other services to help them learn and develop. Children with intellectual disabilities want to develop their skills to the best of their abilities.

3.8.1.1 Sub Theme 1.1: Problems with reading, writing and maths.

All the participants indicated that their children are struggling with their school work. All the children are living with a mental disability, therefore the children are attending Suiderberg High School. The areas that they identified were maths, reading and concentration. Here the participants stated the problem areas:

- *“Ja, ek dink alle kinders doen maar. Ja hy doen. Hy sukkel maar met lees.”*

“Yes I think all children struggle. Yes he does. He struggles with reading.”

- *“Ja hy sukkel maar met wiskunde.”*

“Yes he struggles with Maths.”

- *“Hy lees nog nie vlot vir sy ouderdom nie.”*

“He is not reading as fluently as he is supposed to for his age.”

- *“Baie swak sukkel baie met wiskunde.”*

“Very bad, he is struggling a lot with Maths.”

- *Deelnemer: “Nee, met leer en konsentrasie”*

Participant: “No, with learning and concentration.”

Logsdon (2014) confirms this information, “In the primary school years, difficulty with school work and underachievement may be a signal of the more serious symptoms of learning problems. Students with such symptoms that do not improve over time with appropriate interventions may have learning disabilities.” Kemp, Smith and Segal (2013) agree with this information, and according to them, learning disabilities look very different from one child to another. One child may struggle with reading and spelling, while another loves books but can’t understand Maths. Still another child may have difficulty understanding what others are saying or communicating out loud. The problems are very different, but they are all learning disorders.

From this discussion it can be seen that although every child is different and struggles with different things, their respective struggles all fall under learning and cognitive problems. All the children in this study repeated a grade in primary school and were then referred to the special needs schools.

3.8.2 Theme 2: Emotions regarding a child with special needs.

The participants experienced different emotions regarding their children that have a mental disability. Some of them experience concern for their children; others reported that the children are taking a lot of their time and that it takes a lot of patience to help them. These are some of the responses that the researcher got from the participants:

- *“Net baie besorg oor haar, veral oor die groepsdruk by die skool.”*

“Just very concerned about her, especially regarding peer pressure at school.”

- *“Hy vat partykeer baie tyd in beslag, veral as ons moet leer en dit. Want sy sussie help ek nou glad nie meer met huiswerk nie sy doen dit nou alleen. Nou raak ek ongeduldig as ek moet sy huiswerk doen, want ek dink hy moet actually al op die vlak wees waar sy is om dit alleen te kan doen. Maar hy kan dit nog steeds nie alleen doen nie.”*

“He takes up a lot of my time, especially when he must study. I don’t need to help his sister anymore with homework. Now I get impatient when I must help him with his homework, because he is supposed to be on a level where he must do it on his own but he still can’t do it on his own.”

- *“Weet jy wat op die stadium baie geduld met haar werk want vandag onthou sy more onthou sy nie die goed nie. Baie geduld baie geduld. Medies gewys is dit baie uitputtend met haar want sy het een of twee dinge marfan en sy het die knieg ding ook nou so dis ‘n baie roller coaster ride.”*

“You know what at the moment a lot of patience is required with her work, as today she will remember but tomorrow she will not remember the things. A lot of patience, a lot of

patience. Medically wise it is very exhausting with her. She has one of two things, Marfen and she has this thing with her knee, so it is a roller coaster.”

- “Nie regtig nie ons almal verstaan hom en ons weet hy is spesiaal hy is anders.”

“Not really we all understand him and know he is special and different.”

- *“Ek het al gevoel ag Here kan U my nie maar ook weg vat nie. Dan het ek nie meer nodig om te kommer oor hom nie. Ek is bang vir sy toekoms voorentoe.”*

“I felt, “Please Lord, can you take me away also. Then I don’t have to worry about him. I am scared about his future.”

Some are struggling to cope and are very concerned about their children and others accept that their child is different. This is confirmed by Boström, Broberg and Hwang (2009), that the diagnosis of disability appeared to affect parents differently. Most parents seemed more or less preoccupied with the disability and consequences of the diagnosis, while other parents spoke of the disability as an integrated part of the child and everyday life. According to Ribley and Waghan (2003:2), fear is a common emotion that is experienced by parents that have a child with a disability. They stated that, people often fear the unknown more than they fear the known. Having the complete diagnosis and some knowledge of the child’s future prospects can be easier to deal with than uncertainty. In either case, however, fear of the future is a common emotion: “What is going to happen to this child when he is five years old, when he is twelve, when he is twenty-one? What is going to happen to this child when I am gone?” Then other questions arise: “Will he ever learn? Will he ever go to college? Will he or she have the capability of loving and living and laughing and doing all the things that we had planned?”

The literature is in correlation with the responses of the participants. They confirmed their fears for their children’s future and the unknown factors regarding their children.

3.8.2.1 Sub-Theme 2.1: Influence on the family

The participants indicated that having a child with a mental disability in their house also has an influence on the other members of the family. According to the participants, the children tend to be aggressive and tend to fight with other members of the family. Thus, having a child with a mental disability has an influence not just on the parent but also on the extended family. This is what they responded:

- *“Ja daar is maar bietjie spanning in die huis. Want ek is altyd bang hulle twee sit vas. Ek moet maar altyd die vrede bewaar tussen die twee.”*

“Yes there is some tension in the house. I am always scared that they will not get along. I always have to keep the peace between them.”

- *“Ja tussen hom en sy sussie. Hulle baklei baie.”*

“Yes between him and his sister. They fight a lot.”

- *“Kom ek gaan vir jou se ek is gewoon aan hom met sy, hy is bietjie baie aggresief. Dan as hy kwaad word en iets nie reg kry nie sal hy sy vuiste slaan teen iets en so aan. Maar dan praat ek met hom mooi of ek los hom tot sy grille kla uit is sy emosie. Dan praat ek met hom.”*

“Let me tell you I am used to him with, he is very aggressive. When he gets angry and doesn't get things right he will hit his fists against something. Then I will speak to him or leave him to get his emotions out. Then I will speak to him.”

Reichman, Corman and Noonan (2008:1) assert that living with a disabled child can have profound effects on the entire family, that being the parents, siblings, and extended family members. It is a unique shared experience for families and can affect all aspects of family functioning. On the positive side, it can broaden horizons, increase family members' awareness of their inner strength, enhance family cohesion, and encourage connections to community groups or religious institutions. On the negative side, the time and financial costs, physical and emotional demands, and logistical complexities associated with raising a disabled child can have far-reaching effects. The

parents of children with mental retardation require mutual support from their spouse, their family and other members of society. The presence of behavioural problems in children is known to produce greater stress for parents. Managing such problems requires much effort and skill, and hence such support would be considered as an important factor (Gohel, Mukherjee & Choudhary, 2011:64).

3.8.2.2 Sub-Theme 2.2: Behavioural problems of the child.

The participants experience a lot of behavioral problems with their children that are attending Suiderberg High School. They indicated that their children have behavioral problems like moodiness, aggression and insubordination to discipline. Here are the participants' responses:

- *“Dis maar die buierigheid, die issigrimigheid. Maar ja, hy is ook nou op daai tiener stadium en alles wat te same kom en dit is wat dit so moeilik maak.”*

“It is the moodiness and the grumpiness. And yes he is in his teenage years and everything that goes with that and that makes it difficult.”

- *“Hy wil doen wat hy wil doen. Hy wil nie volgens reëls gaan nie. Hy het ‘n verskriklike dissipline probleem.”*

“He wants to do what he wants. He does not want to follow rules. He has a serious discipline problem.”

- *“So hy raak aggressief as hy te veel energie het om aan uiting te gee en kan nie dit gee nie.”*

“He gets aggressive when he has too much energy and no way of giving expression to it.”

Tonge (2013) explains it as follows: children with mental disability have a least three times the level of serious emotional and behavioural problems than typically developing children. This is due to the complex interaction of bio-psycho-social factors, such as impaired brain function, cognitive deficits, and social stress through ostracism and

rejection. Myrbakk and Tetzchner (2007) agree with Tonge that people with intellectual disabilities seem to be vulnerable for developing behavioural problems. Studies have reported that 7–15% of individuals with “administrative” intellectual disability have severe behavioural problems. Severe behavioural problems among people with an intellectual disability are often termed “challenging behaviour”. Aggression towards others, temper tantrums, screaming or shouting, and self-injury are all examples of behaviours that may be challenging to relate to for family, support staff and others.

3.8.2.3 Sub-Theme 2.3: Concerns regarding a child with special needs.

The participants have a lot of concerns regarding their children with mental disability. They are concerned about their children’s futures as well as what would happen to their children if they as parents passed away. They stated the concerns as follows:

- *“Dat sy die regte besluit sal maak in haar beroeps keuse.”*

“That she will make the right choice regarding her career.”

- *“Dat hy vir homself ‘n lewe sal kan maak eendag. Met sy houding. Dis my grootste bekommernis, ek soek hom nie in die tronk nie.”*

“That he would be able to make a living for himself one day. With his attitude. This is my biggest concern, I don’t want him in jail.”

- *“As ek die dag moet dood gaan ek weet hoe om hom te hanteer so as hy by iemand anders moet wees gaan hulle dieselfde vir hom doen as wat ek vir hom doen?”*

“The day that I die, I know how to handle him. Would somebody else look after him and do the same for him that I do for him?”

- *“Ag jissie gaan daar werk wees waarin hy kan of gaan hy van almoese moet lewe. Gaan hy in iemand se oë moet kyk want ek weet hy sal nooit by n gewone plekke in stap vir n werk nie want hy gaan nie die vermoë he om dit te doen nie. Hy sal basies net moet verf werk doen of bou werk of so. Want as jy vir hom n opdrag geen dan voer hy hom net halfpad uit. Hy voer nie die hele ding uit nie.”*

“Ag, will there be work for him to live on or will he be depending on others. Will he look others in the eye because you know he will not be able to step into a normal job he doesn’t have the ability to do a normal job. He would only be able to do painting jobs and construction work. Because when you give him a task he can only complete it halfway. He cannot complete a task.”

- *“Dat hy sy skool moet klaar maak, laat hy ‘n werk kry as hy groot is. Dat hy vir homself kan sorg.”*

“That he will complete his school and that he will get a job when he is grown up. That he would be able to look after himself.”

Douma, Dekker & Koot (2006) state that, parents of children and adolescents with mental disabilities often experience higher levels of parenting stress than parents of typically developing youths. In addition to the mental disability, many of these youths also have emotional or behavioural problems. These additional problems, and especially behavioural problems, frequently lead to even higher levels of parental stress, which are likely to exceed the parents’ abilities to deal with their child themselves. Broatch (2014) confirms that finding a stable, satisfying job and learning to live independently is challenging for all young people making the transition to adulthood. But it can be especially daunting for those with mental disability and attention problems and their parents.

3.8.3 Theme 3: Financial aspects

The participants responded that some of them are struggling financially, but some of them are able to meet all their financial needs. The six participants that are struggling receive financial support from the local welfare organizations in their communities as well as an allowance from the State. Here are their responses:

These were the participants’ reactions regarding their finances:

- *“Bietjie beroerd maar ek probeer my bes.”*

“Not so well, but I am trying my best.”

- *“Dit gaan broek skeer partykeer as ek vir tannie Soekie n ekstra werkie doen dan sal sy vir my n ekstra geldjie gee. Toe my man selfmoord gepleeg het was daar nie geld wat oor gebly het nie.”*

“It is not going well, if I do extra work for aunt Soekie she gives me extra money. When my husband committed suicide there was no money left.”

- *“Ek sal nie se ons is ryk nie maar ons is ook nie arm nie. So ek dink ons is een van die geseënde huis gesinne wat elke aand kan gaan slaap en sê ons het kos en ‘n warm bed.”*

“I cannot say that we are rich or poor. I think we are one of the privileged families that can say every night we have food and a warm bed.”

Parents experience extra financial concerns regarding a child with special needs. Raising a child with a mental disability may be more expensive than raising a typical child. The care of the child may last a lifetime instead of 18 years. Parents may have to set aside money in a trust fund for the child's care when they pass away. Parents with a low income will not be able to provide for all the financial care that a child with a mental disability may need (Boyd, 2011:1).

3.8.3.1 Sub-Theme 3.1: Finances regarding the child and a social grant from SASSA

Participants have different expenses for their children. From the nine participants three receive no social grant, three receive a child care grant and three receive a foster care grant from the State. Here are their responses regarding the children's expenses and their grants:

- *“Okey ek kry SASSA grant geld vir haar. So ek koop maar net haar basiese goed soos haar sent en toiletware en goed. Dis nie meer as R300 nie.”*

“I receive SASSA grant money for her. I only pay her basic things like her toiletries. It is not more than R300.”

- *“Weet jy ek kry net vir hom en sy sussie ‘n kinder toelaag. Ek is werkloos ek bly net by Aunty Soekie. So ek elke maand dis omtrent so R60 wat ek gebruik om sy medikasie te gaan haal.”*

“I receive a child care grant for him and his sister. I am unemployed I live with Aunt Soekie. I use R 60 per month to go and collect his medicine.”

- *“Ek kry by SASSA geldjies vir hom om rede hy nie ‘n pa het nie.”*

“I receive SASSA money because he doesn’t have a father.”

- *“Nie regtig uitgawes nie dis maar soos klere, skoene, kos dis nie regtig groot uitgawes nie. Want ek bly by my ouers. Die huis is klaar betaal, my ma is oorlede dis my pa se huis. So ons bly in die erf.”*

“Not really expenses, just clothes, shoes, food it is not big expenses. I live with my parents. The house is paid, my mother is deceased it is my father’s house. We live on their property.”

Six of the nine families receive financial support from the Government. There are 130 million people with intellectual disabilities and their families around the world, according to Inclusion International. In Africa, some 10 to 15 million people – from a population of over 800 million – have an intellectual disability. Because of stigma and discrimination, the majority of those affected live in poverty and isolation. Globally, more than for any other group including people with other forms of disability, people with intellectual disabilities experience higher unemployment rates and are excluded from education, employment, health care and other general services, and from “belonging” in their communities. (Paving a way out of poverty for people with intellectual disabilities, 2010). According to South Africa info (2014:1), the number of people receiving a social grant from the State grew from 12.7% in 2003 to 30.2% in 2013, while the number of households receiving at least one social grant increased from 29.9% to 45.5% over the same period, according to Statistics South Africa's latest General Household Survey. South Africa's social assistance system, one of the largest in Africa, is the Government's most direct means of combating poverty. According to the Treasury's

National Budget Review for 2013/14, spending on social grants accounts for 3% of the country's gross domestic product (GDP) and is projected to rise from R118-billion in 2013/14 to R145-billion by 2016.

With the above mentioned information as well as the responses of the participants, we can see that many families rely on social grants from the Government. This also states that some of the participants are struggling financially.

3.8.4 Theme 4: Medication

According to the participants, medication has been prescribed to the children but many of them are not using the medication anymore. People are uneducated about medication for children struggling from mental disability. Five of the nine children used medication at one time but the parent of the child decided it was not necessary anymore. One even refused that her grandchild use medication. This was the feedback from the participants:

- *“Hy was op Ritalin maar hulle het hom afgehaal. Want hy funksioneer heeltemal reg sonder Ritalin.”*

“He used Ritalin but they took him off it. He is functioning well on his own without it.”

- *“Nee hy was op n stadium by n plek gewees toe wou hulle hom Ritalin sit. Toe weier ek want ek het al te veel gehoor van daai goed. So ek glo nie hy het sulke probleme nie behalwe om dat hy stadig begryp hy is slim maar dit vat vir hom n rukkie om te begryp.”*

“At some time they recommended that he takes Ritalin but I refused. I heard too many stories about it. I believe he doesn't have a problem like that he only struggles to understand things but he is clever, it takes him a time to understand things.”

- *“Hy was onder Weskoppies gewees onder medikasie, maar hy het dit net gelos.”*

“He received medication from Weskoppies, but he stopped using it.”

According to Fact for Families (2012), it is very important that the child has a comprehensive evaluation to find out about his or her strengths and needs. Since no specialist has all the necessary skills, many professionals might be involved. General medical tests as well as tests in areas such as neurology (the nervous system), psychology, psychiatry, special education, hearing, speech and vision, and physical therapy are useful. A paediatrician or a child and adolescent psychiatrist often coordinate these tests. Medications can be helpful as one part of overall treatment and management of children with intellectual disabilities.

It is thus important that children are tested and evaluated to see if medication can help them. But medication can only help with the aspect of other professional help. Medication alone cannot solve the problem. The medication must also be coordinated by a professional person.

3.8.4.1 Sub-theme 4.1: Medication that the child is using

Medication was recommended to some of the participants but they refused to put the children on medication. The participants decided themselves to stop the medication or, in some cases, the child himself decided he no longer needs the medication. Here are the responses of the participants whose children are using medication or used medication:

- *“Hy het ‘n leer probleem, hy gebruik Ritalin en Risperdal medikasie”*

“He has a learning problem, he is using Ritalin and Risperdal.”

- *“Nee hy was op Ritalin ne en ek het dit vir hom gekry maar nou sien ek hy het vir my gese ouma ek het dit nie meer nodig nie. Hy wil dit nie drink nie.”*

“No, he was using Ritalin I got it for him but he told me he doesn’t need it anymore. He doesn’t want to drink it anymore.”

- *“Nee glad nie, hy het toe hy klein was was hy op Ritalin, maar dit het hom heeltemal ‘n zombie gemaak toe het ek hom af gehaal.”*

“No, he used Ritalin when he was younger, but it made him a zombie and I took him off it.”

Parents as well as the children decided on their own to stop using the medication. The usage of the medication is not explained properly to the parents as well as the children. There is a stigma around the use of medication.

- *“Dan se ek vir hom jy is nie ‘n Weskoppies geval nie jy het drink die pille om rustig te wees en te konsentreer”*

“Then I tell him, “You are not a Weskoppies case, you are using the medication to help calm you down and to help you with concentration.”

According to The Internet Drug Index (2013), Ritalin is indicated as an integral part of a total treatment program which typically includes other remedial measures (psychological, educational, social) for a stabilizing effect in children with a behavioral syndrome characterized by the following group of developmentally inappropriate symptoms: moderate-to-severe distractibility, short attention span, hyperactivity, emotional liability, and impulsivity. The diagnosis of this syndrome should not be made with finality when these symptoms are only of comparatively recent origin. No localizing (soft) neurological signs, learning disability, and abnormal EEG (**Electroencephalography**) may or may not be present, and a diagnosis of central nervous system dysfunction may or may not be warranted.

Grohol (2013:1) stated that for nearly six decades, many children with attention disorders have benefited from being treated with medication. Three drugs, Ritalin (methylphenidate), Dexedrine (dextroamphetamine), and Cylert (pemoline), have been used successfully. Although these drugs are stimulants in the same category as "speed" and "diet pills," they seldom make children "high" or more jittery. Rather, they temporarily improve children's attention span and ability to focus. They also help children control their impulsiveness and other hyperactive behaviours. Shortly after taking the medication, they become more able to focus their attention. They become more ready to learn. Studies by NIMH scientists and other researchers have shown that

at least 90 percent of hyperactive children can be helped by either Ritalin or Dexedrine. If one medication does not help a hyperactive child to calm down and pay attention in school, the other medication might.

As seen above, Ritalin is used for many different reasons. The reason for using Ritalin is not always explained to the children and the parents. People are uneducated about the medication and form their own perceptions.

3.8.4.2 Sub-theme 4.2: Access to medication

Most of the participants make use of a State clinic or hospital to get the medication. Overall, they are not struggling to get the medications. Only two participants have the financial means to get medication from private doctors or clinics.

- *“By Steve Biko se kinder afdeling. Nee as jy gaan daarso, jy bel en dan wag jy 3 dae vir jou medikasie dan gaan haal jy jou medikasie. En dan twee keer n jaar sien jy die dokter dan word jou goeders net herhaal vir ses maande.”*

“At Steve Biko children’s ward. You phone them and then wait three days then you can collect the medication. Twice a year you see the doctor, then he then extends your prescription for six months.”

- *Deelnemer: “Nee dis net bietjie duur. Jy weet maar ek het oe toe geknyp ter wille van hom.”*

Participant: “No, it is just very expensive. But I just closed my eyes to help him.”

- *Deelnemer: “Een of ander kliniek die kliniek in Pretoria Noord.”*

Participant: “Some clinic, the clinic in Pretoria North.”

Participants are relying on the Government to provide them with medication. None of them are struggling to get hold of the medication. They know where to get it and where to find help regarding the medication. The National Drug Policy of South Africa (1995:6) stated that the pharmaceutical sector, as a component of the health sector, reflected its

deficiencies, most notably the lack of equity in access to essential drugs, with a consequent impact on quality of care. Furthermore, rising drug prices, already high in international terms, gave increasing cause for concern, as did the evidence of the irrational use of drugs, losses through malpractice and poor security, and cost-ineffective procurement and logistic practices. Most of these problems are interlinked. The Government of South Africa decided to tackle them systematically through the development and implementation of a National Drug Policy that would be consonant with and an integral part of the new National Health Policy, which aims at equity in the provision of health care for all. The goal of the National Drug Policy is to ensure an adequate and reliable supply of safe, cost-effective drugs of acceptable quality to all citizens of South Africa and the rational use of drugs by prescribers, dispensers and consumers.

Therefore, people have access to medication. As seen in the study, the participants make use of these services to receive medications.

3.8.5 Theme 5: Resources

None of the participant's children are receiving any professional services at the moment. None of the children are seeing a social worker, psychologist or an occupational therapist at the moment. Only one of the participants is aware of professional services in the community. They responded as follows:

- : *"In Bougainville, ja, en in Daspoort omgewing ken ek wel."*

"In Bougainville, yes, and in Daspoort area I know someone."

- *"Nee"*

"No"

- *"Nee nee."*

"No no."

The participants have limited knowledge about resources in their community. Adnams (2010:439) stated that in line with policies, a range of services for People With Intellectual Disability (PWID) is outlined by government sectors, but a comprehensive and integrated approach is often hampered by a lack of prioritization of resources. In many areas, basic and other services are provided by the nongovernmental sector. Services tend to be concentrated in larger centres and many PWID's in rural areas have no meaningful access to services at all. Specialized health services, including mental health services for PWID's, are few and largely focused in secondary and tertiary centers in towns and cities. In all regions, in spite of the policy for rehabilitation, there is inadequate provision for multidisciplinary health services for PWID's (Adnams, 2010:439).

3.9 SUMMARY

In this chapter the research methodology was discussed. Data from semi-structured interviews were collected and studied in order to identify themes and sub-themes that are related to the objectives of the study.

Five themes emerged and these were: Reason for child attending a special needs school, emotions regarding a child with special needs, financial aspect, medication and resources. The themes and sub-themes were identified from the transcripts which in turn acknowledged and represented the voices and perspectives of the participants in the study. These were substantiated through quotations with the integration of literature where applicable. Conclusions and recommendations of the study will be presented in the next chapter.

The theoretical framework that was used in this study was the bio-psycho-social model. The bio-psycho-social model is a method of understanding health and illness through biological, psychological, and social factors. The principle of the bio-psycho-social model states that all issues relating to health are products of a complex interplay of these three factors. Biological influence plays a key role in the bio-psycho-social model.

In this aspect of the model, the physiological causes of an illness are identified and studied. With this model the researcher was able to understand mental disability as an illness as well as the psychological and social impact that it has on the family members that lives with child that suffers from mental disability.

CHAPTER FOUR:

CONCLUSIONS AND RECOMMENDATIONS

4.1 Introduction

In this chapter the researcher explains how the goals and objectives of the study were reached. The researcher explains how the objectives were reached by highlighting the main findings of the study. Conclusions will be drawn from the study and recommendations will be made on the key findings of the study.

4.2 Goals and Objectives

4.2.1 Goal

The goal of this study is to explore the impact of socio-economic factors in raising a child with a mental disability. The research question of the study was: **“What is the impact of socio-economic factors in raising a child with a mental disability?”**

4.2.2 Objectives

The goal was achieved through the attainment of the following objectives:

Objective 1: To describe the socio-economic factors that impacts a child with a mental disability.

This objective was met in Chapter One in section 1.2.2 and 1.2.3, Chapter Two in section 2.6.

Raising a child with a mental disability has a socio-economic and psychosocial impact on the family. Psychologically, raising a child with a mental disability can be emotionally exhausting for the parents as well as for the siblings. The siblings may feel that they are

not important and that the brother or sister gets all the attention. Parents will also stress about the future of this child (Chandrashekar, 2011:1).

Having a child with a mental disability includes different socio-economic factors that impact the family. Factors regarding children with a mental disability that were discussed and described in detail were: *acceptance, self-blame, stigma, helplessness, behavioural problems, unrealistic expectations, worry about the future, marital/family problems and financial burdens.*

Objective 2: To explore the role of socio-economic factors in raising a child with a mental disability.

In Chapter Three in section 3.8.2, 3.8.3 and Chapter Four in section 4.3, 4.4 this objective was met. Participants explain how socio-economic factors influence their lives. They stated their fears for their children's future and the unknown factors regarding their children. The participants indicated that having a child with mental disability in their house also has an influence on the other members of the family. According to the participants, the children tend to be aggressive and fight with other members of the family. Thus, having a child with mental disability has an influence not just on the parent but also on the extended family. The participants experience a lot of behavioural problems with their children that are attending Suiderberg High School. They indicated that their children have behavioural problems like moodiness, a struggle with aggression and discipline.

Objective 3: To make recommendations on strategies that may improve services to families with children with mental disabilities.

This objective has been met in the empirical study in Chapter Three and Chapter Four. Participants are unaware of resources in their communities and are not making use of them. It was concluded that creating awareness regarding mental disabilities and the impact that it has on a family can be done through training, promotion and education.

Department of Social Development as well as Department of Health have great policies regarding children with disabilities and services that need to render but these services are lacking and people are unaware of the services that are in place.

4.2 Key findings of the study

Key findings of the study were as follows:

- None of the participants' children could develop according to their age and grade. All of the children repeated a grade in the mainstream school and were then referred to the special education school.
- Children living with mental disability are struggling with basic school work. One child may struggle with reading and spelling, while another loves books but cannot understand mathematics. Still another child may have difficulty understanding what others are saying or communicating out loud. The problems are very different, but they are all learning disorders.
- Different emotions regarding children that have a mental disability are experienced by parents. Some experience concerns for their children. These concerns include worries about their child's future, will the child be able to live on their own and look after themselves; others reported that the children are taking a lot of their time and that it takes a lot of patience to help them.
- Having a child living with a mental disability in the house has an influence on the other members of the family. The children tend to be aggressive and fight with other members of the family. Thus, having a child with a mental disability has an influence not just on the parent but also on the extended family.
- Factors regarding children with mental disability that were discussed and described in detail were: *acceptance, self-blame, stigma, helplessness, behaviour problems, unrealistic expectations, worry about the future, marital/family problems and financial burdens*. Participants accepted that their child is different and they treat them differently to ensure that they reach their full potential. None of the participants experienced self blame or stigma around their children. Some of the participants tended to feel helpless where their child is

concerned. Participants experience behavioural problems with their children like aggression and children that struggle to follow rules. All of the participants are worried about their child's future, will they be able to look after themselves and will they find work. Having a child with a mental disability in your home has an influence on the family as well as on the marital relationship.

- Children living with a mental disability tend to have behavioural problems like moodiness, struggles with aggression and discipline.
- Many families rely on social grants from the Government. This also states that some of the families that have a child living with a mental disability are struggling financially. This proves that there is a direct link between poverty and mental disability. Families rely on support from the Government to provide their financial needs.
- Most of the participants are not well informed about medication for children living with mental disability.
- Participants are unaware of resources in their community and make little use of the resources that are available.
- Most participants relied on government hospitals and clinics to provide them with medication for their children that suffer from mental disability.

In summary, the overall information that was gathered throughout the study stated that having a child living with a mental disability has a lot of challenges, not just for the parents, but also for the extended family members. The bio-psycho-social model helps to explain and fosters an understanding of mental disability through biological, psychological and social factors. An illness cannot stand alone - it goes together with psychological and social factors.

4.3 Conclusions

The following conclusions were compiled from the literature review and empirical research findings of the study:

- The researcher concluded that many parents have to deal with the problems and challenges of raising a child with mental disability.
- The literature review as well as the empirical study stated that there is a direct link between poverty and mental disability. Families living in poor communities do not have access to resources to help them with their mentally disabled children.
- A family who has a child with a mental disability will experience many challenges, such as repeated physical and emotional crises, interactive family issues, ruined schedules, and additional expenses, which can create financial burdens for a family.
- Children suffering from mental disability struggle with school work. They need special education.
- Parents have a lot of fear for their children's future and the unknown factors regarding their children.

The study concluded that there are different socio economic factors that have an impact on raising a child with mental disability. These factors were discussed through literature as well as in the empirical study. Participants confirmed the different factors. Having a child with mental disability in the house has an influence on all the members of the family. Children with mental disability have serious emotional and behavioural problems. Parents of children living with mental disability commonly experience different emotions. Raising a child with a mental disability may be more expensive than raising a typical child.

Therefore it can be said that a family that has a child with mental disability has a lot of challenges. There are a lot of socio-economic factors that influence the family. There is a direct link between poverty and mental disability. The study confirmed that parents experience emotions and concerns regarding their children. They also experience behavioural problems with their children. The families have little access to resources.

4.4 Recommendations

Based on the key findings and conclusions of the study, the following recommendations were made:

- More should be done in creating awareness about mental disability and the impact that it has on the family.
- It is recommended that special needs schools have information days to inform parents on mental disability and how it works and what they can do to help their children.
- There should be more programmes in the community that help children living with mental disability. These programmes must focus on life skills as well as extra classes for children struggling with school work.
- There should be support groups for parents that have a child with mental disability. These groups must be run by professional people to explore parent's emotions.
- From the study it can be recommended that the Government, in collaboration with the private sector, should establish more special needs schools. The Government should also support families with special needs children financially.
- Socio-economic factors that have an influence on a family that has a child with mental disability are: emotional burdens, financial burdens, burdens on marital and family relationships and worries about the child's future.
- **Further research:** Future research can look at establishing support groups for families suffering from socio-economic factors, such as unresolved emotions and financial concerns regarding their children that suffer from mental disability.

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APPENDIX A:

Interview schedule

The impact of socio-economic factors in raising a child with mental disability in the North West of Pretoria.

Section A:

- Biographical information

Section B:

- Theme 1: Reason for child attending special need school
- Theme 2: Emotions regarding child with special needs
- Theme 3: Financial aspect
- Theme 4: Medication
- Theme 5: Resources



Geagte Mnr/ Mev

Naam van navorser: Eldene Trollope
Naam van instansie: Universiteit van Pretoria

Hierdie is 'n vraelys wat gebruik sal word vir navorsing by die Universiteit van Pretoria. Die navorser is Eldene Trollope 'n maatskaplike werk student besig met haar Meesters graad in Maatskaplike Werk Gesondheidsorg.

Die titel van die studie is; "The impact of socio-economic factors in raising a child with mental disability in the North West of Pretoria". **Die doel van die studie** is om die impak van sosio-ekonomies fakotore wat 'n invloed op die gesin het te identifiseer.

Deelnemers se regte, konfidensialiteit, anonimiteit en ontlooting: Die inligting sal slegs vir navorsings doeleindes gebruik word. Deelname aan die studie is vrywillig. Alle inligting sal vertroulik hanteer word. Die onderhoude sal op geneem word en dan sal die inligting verwerk word in die studie in. Geen persone se identiteit sal bekend gemaak word nie. Daar is geen risikos verbonde aan die deelname van die studie nie. Die deelnemers sal geen voordele kry deur deel te neem aan die studie nie. Alle inligting sal saamgevat word in 'n navorsings verslag. Navorsings inligting sal gestoor word by die Universiteit van Pretoria vir 15 jaar. Daar is ook voorsiening gemaak dat u met ander maatskaplike werkers in die omgewing kan gesels indien u ontlooting nodig het na u onderhoud.

Prosedure: 10 Afrikaans sprekende gesinne sal van Hoërskool Suiderberg geidentifiseer word. Onderhoude sal deur die navorser met die gesinne gehou word.

Vir meer inligting kan die navorser gekontak word.

Baie dankie

Eldene Trollope

0839511720

Hiermee gee ek (volle name) _____ toestemming om deel te neem aan die studie en my onderhoud mag gebruik word vir navorsingsdoeleindes.

Datum

Plek

Handtekening

Datum

Plek

E. Trollope (Navorser)



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

26 May 2014

Dear Prof Lombard

Project: The impact of socio-economic factors in raising a child with a mental disability in the northwest of Pretoria
Researcher: AME Snyman
Department: Social Work and Criminology
Supervisor: Ms NJ Bila
Reference number: 26060648

Thank you for your response to the Committee's letter of 24 April 2014.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study at an *ad hoc* meeting held on 26 May 2014. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof. Karen Harris
Acting Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: karen.harris@up.ac.za

Research Ethics Committee Members: Dr L Blokland; Prof M-H Coetzee; Dr JEH Grobler; Prof KL Harris(Acting Chair); Ms H Klopper; Dr C Panebianco-Warrens; Dr C Puttergill; Prof GM Spies; Dr Y Spies; Prof E Taljard; Dr P Wood

