The role of psychosocial counselling in the lives of parents of children with neurodevelopmental disabilities treated at Tygerberg Academic Hospital

by
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ABSTRACT

Having a child with neurodevelopmental disabilities has a significant impact on the well-being of parents, including experiencing distress and enduring emotional, financial and physical pressure, due to caring for their. They require formal and informal support systems. Formal support includes counselling services.

The purpose of the study was to determine what role psychosocial counselling at Tygerberg Academic Hospital (TAH) plays in the lives of parents of children with neurodevelopmental disabilities.

A descriptive, qualitative approach was followed using semi-structured interviews that focused on the participants' experiences and perceptions regarding their psychosocial needs and counselling. Eleven parents participated in the study. They were sampled purposively. Emerging themes were identified through content analysis of interviews.

The themes identified were:

- Emotions;
- Parents' life and relationships;
- Lack of support systems to deal with the pressure of care giving;
- Social workers;
- Challenges with regard to compliance with healthcare provision; and
- Gaps identified.

The interviews found that parents received no psychosocial counselling at TAH. This was a disappointment to participants. They indicated feeling very isolated and emotional, and experiencing psychological burnout, while such social work services provided focussed on applications for social grants and patient healthcare treatment. Parents identified a great need for counselling services at the hospital as they believed counselling would assist them to work through emotions, address psychosocial needs, find coping strategies and identify available resources within their communities, which would be beneficial to the psychosocial functioning of the whole family. The parents also identified a need for parent support group services at the hospital.

The initiation of this service and support groups for parents is recommended.

KEY WORDS

Counselling, parents, neurodevelopmental disabilities, support, psychosocial needs

ABSTRAK

Om 'n kind met neuro-ontwikkelingsgestremdhede te hê, het 'n beduidende impak op die welstand van ouers, insluitend spanning en verduur van emosionele, finansiele en fisieke druk, as gevolg van die versorging van die kind. Hulle benodig formele en informele ondersteuningsnetwerke. Formele ondersteuning sluit beradingsdienste in.

Die doel van hierdie studie was om te bepaal wat die rol is van psigososiale berading by die Tygerberg Akademiese Hospitaal in die lewens van ouers van kinders met neuro-ontwikkelingsgestremdhede.

'n Beskrywende, kwalitatiewe benadering is gevolg deur gebruik te maak van semi-gestruktureerde onderhoude wat fokus op die deelnemers se ervarings en persepsies ten opsigte van psigososiale behoeftes en berading. Elf ouers het aan die studie deelgeneem. Die deelnemers was doelgerig geselekteer. Temas is geïndentifiseer deur die inhoud van die onderhoude te analiseer.

Die temas was as volg:

- Emosies;
- Ouers se lewens en verhoudings;
- Tekort aan ondersteuningstrukture om die druk van versorging te hanteer;
- Maatskaplike werkers;
- Uitdagings met betrekking tot nakoming met gesondheidsorgvoorsiening en
- Identifisering van gapings.

Die onderhoude het bevestig dat ouers geen psigososiale berading by Tygerberg Akademiese Hospitaal ontvang nie. Dit was teleurstellend aan die deelnemers. Hulle is geneig om geïsoleerd en emosioneel te voel en beleef ook psigiese uitbranding, terwyl maatskaplikewerk dienste hoofsaaklik fokus op toelaagaansoeke en die pasiëntgesondheidsorgbehandeling. Ouers het 'n groot behoefte aan beradingsdienste by die Tygerberg Akademiese Hospitaal geïdentifiseer, omdat hulle glo dat berading hulle sal help om deur emosies en psigososiale behoeftes te aan te spreek, baasraakstrategieë te vind en beskikbare hulpbronne binne hul gemeenskappe wat voordelig sal wees vir die psigososiale funksionering van die gesin te identifiseer. Die ouers het ook 'n behoefte vir ouerondersteuningsgroepdienste by die hospitaal geïdentifiseer.

Die inisiasie van beradingsdienste en ouerondersteuningsgroepdienste word aanbeveel.

SLEUTELWOORDE

Berading, ouers, neuro-ontwikkelingsgestremdhede, ondersteuning, psigososiale behoeftes.

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GLOSSARY OF TERMS

Childhood neurodevelopmental disabilities

This is described as a diverse group of chronic disorders, which can begin at any stage of the development process between conception to birth and growth, and lasts throughout the individual's lifetime. It includes major disabilities such as cerebral palsy, intellectual disabilities, learning disabilities, autism spectrum disorders, communication disorders and neural tube defects (Patel, Greydanus, Omar & Merrick, 2011).

Counselling

An interview procedure that aims to guide the client towards insight with a view to promoting his or her social functioning (Social Work Terminology, 2006).

Disability

Disability is an umbrella term for impairments, activity limitations, and participation restrictions. It denotes the negative aspects of interaction between an individual (with a health condition) and the individual's contextual factors (environmental and personal factors) (WHO: International Classification of Functioning, Disability, and Health: Short version, 2001).

Family

Smallest social unit in society consisting of a man and his wife and child; or a woman and her child; or a man and his child; usually living under one roof (Social Work Terminology, 2006).

Parent

The father or mother of a child born legitimately by marriage; an illegitimate child; and an adopted child (Social Work Terminology, 2006).

Psychosocial counselling

Psychosocial counselling is described as "a service provided by a skilled professional counsellor to an individual, family, or group of people for the purpose of improving well-being, alleviating distress, and enhancing coping skills” (Florida Department of Health, 2009: 1).

Social Work

Professional services by a social worker aiming to promote the social functioning of people (Social Work Terminology, 2006).

Support

A technique in social work to assist a client, through encouragement, generalisation, and acceptance to reduce strain and promote self-confidence (Social Work Terminology, 2006).

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LIST OF ACRONYMS

CDG	Care Dependency Grant
CP	Cerebral Palsy
DoH	Department of Health
FAE	Foetal Alcohol Effects
FAS	Foetal Alcohol Syndrome
HIV	Human Immunodeficiency Virus
PANDAS	Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus
PKU	Phenylketonuria
SANCA	South African National Council on Alcoholism
SASSA	South African Social Security Agency
TAH	Tygerberg Academic Hospital
UNCRPD	United Nations Convention on the Rights of People with Disabilities
WCCPA	Western Cape Cerebral Palsy Association
WHO	World Health Organization

CHAPTER 1: INTRODUCTION TO THE STUDY

1.1 INTRODUCTION

The use of appropriate counselling skills or methods can improve psychosocial distress of parents. It assists them with adapting to difficulties with caring for children with neurodevelopmental disabilities and challenges faced on a daily basis (Davis, 1993). Juntunen and Atkinson (2002) outline counselling in a healthcare setting according the psychosocial model, which involves the entire family. This emphasises the need for parents to understand the condition of the child and to provide treatment in a biological, psychological and social context.

Parents of children with neurodevelopmental disabilities can experience very heavy emotional, financial and social burdens. They have to come to terms with these burdens, which may be present in the family for their entire lifespan (Good, Whyte, Harris, Glynn, Nicholl & Greene, 2005). The stress can be aggravated by a lack of coping strategies and negative societal attitudes (Buckley, 2002). They also often face enormous challenges in gaining knowledge about the child’s condition and in understanding the needs of the child (Good et al., 2005). Furthermore, they often struggle to access effective psychosocial counselling services in their communities.

Parents of children with disabilities need specialised counselling interventions to help them accept their child’s disability and to cope with the ensuing challenges (Palit & Chatterjee, 2006). A multi-disciplinary healthcare team should render these services (Trute, Hiebert-Murphy & Wright, 2008).

However, there is a paucity of knowledge in South Africa and other developing countries about the adequacy of current counselling services. Given the critical shortage of trained professional social workers in South Africa it is unlikely that such services are provided in sufficient quantities, but this not been verified through research. The proposed study will investigate the role of psychosocial counselling in promoting wellness for parents of children with neurodevelopmental disabilities at Tygerberg Academic Hospital (TAH).

1.2 MOTIVATION AND SIGNIFICANCE OF THE STUDY

As a professional social worker involved in counselling parents of children with neurodevelopmental disabilities, I developed an interest in this area of research. Children with neurodevelopmental disabilities have a severe psychosocial impact on their parents and the rest of their families.

In my experience, mothers mostly find it very difficult to accept their child’s disability and they also experience a lack of support from other family members. Furthermore, some parents indicated they found the counselling service at the hospital to be minimal and that it only focused on the child’s disability and healthcare treatment outcomes. They felt their own psychosocial needs were not being satisfied through counselling and that they needed a “professional ear” to listen to them.

Counselling services (psychosocial counselling) aspire to promote and enhance the quality of life of parents of children with neurodevelopmental disabilities and to strengthen their well-being. However, it seems that parents have almost no access to counselling services in the study setting. This led to formulation of the study, to explore and identify challenges in current counselling practices in the study setting and to improve the perceived lack of access to counselling. The study should therefore assist in enhancing the effectiveness of the counselling provided in the study setting.

The study would provide social workers and the rest of the multi-disciplinary team with information on the needs of parents concerning psychosocial counselling, and propose strategies on how counselling services for parents can be included in the child’s treatment program.

Furthermore, this work, through raising awareness of the need for counselling, would lead to an enhanced use of counselling services by the professional team.

Parents would get an opportunity to explore their feelings and experiences of having a child with neurodevelopmental disability. This would empower them and it would be observed if their own needs for support through counselling had been addressed.

There would also be a platform for them to share their experiences with other parents who are going through the same efforts of caring for a child with a disability.

Findings from the study could add to the knowledge necessary to include counselling services for parents, with the child's health treatment outcomes.

1.3 STATEMENT OF THE PROBLEM

According to Senel and Akkok (1996), the needs of children with neurodevelopmental disabilities demand greater attention, more vigilance and increased effort of parents. Psychosocial issues such as social burdens, marital adjustment and financial distress, which can be caused by having a child with a neurodevelopmental disability, are emotionally and psychologically traumatic for most parents. Thus there is a need for support and psychosocial counselling intervention for these parents. However support systems, e.g. rehabilitation, professional assistance and psychosocial counselling, are often lacking, especially in developing countries.

It is unsure to what extent this need in parents of children attending the neurodevelopmental clinic at TAH is addressed by social workers.

1.4 STUDY AIMS AND OBJECTIVES

The aim of the study was to determine the role that psychosocial counselling at TAH plays in the lives of parents of children with neurodevelopmental disabilities. It also aimed to identify potential shortcomings in the counselling services with a view to improving these services. These aims will be achieved through the following objectives:

- describing the experiences of parents with children with neurodevelopmental disabilities with regard to the child's disability;
- identifying the psychosocial needs of parents of children with neuro-developmental disabilities;
- describing and evaluating parents' experiences about the current psychosocial counselling process at TAH;
- identifying any gaps or shortcomings in the counselling process; and
- making recommendations for future psychosocial counselling services based on the study findings.

1.5 PRESENTATION OF THE STUDY

The study and its findings comprise five chapters and are presented as follows: **Chapter 1** serves as an introduction and outlines the study motivation and significance, the aims and objectives, and statement of the problem. **Chapter 2** presents a literature review based on information related to neurodevelopmental disabilities in children, its manifestation and symptoms. The psychosocial profile and understanding of psychosocial functioning of the family unit in general is reviewed. The importance of the psychosocial counselling approach, using different support structures to improve the well-being of parents, is investigated, and the key role of the social worker and multi-disciplinary team in the lives of parents of children with neurodevelopmental disabilities is detailed. **Chapter 3** consists of the research methodology and describes the research design, study setting, study population, sampling, data measurement instruments, pilot study, data collection procedure, data analysis, rigor of study procedures, and ethical considerations of the study**.** The results of the study are presented and discussed in **Chapter 4. Chapter 5** provides a conclusion of the study findings, and makes recommendations, based on the study, for future psychosocial counselling services at TAH**.**

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

The study seeks to determine the role that psychosocial counselling at TAH plays in the lives of parents of children with neurodevelopmental disabilities. It also aims to identify potential shortcomings in the counselling services with a view to improving these services. Therefore, the literature reviewed focused on conceptualisations of disability, neurodevelopmental disabilities in children, its manifestation and symptoms. The psychosocial profile and understanding of psychosocial functioning of the family in general was defined. The importance of psychosocial counselling using different support structures to improve the well-being of parents was investigated and the role of social worker and multidisciplinary team in the lives of parents of children with neurodevelopmental disabilities was reviewed.

2.2 CONCEPTUALISATIONS OF DISABILITY

According to the International Classification of Function, Disability and Health, disability is a human condition, either temporary or permanent, that almost everyone is likely to experience at some point in life (WHO, 2001). However, the experience of disability varies from person to person and culture to culture. Factors such as the nature and severity of the impairment, the person`s social roles, the impact of the environment, and personality, interact in complex ways to determine whether disability is present or not and the level of actual experienced disability (WHO, 2001). In the past people with disabilities were mostly provided for through solutions that segregated them, such as residential institutions and special schools in what was known as the medical model of disability (Shakespeare, 2006).

In the medical model the emphasis is placed on the impairment, rather than the important social needs of the person (United Nations, 2006). The power to change live’s of people with disabilities seems to lie with the medical and associated professions, with their talk of “cures”, “normalisation” and “science”. Often, the lives of people with disabilities are handed over to these specialists. Their decisions influence where disabled people go to school; what support they get; where they live; what benefits they are entitled to; whether they can work; and even, at times, whether they are born at all, or allowed to have children of their own (Office of the Deputy President, 1997; United Nations, 2006). This is still the dominant view in society, although it is changing to a model of empowerment and engagement, especially at governmental and policy level. However, the changes are slow to filter down into schools, the community or hospitals (United Nations, 2006).

In contrast, the so-called ‘social model’ has provided a powerful framework for bringing disabled people together in a common struggle for equality and rights. By doing this the social model has promoted the idea that disabled people should be actors in their own lives rather than passive recipients of care. This equates almost exactly to current thinking on a rights-based approach to development, adopted by governments and development agencies throughout the world (United Nations, 2006).

The organised drive by disabled people for their rights and equality has lead, all over the world, to perceptions and views of disabled people changing significantly in recent years. This is also true in South Africa where there has been a shift in focus away from viewing people with disabilities as having primarily medical problems that need to be cured for them to function as normally as possible in society, to a recognition that many impairments cannot be cured and that people with disabilities should be accepted for who they are (South Africa. Office of the Deputy President, 1997).This culminated in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2006. The UNCRPD, based on a social model way of thinking, is a rights-based document that provides guidance on the inclusion of persons with disabilities in all parts of life (UN, 2006). It was adopted in 2006 and ratified by the South African government on 30 November 2007. It addressed a range of issues relating to disability, including the rights of children with disabilities (Article 7), awareness raising (Article 8), accessibility (Article 9), health (Article 25) and habitation and rehabilitation (Article 27).

The purpose of the Convention is to

- “promote, protect and ensure full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities”; and
- “promote and respect the inherent dignity persons with disabilities, including those who have long term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full

> and effective participation in society on an equal basis with others" (Article 1: UNCPRD, 2006:5).

2.3 NEURODEVELOPMENTAL DISABILITIES IN CHILDREN

Neurodevelopmental disability has been defined as "an impairment of the growth and development of the central nervous system or disorder of brain function, which affects emotions, learning abilities, physical memory and unfolds as the individual grows" (Reynolds & Goldstein, 1999:34). Behrman and Butler (2007:348) also define neurodevelopmental disabilities "as a group of chronic interrelated disorders of central nervous system function due to malformation of, or injury to the development of, the brain." It occurs during infancy and childhood (Cerebra, 2010). It includes a spectrum of neurodevelopmental conditions such as cerebral palsy (CP), mental retardation, attention deficit hyperactivity disorder (ADHD), autism, foetal alcohol syndrome (FAS), and Fragile-X syndrome. Neurodevelopmental impairments include visual- and hearing-impairments, learning disabilities, communication, speech and language disorders, and impairments in gross and fine motor function (Behrman & Butler, 2007).

Scientists and researchers list the following factors as risk factors and causes of neurodevelopmental disabilities:

Genetic disorders: In the case of genetic disorders, congenital impairments are passed via the mother to the unborn child. In some instances the condition is detectable at birth due to physical signs, such as in Down syndrome or Cornelia de Lange syndrome, while in others it is difficult to diagnose genetic conditions during early infancy because the impairments only became apparent as the child grows older and milestones are missed (Behrman & Butler, 2007; Cerebra, 2010). Because genetic factors can be passed from one generation to another, a family history of a specific genetic disorder increases the risk of development of that neuro-developmental disorder in future generations. Research (Behrman & Butler, 2007) noted that genetic factors may cause the development of a range of neurodevelopmental disorders, including Down syndrome (caused by abnormality of chromosome 21) and Williams syndrome (caused by abnormality of chromosome 7). Children suffering from Down syndrome experience delays in neurological and intellectual development while children diagnosed with Fragile X-syndrome or Rett syndrome experience severe functional limitations (Merla, Howald, Henrichsen et al, 2006).

Metabolic Disorders: Metabolism refers to the various chemical processes that occur in the body. Should these processes be affected, chemical substances can be present in harmful quantities in the body. Metabolic disorders are diagnosed through urine or blood samples and managed through the correct diet and/or chemical substitutes. Phenylketonuria (PKU) is an example of a metabolic disorder. Individuals suffering from PKU have increased levels of phenylalanine in the human body. If this disorder is untreated, it may cause intellectual disability. Uncontrolled diabetes of the mother during pregnancy may also cause neurodevelopmental disabilities in the child (Cerebra, 2010).

Immune dysfunction: The immune dysfunction of both the mother and the developing foetus can create neurodevelopmental disorders in the developing foetus (Behrman & Butler, 2007). Immune dysfunction in early childhood can also lead to neurodevelopmental disorders. One example of such an immune response is PANDAS (Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infection). This particular disorder attacks the brain, which can lead to abnormal movements of the body, emotional disturbance and obsessive-compulsive disorder symptoms (Pavone, Bianchini, Parano, Incorpora, Rizzo, Mazzone & Trifiletti, 2004; Dale, Heyman, Giovannoni & Church, 2005).

Infectious diseases: Various infectious conditions can be transmitted during pregnancy from the mother to the unborn baby (Harpin & Gentle, 2007). These include congenital toxoplasmosis, herpes, congenital syphilis, Human Immune Virus (HIV), Rubella, Hepatitis B, Varicella-Zoster virus, Parvovirus B19, and Cytomegalovirus. These infections can cause developmental abnormalities in the unborn foetus, or even miscarriages. Untreated sexually transmitted infections can be harmful to the unborn foetus, and could cause neurodevelopmental disabilities such as CP (Harpin & Gentle, 2007).

Nutritional deficiencies: Folic acid and iodine deficiency during pregnancy have been associated with a high risk for neurodevelopmental disabilities in the unborn infant (Cerebra, 2010; Gillberg, 2010). Folic acid is a B-vitamin mostly found in fruits, vegetables, whole grains and dairy products, which can reduce the development of neural tube defects such as spina bifida and anencephaly (Cerebra, 2010). These neural tube defects include malformation and dysfunction of the central nervous system, which cause severe physical disabilities and emotional sequellae. Iodine deficiency creates a variety of neurodevelopmental disorders such as emotional disturbance, obsessive-compulsive disorder and mental retardation (Behrman & Butler, 2007; Gillberg, 2010).

Trauma: Traumatic brain injury in infancy is mostly caused by congenital injury or complications during childbirth. It is often related to a lack of oxygen transfer to the brain (hypoxia), which damages the brain tissue. Asphyxia is another common cause of congenital brain trauma; this happens when the trachea is obstructed. Brain trauma to the foetus during pregnancy or birth can cause CP (Behrman & Butler, 2007).

Prematurity or low birth weight: Low birth weight complications are usually related to risk factors prior to birth. Low birth weight children are more likely than their counterparts to develop complex cognitive problems, speech and language difficulties, attention and social difficulties, learning disabilities and hyperactivity (Cerebra, 2010).

Toxins and environmental factors: Toxins may enter a child’s system through the placenta during pregnancy. Some children are exposed to environmental toxins, which can affect their development and may lead to the development of intellectual disabilities or difficulties in behaviour (Cerebra, 2010; Gillberg, 2010). There are numerous examples of toxins. Three of the most common are:

- **Substance abuse-**–Childhood neurodevelopmental disability as a result of substance abuse is usually caused by excessive intake by the mother, during the pre-natal phase, of substances harmful to the baby. Alcohol is the substance most commonly abused. Alcohol abuse by pregnant women can cause severe brain damage in the unborn child through toxins harming the development of the central nervous system. The brain damage caused in unborn babies due to maternal alcohol abuse is known as foetal alcohol syndrome (FAS) (Martha & Lie, 2008; Cerebra, 2010).

Maternal drinking in the Western Cape is a serious health problem. Alcohol is the most frequently abused substance in the Western Cape, South Africa. Research has confirmed that in the Western Cape the rate of foetal alcohol syndrome (FAS) is as high as 46 cases per 1 000 births (May, Gossage, Brooke, Snell, Marais & Hendricks, 2005).

Methamphetamine drugs, commonly known as speed, crack, crystal or glass (and locally named “Tik”), is the most frequently abused drug in the Western Cape. In Cape Town, each year approximately 1 000 young mothers who use “Tik” give birth to so-called “Tik-babies” (Jones, Browne, Myers, Carney, Ellerson, Kline, Poulton, Zule, & Wechsberg, 2011). It is a threat to the brain development and the physical health of pregnant mothers and their children as it reduces the size of the region of the brain essential for learning and memory (Health e-News Services, 2012). According to Professor Smith, head of the Neonatal Unit at TAH, infants exposed to high doses of methamphetamine through their mothers can suffer acute symptoms of withdrawal. These infants are very agitated, irritable, cry a lot and may experience seizures (Health e-News, 2012).

- **Mercury-**–Mercury poisoning can lead to a variety of problems from learning to developmental disabilities, with progressive brain damage, visual impairment, coordination and ambulation impairments, hallucinations, mental retardation, depression, and death (Cerebra, 2010). During the 20th century scientists found that Minamata disease is caused by heavy metal poisoning (Gillberg, 2010). In 1956, the Kumamoto University research group in Japan assumed that the cause of heavy metal poisoning was eating contaminated fish. In 1958 neurologist Douglas McAlpine found that Minamata disease symptoms resemble those of organic mercury poisoning (Gillberg, 2010).
- **Tobacco-**–Smoking during pregnancy may harm the unborn foetus’s development, which can cause developmental delay or difficulties in behaviour (Cerebra, 2010; Gillberg, 2010).

2.4 THE SYMPTOMS OF NEURODEVELOPMENTAL DISABILITIES

Researchers and paediatric neurologists have noted that neurodevelopmental disabilities comprise a series of complex symptoms that affect all aspects of the child's functioning and include movement, vision, hearing, communication, sleeping function, information processing, intellectual ability, social interaction and mental ability (Wing, 2005; Stores, 2006; Gillberg, 2010; Cerebra, 2010). Children suffering from neurodevelopmental disabilities usually have more than one clinical diagnosis, and their symptoms and impairments differ widely from each other (Cerebra, 2010). Each child is unique and will experience neurodevelopmental disability symptoms differently. They may suffer from a broad range of physical, cognitive, emotional and behavioural difficulties. These complex symptoms usually impact negatively on the child's ability to achieve development milestones. Complex symptoms usually become noticeable in children between the ages of three to five years (Wing, 2005; Gillberg, 2010; Cerebra, 2010).

Wing (2005), Cerebra (2010) and Gillberg (2010) present the symptoms in the following three categories:

Physical symptoms are very complex and consist of motor impairment, motor-coordination and motor-planning impairments; communication and language impairments; sensory impairment or difficulty, fatigue problems, seizures, weakness in the limbs, stiffness or spasticity, and feeding difficulties.

Cognitive symptoms consist of cognitive impairment, intellectual disability, memory and impulse difficulties, complex language processing impairments, lack of perception, lack of problem solving abilities, hyperactivity or impulsivity, and inattention.

Emotional and behavioural symptoms include anxiety, obsessive, repetitive and anti-social behaviour; aggressive behaviour, hyperactivity, problems with social interaction, impulsiveness, and mood swings.

Children with some of these symptoms are often referred to and managed by a multi-disciplinary team, consisting of nurses, paediatricians, social workers, child neurologists, physiotherapists, speech therapists, occupational therapists and educational psychologists (Gillberg, 2010).

2.5 SOCIO-ECONOMIC PROFILE OF PARENTS OF CHILDREN WITH NEURODEVELOPMENTAL DISABILITIES

May, Gossage, Brooke, Snell, Marais and Hendricks (2005) and Canary (2008) cite poverty as both a cause and consequence of disability, including neuro-developmental disabilities. Some of the risk factors related to neurodevelopmental disability, as presented in Section 2.2, such as nutritional challenges, substance abuse and environmental hazards are more common in poor communities (May et. al., 2005; Canary, 2008). In addition, a child suffering from a neurodevelopmental condition can put severe strain on a family's income, which can lead to poverty (Canary, 2008).

Several studies noted that children with neurodevelopmental disabilities had a significant impact on a family's economic status (Shin, Nan, Crittenden, Hong, Flory & Ladinsky, 2006; Ellis & Adams, 2009; Osborne & Reed, 2009). A study conducted in southeast England by Osborne and Reed (2009) focused on sixty-five parents of children with neurodevelopmental disabilities; it found that one of the major stressors experienced by parents was financial constraints and the majority of parents were living in poverty. About 50 per cent of mothers and eight per cent of fathers were unemployed. The families' monthly incomes ranged from £71-£355, approximately equivalent to R1 000-R5 000. Shin et al. (2006) found that 46 per cent of families with a child with neurodevelopmental disability lived in extreme poverty and many families struggled to meet their daily basic needs. They also noted that fathers experienced more stress due to not having stable employment, which created a lower economic status. A study conducted in Tanzania found that in a family where a child had multiple disabilities, they received material support from extended family members to meet their daily basic needs, such as food, clothes for their child and money, but no state or non-governmental assistance (Mbwilo, Smide & Aarts, 2010).

Mulvihill, Wingate, Altarac, Mulvihill, Redden and Telfair (2005) found that families with children who had neurodevelopmental disabilities who lived in poverty tended to experience treatment delays. Furthermore, Emerson (2003) noted that families who support children with neurodevelopmental disabilities are significantly economically underprivileged in the sense that they are more likely to experience financial burdens than those families who have children without neurodevelopmental disabilities.

Several studies noted that low-income families usually have minimum knowledge about informational support. They also have limited access to resources in their own community and support systems are not easily available (Williams, Williams, Graff, Hanson, Stanton & Hafeman, 2003; Diamond & Kontos, 2004; Dudevany & Vudensky, 2005).

Single mothers who have children with neurodevelopmental disabilities are hugely affected by the lack of situational resources, such as availability of transportation to take the child for regular medical intervention, isolation from family members and spousal support. Furthermore, the monthly expenses of families who have children with neurodevelopmental disabilities in the lower-income bracket are more than those who do not have children with neurodevelopmental disabilities (Parish, Cloud, Huh & Henning, 2005). A research study conducted on mothers who serve in the military and have children with neurodevelopmental disabilities found them to be isolated from spousal support and extended family members; they also experienced challenges regarding accessing professional services, which had a negative impact on their well-being (Taylor, Wall, Liebow, Sabatino, Timberlake & Farber, 2005).

Lewis, Kagan, Heaton and Cranshaw (1999) noted that mothers of children with neurodevelopmental disabilities most frequently use employment as an economic- and social resource. But due to the absence of organisational support this frequently does not allow them to access essential internal or external resources, which being employed could make available to them. They also noted that such resources could be beneficial to the mothers' well-being. These resources can also focus on intervention support programs to avoid distress in the family functioning.

Canary (2008) concludes that an improved socio-economic status and access to resources are beneficial to the psychosocial functioning of parents of children with neurodevelopmental disabilities.

2.6 PSYCHOSOCIAL FUNCTIONING OF PARENTS OF CHILDREN WITH NEURODEVELOPMENTAL DISABILITIES

The success of the psychosocial functioning of parents of children with neuro-developmental disabilities is determined by indicators such as family stressors, marital satisfaction, family functioning, empowerment, socio-economic status and resources, self-esteem, adaptability and support (MacDonald & Callery, 2004; Dudevany & Vudensky, 2005; Canary, 2008). On the other hand stressors that negatively influence family functioning include insufficient income, lack of social networks, unemployment, lack of appropriate healthcare and the social, emotional and physical burdens that caring for a child with a neurodevelopmental disability brings (Hepworth, Rooney, Rooney, Strom-Gottfried & Larsen, 2006).

Approximately 10 per cent of children experiencing neurodevelopmental disabilities required substantial caregiving from parents or families, from early childhood until adulthood, due to sensory and functional limitations (Raina, O'Donnell, Schwellnus, Rosenbaum, King, Brehaut, Russell, Swinton, King, Wong, Walter & Wood, 2004). Recent research studies found that parents of children with neurodevelopmental disabilities, for example CP, are more likely to experience high levels of stress due to the child's sensory and intellectual impairments and complicated limitations in self-care functions. As a result, children with CP required long-term care from parents, which can be a burden and may impact on the family functioning (Raina et al*.,* 2004; Majenemer, Shevell, Law, Poulin & Rosenbaum, 2012).

Family distress has a negative impact on the family and child's functioning, well-being, marital satisfaction, and social support (Lach, Kohen, Garner, Brehaut, Miller, Klassen & Rosenbaum, 2009). This impact could lead to creating smaller family units and an increased rate of parents separating (Raina et al*.,* 2004).

2.7 THE INVOLVEMENT OF EXTENDED FAMILY MEMBERS

Studies have shown there is a significant positive relationship between availability of social support networks and increased parental well-being (Green, 2001; Katz & Kessel, 2002). The involvement of extended families, especially grandparents, plays a significant role through the provision of childcare and financial and emotional support to parents (Green, 2001). A study conducted by Gardner, Scherman and

Efthimiadis (2004) found that grandparents believed that their grandchild/ grandchildren's disabilities would not affect their family relationship and they continued to provide emotional and instrumental support to the parents. These researchers found that parents experienced less distress because grandparents provided support. Lach et al. (2009) also noted that parents of children with neurodevelopmental disabilities who received support from other family members experienced less distress. Trute (2003) indicated there is significant relationship between maternal grandmothers providing additional instrumental support (child caring and financial assistance) and emotional support to mothers than to other family members. In addition, grandparents who provide emotional support to fathers contributed significantly to the fathers' well-being (Trute, 2003).

2.8 DEFINING COUNSELLING

Davis (1993) defines counselling as a process that involves listening, helping, empowering and befriending. Counselling is a face-to-face communication and interaction process between the client and the counsellor to assist the client in making decisions regarding problem solving. It involves active listening regarding people's problems; giving them comfort through empathy; and working for the empowerment of the person. It is also a process of assisting relationship building, aimed at enabling the client to explore personal problems amongst other things (Payne, 2005). Counselling is a planned intervention aimed at improving a particular situation of the client. The counsellor assists the client to find solutions to resolve present difficult situations. It is also a process of assisting people to develop new coping mechanisms, which may be beneficial in the future (Nelson-Jones, 2003). The World Health Organization (2001) defines counselling as a process of dialogue and mutual interaction, which aim at facilitating, problem solving, motivation, and decision-making. Palmer and MacMahon (2000:178) define counselling as "a process that involves acceptance, trust and that creates a safe relationship between the counsellor and client." It assists the client understand the children with neuro-developmental disabilities, to construct goals for problem solving (Palmer & MacMahon, 2000).

2.9 COUNSELLING PARENTS OF CHILDREN WITH NEURODEVELOPMENTAL DISABILITIES

2.9.1 Counselling parents

Parents will have to adjust to a range of psychological and emotional problems when their child is diagnosed with a neurodevelopmental disability. They are likely to experience emotional reactions to the child's disability (Walton, 1993; Davis, 1993) and may need support in the form of counselling to cope with their problems and addressing the child's needs (Davis, 1993).

Counselling is a formal procedure, where both parents and the counsellor aim to find an appropriate strategy of adjustment regarding their child's disabilities. (Davis, 1993) listed three general aims of counselling parents of children with neuro-developmental disabilities:

1. Facilitating approaches that are useful to support parents in adjusting psychologically, socially and physically in their daily lives to the child's disability;
2. Empowering parents to meet the needs of their children with neuro-developmental disabilities without neglecting their own needs; and
3. Facilitating support systems that assist parents to focus on the well-being of the child with neurodevelopmental disabilities and to ensure that these children have the best possible quality of life.

Counselling procedures should firstly allow parents to work through their emotions before developing and receiving knowledge on how to accept their child's condition (Davis, 1993). These emotions are connected to stress-related factors (Walton, 1993).

Walton (1993) indicated that most parents go through the same series of emotions before developing knowledge on how to accept their children's neurodevelopmental disability: denial, projection of blame, fear, guilt, mourning or grief, withdrawal, depression, helplessness, rejection of child or assistance from others, and, finally, acceptance. Over the past two decades research has shown that many parents go through the same series of emotional reactions, even though other parents may experience it differently. Research also indicates that once parents developed knowledge about their children's neurodevelopmental disability, they began the process of acceptance, and searched for, and engaged in, support systems to help them deal with the problems (Walton, 1993; Davis, 1993; Siklos & Kerns, 2006).

Several research studies noted that any one of the above-mentioned series of emotions might affect the levels of stress that parents experience during the process of acceptance and dealing with their children's neurodevelopmental disabilities. The social worker or counsellor should provide support to parents struggling to work through one or more of the emotions (Walton 1993; Davis 1993; Siklos & Kerns, 2006, Canary, 2008). Once parents have accepted their situation, they can start to support and help their children with neurodevelopmental disabilities. At this point they may encounter another complex array of stressors, including transportation difficulties, extreme time demands, lack of counselling and support services, lack of disability information and financial burdens (Davis, 1993; Canary, 2008). The social worker or counsellor could be a great benefit to parents to support and refer them to relevant resources to alleviate or minimise current stressors (Canary, 2008).

Davis (1993) suggest that a multi-disciplinary team (medical doctors, occupational therapists, nurses, physiotherapist, speech therapist, radiographers, social workers and teachers) should work together and incorporate knowledge and skills of basic counselling into their everyday work environment. Parents of children with neurodevelopmental disabilities will greatly benefit from this process whenever they come across any healthcare professional regarding their children's condition. Counselling skills should form a fundamental part of the daily work of multi-disciplinary team members in a heath setting. It would enable the multi-disciplinary team to enhance their daily healthcare practice (Burnard, 1994).

Davis (1993) has noted that counselling is a neglected procedure in most healthcare settings, because most healthcare professionals are not significantly involved in the counselling procedure. The lack of counselling is caused by an absence of appropriate relationship-building skills. The task of relationship building is recognised in professional training, but not much attention has been given to this process. Davis (1993) summarises the reasons as follows:

- lack of an appropriate model;
- the lack of appropriate relationship-forming skills;

- parents might experience anxiety regarding their skills to deal with psychosocial problems;
- the presence of severe psychological difficulties in parents such as depression, which prevent them relating with others; and
- deep-rooted parental distrust, arising from unsatisfactory past experiences with healthcare professionals.

In addition, Payne (2005) noted that parents who access healthcare facilities often experience enormous distress and their major concern is that healthcare professionals do not have enough time to attend to their problems, such as counselling or providing moral support.

Davis (1993) noted that the needs of the children with disabilities came first, and that healthcare professionals often neglect the psychosocial needs of the family unit. The involvement of a multi-disciplinary team is significantly important in addressing the needs of the parents. Addressing their needs will be beneficial to the well-being of both the parents and the children with neurodevelopmental disabilities.

Ziolko (1991) and Davis (1993) specified that a counsellor or social worker should adopt an eclectic approach to counselling, which would give them the opportunity to use different counselling methods purposefully, thoughtfully and strategically to enhance the counselling progress. During the stages of adjustment it would give both the counsellor and client the opportunity to work together to find solutions in a timely and practical manner. Walton (1993) noted that lack of information is the main cause for some of the anxiety experience by parents. Significant emotional and information support is needed to assist parents to adopt adjustments. After the counsellor/social worker address the parents’ negative reactions regarding the diagnoses of their child’s disability, they will begin to cope constructively after they have enough knowledge and understanding of the disability and may accept the implications of the disabilities (Ziolko, 1991; Davis 1993; Walton, 1993).

2.9.2 Eclectic Model applied to counselling

Ziolko (1991) described the Eclectic Model of counselling as the most effective model in counselling parents of children with disabilities. It proposes different stages in counselling. The evolution of the stages should be a flawless process with the ultimate goal of ensuring individual parental adjustment to the challenges caused by having a child with neurodevelopmental disability. The stages of adjustment give parents the opportunity to respond effectively to their child's disability:

2.9.2.1 Stage 1

Stage one is to build a trusting relationship between the parents and the social worker/counsellor. Trust is sometimes difficult for some parents who are dealing with overwhelming feelings of having a child with neurodevelopmental disabilities. A professional social worker/counsellor works to gain their trust by encouraging them to express their feelings, fears and worries and progressively build a relationship of trust (Ziolko, 1991). Davis (1993) emphasises the importance of attending to parents who found it difficult to accept children with neurodevelopmental disabilities in a way that would enable them to express their concerns. The social worker/counsellor should show an interest in and be concerned about the well-being of the family system. They must help the parents to overcome their fears and to value the child and accept their child's condition. Ziolko (1991) stated that it is an obligation of the professional social worker/counsellor to build a comfortable counselling environment for parents. They should give attention to the different phases of devastation of having children with neurodevelopmental disabilities and remain sensitive towards the needs of the parents.

2.9.2.2 Stage 2

The aim of the second stage deals with the expressions of emotions and the nature of the parent's problems. The process continues until the professional social workers/counsellors and parents totally understand the problem (Gilliland, James & Bowman, 1989). Any options or available resources to assist parents to accept the child's disability must be used (Ziolko, 1991). Ziolko recommends the social worker/ counsellor should observe parents' responses and interactions when healthcare professionals, especially doctors, provide information regarding their children's condition. This researcher further recommends that professional social workers/ counsellors should make use of Maslow's hierarchy of needs (physiological; security; social; esteem; and self-actualizing needs) when assessing parents' burdens. Maslow's hierarchy of needs determines the family system's strengths and weaknesses. For example it cannot be assumed that parents will attend follow-up therapeutic treatment interventions for the children if they are unable to provide food or security for themselves and their family due to financial constraints (Ziolko (1991). Therefore, the healthcare professional should be familiar with available resources in the environment of the parents/families when assisting them with their needs.

Canary (2008) recommends that professional social workers/counsellors should enable parents to find their own support systems besides the immediate family systems, and assist them to develop their own coping mechanisms, to enable them to analyse problems, determine opportunities and formulate plans of dealing with any situations at any stage.

2.9.2.3 Stage 3

This stage involves identifying and evaluating alternatives, and commitment to plans of action. This stage is pivotal to the success of counselling. It assists in evaluating how successful the process of counselling is and when it should terminate. Once the professional social worker/counsellor and parents agree on establishing goals, the following step is to formulate a plan of action and implement it, given that the core object of counselling is to initiate and facilitate desirable change. Parents need to explore all options during decision making to achieve the goals. This teaches parents how to solve problems that arise and develop their own techniques to manage a variety of situations (Davis, 1993). Coulshed and Orme (2006) also recommend allowing parents to develop their own strategies, since it is beneficial to their own psychosocial needs. In addition, the involvement of other healthcare professionals, such as physiotherapist, occupational therapist, medical doctors and speech therapist, is greatly beneficial to parents in dealing with their child with neuro-developmental disabilities, and to reach established goals.

Coulshed and Orme (2006) advised that social workers/counsellors should have a list of available community referral services that are easily accessible for parents, including counselling and support groups, educational services and names of other therapists e.g. occupational and speech therapists. Davis (1993) also advises that all healthcare professionals who are dealing with the child with neurodevelopmental disabilities should provide regular support to parents during treatment intervention and through having telephone communication, even if the child has been referred to other community healthcare professionals. He also highlights that some healthcare professionals communications may be unclear to parents, which may have a negative impact on the parents' self-esteem, especially when parents receive more bad news about their children's neurodevelopmental disabilities (Davis, 1993).

2.9.2.4 Stage 4

The social worker/counsellor and or other healthcare professionals should evaluate the goals and achievement of the parents regarding improvement of psychosocial functioning of the family, psychosocial needs, and strengths and appropriate available resources (Ziolko, 1991). The evaluation processes involves feedback on the effectiveness of problem solving during counselling and referral services. Furthermore, these processes seek to provide guidance to parents by using their own strategies to solve problems within their family unit (Davis, 1993).

2.10 SUPPORT STRUCTURES TO FURTHER THE WELL-BEING OF PARENTS OF CHILDREN WITH NEURODEVELOPMENTAL DISABILITIES

2.10.1 Respite care services

Many studies have noted that parents caring for children with developmental disabilities require respite care, which aims to alleviate distress in families and can improve well-being of parents and family functioning, and increase quality of life (Chan & Sigafoos, 2002; MacDonald & Callery, 2004). It involves the provision of temporary services or breaks for short periods of time on a regular basis to support and maintain the caregiving relationship. There are various models for providing respite care services such as in-home respite; specialized facility; emergency and sitter-companion services (Chan & Sigafoos, 2002; Macdonald & Callery, 2004; Cramer & Carlin, 2008).

Redmond, Bowen and Richardson (2000) noted that mothers experience severe parental stress due to caring for a child with neurodevelopmental disabilities. Using direct in-home support services was highly beneficial to them. It allowed them to continue caring for their children without neglecting the needs of other family members or household activities. Redmond et al. (2000) recommend that respite care services should allow parents to continue caring for their children while decreasing social, emotional, financial and psychological burdens. Another research study noted that respite care services help to sustain caregiver's and family members' health and well-being, and reduces marital problems within the family unit (Forde, Lane, McCloskey, McManus & Tierney, 2004).

Chan and Sigafoos (2000) conducted research on in-home based respite care service for parents of children with neurodevelopmental disabilities. The service required that other family members or friends took care of the children for short periods, while the mothers could take a break to spend time with the other siblings or do household activities. Participation in the research project reduced stress in 49 per cent of parents. This improved the psychosocial functioning of the family and parental attitudes towards their children. Forde et al. (2004) found a significantly positive relationship between the respite care for children with multiple disabilities and decreased levels of parental stress, which also enhances spousal relationships between parents.

Researchers advise families to use an in-home based respite care service instead of out-of-home based respite care services. They further advise that trained respite care workers should provide training to parents in the home, which would give parents the opportunity to observe their skills, knowledge and attitude while interacting with their children. These studies concluded that using in-home based services may help parents have positive attitudes towards caring for their children with neurodevelopmental disabilities (Chan & Sigafoos, 2002; McDonald & Callery, 2004; Forde et al., 2004).

In the Western Cape, particularly in Cape Town, there are several respite care facilities for families of children with neurodevelopmental disabilities. The Woodside Special Care Centre is situated in Rondebosch East, in Cape Town's southern suburbs. The centre provides hourly, daily and monthly respite care to families of children with intellectual and physical disabilities (Woodside Special Care Centre, 2012). Parents must complete an application form and stipulate why they need the respite care service. The Centre offers the children skills development, such as dressing, feeding and self-help, social interaction, play time, water therapy, outdoor-play and walks (Woodside Special Care Centre, 2012).

Iris House Children's Hospice is situated in the northern suburbs of Cape Town. This centre was established in August 2011 and provides a community-based care service, including in-house respite care for families. Its goal is to enhance the quality of life of special needs children and young people with complex health needs. It provides support to families of children with multiple complex disabilities between the ages of 0–18 years. The centre has a team of carers who stay at the families' homes for a maximum of four hours. They provide opportunity for play and recreational activities to the children and also offer assistance to the parents. This allows parents to enjoy life and do shopping and visiting friends. They operate a strong non-discriminatory policy and welcome referrals from all ethnic, cultural and sexual orientation backgrounds. All their services are completely free to families (Iris House Children's Hospice, 2012).

2.10.2 Informal support

Dudevany and Vudensky (2005) found parents of children with neurodevelopmental disorders experienced lower levels of parental stress if they received regular informal support from immediate and extended families and friends. These informal support systems create greater feelings of parental management and marital satisfaction. A quantitative study implemented by the Family Support Scale (FSS) that particularly focused on informal support systems found there is a significantly strong relationship between receiving informal support and decreased levels of parental distress. The FSS also found there is a relation between the effective functional levels of children with CP and available perceived levels of support and maternal distress (Manual, Naughton, Balkrishnan, Smith & Koman, 2003). Wilgosh, Nota, Scorgie and Soresi (2004*)* indicate that regular contact between parents of children with neurodevelopmental disabilities is also a huge source of social support and is beneficial for effective family management.

Turnbull, Summers, Lee and Kayzar (2007) also found that parents living with a child with neurodevelopmental disabilities face extreme challenges on a daily basis and need family support. Family support systems that provide support to parents in their home environment empowers them, and usually decrease indicators which are associated with family distress such as financial, social, health and emotional burdens, while increasing the psychosocial functioning of the family unit. Therefore, family support systems successfully improve and enhance the lives of the parents as well the children with disabilities (Wang & Brown, 2009).

2.10.3 Formal support

Several studies found that parents of children with neurodevelopmental disabilities need and depend on professional support services (Heiman, 2002; Taanila, Syrjala, Kokkonen & Järvalin, 2002; Brown, Anand, Isaacs, Buam & Fung, 2003; Poston, Turnbull, Park, Mannan, Marquis & Wang, 2003; Nachesehen, Garcin & Minnes, 2005). Services must be family-centred with the main goal being to have effective social and health interventions with parents and children with neurodevelopmental disabilities to enhance quality of life of all family members (King, Teplicky, King & Rosenbaum, 2004). A family-centred services approach should include parental involvement in decision-making during treatment intervention of their children; obtaining social and health information; and treating parents with mutual respect and support. Other research studies showed there are positive associations between the use of family-centred interventions and decreased levels of parental stress, greater emotional well-being, and parental empowerment (King et al., 2004). Dudevany and Vudnesky (2005) found that single parents with children with neurodevelopmental disabilities experience higher levels of stress due to lack of social support and formal support, such as professional services in a particular healthcare setting. According to Turnbull et al. (2007) parents do not receive sufficient formal support which would benefit their entire family well-being outcomes, since raising a child with a neurodevelopmental disability can be a great challenge for the entire family.

Hudson, Matthews, Gavidia-Payne, Cameron, Mildon, Radler and Nankervis (2003) noted that parents participating in parental support group programmes found it very beneficial to receive emotional and informational support, as it improved their ability to solve their own problems and enhanced their coping abilities.

In the Western Cape, there are numerous family-centred services providing formal support to parents children with neurodevelopmental disabilities. The Western Cape Cerebral Palsy Association provides health services to patients with CP (Western Cape Cerebral Palsy Association, 2012). It runs the Western Cape Cerebral Palsy Clinic, which has been operating since 1988. The clinic is accessible to all children with CP living in the Western Cape Province and most come from disadvantaged communities. It collaborates with Red Cross War Memorial Children's Hospital, which provides healthcare facilities, doctors and treatment, while the Association provides staff to manage and run the clinic (Western Cape Cerebral Palsy Association, 2012). The clinic provides clinical assessment and treatment to children with cerebral palsy, and offers services such as physiotherapy, speech therapy, feeding therapy, occupational therapy and advice. It also provides transportation for children who are wheelchair-bound, since public transport is inaccessible for wheelchairs. A multidisciplinary team of therapists, specialist doctors, nurses, social workers and language interpreters implements interventions. Approximately 250–350 children receive therapy on a monthly basis (Western Cape Cerebral Palsy Association, 2012).

In addition the clinic provides skills development training and health education and information to parents and carers of children who attend the clinic. It also conducts outreach programmes, including assessment, treatment, counselling and training, in several communities in Cape Town, *viz.* Guguletu, Nyanga, Langa, Phillipi, Crossroads, Khayelitsha Site C (at Nolungile Day Hospital) and Site B (at Michael Mapongwana Day Hospital), and Mitchells Plain, Bontenheuwel and Claremont. The satellite clinic in Kraaifontein serves Wallecedene, Scottsdene and Bloekombos informal settlement areas (Western Cape Cerebral Palsy Association, 2012).

The South African National Council of Alcoholism (SANCA) Western Cape conducts prevention programs about foetal alcohol syndrome (FAS) which is the leading cause of mental retardation in the Western world; sadly, the Western Cape has the highest levels of FAS in the world. SANCA has six branch offices that offer FAS programs in under-resourced, high-risk poor communities primarily on farms and rural areas, including the Cape Peninsula, Paarl, Wellington and Vredenburg (SANCA, 2012). It supports mothers who have children with growth deficiencies, mental retardation, physical and central nervous system abnormalities due to mothers consuming alcohol during pregnancy (SANCA, 2012). The FAS programme focuses on awareness, educational and community based-prevention. This service is offered by social workers in the communities and targets teenage girls of childbearing age and high-risk mothers. They assist them to make informed choices to protect their unborn babies from devastating complex effects due to consuming alcohol during pregnancy, provide counselling regarding the dangers of alcohol abuse; and to reduce and prevent alcohol-related births (SANCA, 2012).

The programme also runs capacity building and training initiatives for role players in the community by identifying, recruiting and educating them to implement awareness and education programs in high-risk communities to reduce the prevalence of FAS. The role players are healthcare workers, educators, professionals such as social workers and community volunteers. They attended a two-day workshop, which focuses on information about alcohol abuse, FAS and foetal alcohol effects (FAE); exposes them to practical exercises on prevention and intervention strategies; an introduction to basic counselling skills, conduct assessment and how to make referrals to appropriate treatment resources within the community (SANCA, 2012).

The purpose of Autism Western Cape is to raise awareness and understanding of Autism Spectrum Disorders. This organisation provides information and diagnosis support, counselling and an advisory service to parents or caregivers whose children have Autism Spectrum Disorder. The organisation advocates and lobbies for the rights of children who are affected by this particular disorder. It conducts outreach programs, education and training workshops in communities for role players including parents and caregivers to empower them with information on autism, as parents need to play a role in the early intervention and treatment of their child. Capacity building opportunities and training for public health professionals and educators, conducted at public and education facilities, increase awareness and early intervention. The organisation also offers learner facilitator training courses for educators who want to acquire new skills, knowledge and understanding to manage difficult and disruptive classroom behaviours (Autism Western Cape, 2012).

2.11 THE ROLE OF THE SOCIAL WORKER

It is evident that when a child is diagnosed with neurodevelopmental disabilities, parents experience shock, disappointment and stress that often lead to psychological crisis, as parents normally hope their children will be born or live without any disabilities (Raina et al., 2004). Hepworth et al. (2006:39) referred to a ‘crisis’ as “a perception of an event or situation as an intolerable difficulty, that exceeds the resources or coping mechanism of the person” and notes that prolonged crisis-related stress can severely affect the family’s functioning.

The major goal of the social worker is to reduce stress and depression, and assist the client *(parents)* and those *(other family members*) being affected by the crisis (*child being diagnosed with neurodevelopmental disability*) to strengthen their coping abilities and acceptance of their child's disability (Canary, 2008). Payne (2005) states that the role of the social worker is to decrease problems that arise from within the person and the environment that can cause stress. It requires psychoanalysis, which involves releasing and dealing with hidden feelings and going deeply into the person's (*parent*) problem. While there are various theories social workers can use in dealing with individuals and families during crisis intervention, systems theory seems the most appropriate theory for parents dealing with children with neuro-developmental disabilities. The main principle of this theory is that people depend on their immediate environment for a satisfactory life and systems like families, friends, community and healthcare facilities can provide that support (Payne, 2005).

Payne (2005) noted that families or parents in distress might not always use these helping systems, because they may not currently exist in their lives. Parents of children with neurodevelopmental disabilities may wish to use them, but due to isolation within the family and community, or because of caring for a child with a disability, they might not be able to.

In addition, the systems may be in conflict with one another, for instance when parents caring for a child with neurodevelopmental disabilities experience burdens due to shifting roles, being both parent and home-based caregiver, which can result in life-long dependency of the child with the disability, and can lead to conflicts of interest with other family members.

Payne (2005) summarises the social worker's task as follows:

- enabling parents to help themselves through empowering them with new skills to utilise in dealing with current or new problems;
- providing effective psychosocial counselling;
- referring parents to appropriate community resources, which can positively improve their well-being;
- improving interaction with immediate and extended family members and educating them on how to handle various situations;
- acting as agents of social control; and
- giving practical assistance when help is needed.

Social workers are qualified and skilled professional workers who can assist parents of children with neurodevelopmental disabilities experiencing distress in their lives. They support parents by advising and introducing appropriate services to them.

2.12 THE ROLE OF MULTI-DISCIPLINARY TEAM

The multidisciplinary team focuses on the provision of a continuum of care between service users and assisting agencies. The team facilitates decision-making regarding medical intervention, influences allocation of resources, and determines the possible risk in a particular situation (UNAIDS, 2003).

Dennill, King and Swanepoel (1995:12) defined the multidisciplinary healthcare team as “a group of people who share a common health goal and common objectives, determined by community needs, to the achievement of which each member of the team contributes, in accordance with his/her competency skill, and in coordination with the function of others.” The multidisciplinary team in an outpatient neuro-developmental clinic is a group of healthcare professionals each with various specialist knowledge related to the assessment and management of children with neurodevelopmental disorders, working together to enable optimal early medical intervention, parental education and to improve the child’s health and developmental outcomes (Canary, 2008).

Barratt and Ogle (2010) noted the management of complex child neuro-developmental disorders requires a multi-disciplinary approach involving various disciplines such as paediatrician neurologists, speech and language therapists, occupational therapists, physiotherapists, dentists, dieticians, social workers and other relevant healthcare professionals.

Some researchers recorded the effective use of multidisciplinary team intervention programmes which had a great influence on the improvement of family well-being and increased parent’s knowledge of neurodevelopmental disabilities. These programmes consisted of crisis and family counselling, disability information programs, respite care and support groups for parents. Overall they had significantly positive outcomes on parents caring for a child with complex neurodevelopmental disabilities and improved the psychosocial functioning of the family (Evans, Jones & Mansell, 2001; Lobato & Kao 2002; Boettcher, Koegel, McNerney & Koegel, 2003;

Williams et al. 2003; Baldry, Bratel, Dunsire & Durrant, 2005; D'Arcy, Flynn, McCarthy, O'Conner & Tierney, 2005). Other studies indicated that while support programs are greatly beneficial for parents, various factors could prevent them from participating, such as cultural norms, lack of transportation, difficulties in understanding disability issues, financial and/or time constraints or other family members' needs (Hendriks, De Moor, Oud & Franken, 2000; Vardi & Merrick, 2003).

It is evident that effective implementation of intervention and support programmes by a multi-disciplinary team significantly enhances the well-being of parents and the psychosocial functioning of the family.

2.13 CHAPTER SUMMARY

The chapter started with an overview of conceptualisations of disability which included the shift in attitudes and in practice from the medical model to social model. This was followed by a review of neurodevelopmental disabilities in children, their causes and symptoms. Eight causes (genetic and metabolic disorders; immune dysfunction; infectious diseases; nutritional deficiencies; trauma; prematurity and low birth weight and, finally, toxins and environmental factors) were broadly discussed, each with their characteristic conditions and impairments. Particular attention was paid to the role of substance abuse, both drug- and alcohol-related, because of their high incidence in the Western Cape. Physical, cognitive and emotional and behavioural symptoms were then reviewed. The influence of poverty, as both a cause and consequence of disability, was extensively explored.

Given that the aim of the study was the improvement of psychosocial functioning of parents of children with neurodevelopmental disabilities, the next phase of the literature review was the exploration of psychosocial functioning of parents with regard to indicators such as family stressors, marital satisfaction, family functioning, empowerment, socio-economic status and resources, self-esteem, adaptability and support. Each of these was briefly discussed.

This was followed by an in-depth look at counselling: its definitions, the general aims of counselling, the specific requirements of parents of children with neuro-developmental disabilities, the reasons why it is a neglected procedure in most healthcare settings, and the best model to use. The so-called Eclectic Model was described in depth.

An overview of the benefits of other types of parental support, including respite care, and formal and informal support systems, was given. Examples of such services in the Western Cape were listed, including the range and type of services offered and their localities. The necessity of using a family-centred approach was explored.

Finally, literature relating to the role of the social worker/counsellor and multi-disciplinary team was reviewed, in terms of their goals, management foci and approaches. The positive benefits of support from both these sources were noted, for parents, children with neurodevelopmental disabilities, and the family unit as a whole.

The research methodology will be discussed in the following chapter.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 INTRODUCTION

This chapter outlines how the study was conducted to achieve its aims and objectives. The key aspects regarding the methodology of the study are discussed. It includes the study design, study setting, study population, sampling, data measurement instruments, pilot study, data collection, data analysis, and ethical implications of the study.

3.2 STUDY DESIGN

To collect data a descriptive, qualitative approach was followed using semi-structured interviews as this focuses on the participants' experiences and perceptions regarding psychosocial needs and counselling (Neuman, 2003). This approach was employed to gain a better understanding of the life experiences of parents of children with neurodevelopmental disabilities; the implications on their everyday lives and the role of counselling in their lives. It gave study participants the opportunity to express themselves in their own words and explored their beliefs about and experiences of counselling services at TAH.

3.3 STUDY SETTING

The study was conducted in April 2011 at the Neurodevelopmental Outpatient Clinic at Tygerberg Academic Hospital, in Cape Town, South Africa. The hospital is a tertiary referral centre and the Neurodevelopmental Outpatient Clinic manages approximately 2 000 patients per year. About 280 patients from the clinic are admitted to the hospital per year and approximately 33 patients are treated via outreach services. In 2010 the Neurodevelopmental Outpatient Clinic saw 2 537 patients for treatment interventions, and in 2011 it saw 2 632 patients.

Table 3.1(next page) shows the number of patients seen per month in 2010 and 2011.

Table 3.1 Monthly treatment rates at Tygerberg Academic Hospital Neurodevelopmental Outpatient Clinic, 2010–2011

Month	Number of patients in 2010	Number of patients in 2011
January	171	162
February	202	202
March	221	219
April	181	188
May	225	286
June	235	183
July	174	218
August	241	240
September	289	276
October	229	228
November	258	279
December	111	151
Total	**2 537**	**2 632**

Information obtained from the Neurodevelopmental Outpatient Clinic, TAH, by permission of Dr. Springer, senior neurologist, and nursing Sister Opperman, Manager, Neurodevelopmental Outpatient Clinic.

The researcher chose to conduct her research at the Neurodevelopmental Outpatient Clinic because parents of children with neurodevelopmental disabilities attended their children’s healthcare appointment there. The research office located at the clinic was provided by Dr. Springer. Thus it was very convenient for parents to participate in the study (see Section 3.7 below).

The Neurodevelopmental Outpatient Clinic team healthcare team conducts seven clinics per week for general neurodevelopmental disability, one clinic per week for CP patients and one clinic quarterly for epilepsy patients. There is a waiting period of four to six months for newly-referred patients. The clinic has eight primary staff members including a professional nurse, a staff nurse, two assistant nurses, two full time neurology specialists, a part-time neurology specialist and two registrar neurologists. The other members of the multi-disciplinary team are not stationed at the clinic. Patients are referred, if necessary, to occupational therapy, physiotherapy, speech therapy, the social work department and radiology at TAH.

Outreach programmes are conducted at Paarl Primary School for Physically Disabled Children (twice a month); Alta Du Toit, a special school for children with intellectual disability (once quarterly); Paarl hospital (once a month); Eben Donges

Hospital (once a month) and Karl Bremer Hospital (once a month) (Paediatric and neurology and child development service in South Africa, 2003).

Currently TAH has 22 qualified social workers of whom four are in managerial positions and the remainder provide clinical services, including counselling to parents of children with neurodevelopmental disabilities if referred to them.

3.4. STUDY POPULATION

The study population included all parents of children with neurodevelopmental disabilities, aged 1–15 years, who were seen at the Neurodevelopmental Outpatient Clinic at TAH during 2010.

3.4.1 Inclusion criteria

- Parents, foster care parents or legal guardians of children with a confirmed diagnosis of neurodevelopmental disability aged between 1–15 years old who received treatment at the Neurodevelopmental Outpatient Clinic at TAH.
- Signed informed consent by the parent/guardian to participate in the study.

3.4.2 Exclusion criteria

- Parents/guardians who chose not to sign informed consent.

3.4.3 Sampling and participants

3.4.3.1 Sampling

The researcher used purposive sampling to recruit 11 participants, the parents of 10 children, who received treatment at the Neurodevelopmental Outpatient Clinic during the study period. The participants were chosen because of their ability to provide information needed to address the aims and objectives of the study (Strydom, 2005). Participants were identified with the assistance of Dr. Springer at the Neurodevelopmental Clinic at TAH. Two of the 11 participants were known to the researcher. The other nine were known to Dr. Springer who indicated that they would be able to supply rich information on the topic under study.

To ensure maximum variability, the parents sampled represented the whole spectrum of parents of children seen at the Neurodevelopmental Outpatient Clinic.

The sample included parents of children with different neurodevelopmental disabilities, parents from different socio-economic and cultural backgrounds, different age groups, education levels and employment status. Finally the children's medical status and age differed.

Dr. Springer provided the researcher with the medical folders of the 10 children. The researcher made contact with the Neurodevelopmental Outpatient Clinic staff to introduce the study. They assisted the researcher in determining the next scheduled appointment for each child. The researcher was present at the clinic on these days. As described under Section 3.7, the researcher arranged meetings to introduce the study to the relevant parent, to obtain their consent, and to conduct the interviews.

3.4.3.2 Participants

The participants in this study were 11 parents (10 mothers and 1 father), of 10 children diagnosed with neurodevelopmental disabilities. They lived in the Cape Town area of the Western Cape, South Africa. One couple (father and mother) were interviewed jointly in a single session.

3.5 INSTRUMENTS USED TO COLLECT STUDY DATA

3.5.1 Interview guide schedule for audio tape recording

An interview schedule (see Appendix 4) was used to collect data from the study participants. It consisted of semi-structured questions and was developed by the researcher according to the practical guidelines on the development of interview schedules to collect qualitative data by Mji, Melling-Williams, Mclaren and Chappell (2009). The main topics covered in the interview schedule were:

1. Tell me about your life as a parent with a child with disability?
2. How does the child's disability influence your life?
3. What are your psychosocial needs and how are they addressed?
4. What are your experiences of respite care services?
5. What are your current experiences of counselling services?
6. What are your suggestions to improve counselling services?

3.5.2 Socio-economic demographic data sheet of the parents

The researcher designed a demographic data sheet (see Appendix 2) to collect demographic data from the parents. It contained questions on age, gender, ethnicity, marital status, and level of education, employment status, source of income, and whether the parents rented or owned property.

3.5.3 Demographic data sheet of the child

The researcher designed a demographic data sheet for the child (see Appendix 3). It contained questions regarding demographic details and medical status of the child such as age, gender, ethnicity, and diagnosis.

3.5.4 Identification details code list

The researcher designed an ID code list for the study participants. It comprised of personal information such as name and surname, child's name, home address and telephone numbers, and the date participants enrolled in the study.

3.6 PILOT STUDY

In April 2011 the researcher conducted a pilot study, aimed at evaluating the methodology of the study, with two participants who were not included in the main study. These participants were randomly selected from the Neurodevelopmental Outpatient Clinic. It focused on the semi-structured questionnaire and the socio-economic data measurement tool. The researcher discovered that some parents did not see children with learning disabilities as disabled, but as children with special needs. There was also a lack of information gathering regarding respite care for parents, as the researcher was not aware of this need. The tools were changed accordingly.

The tools were then presented to Dr. Springer, senior neurologist at the Neurodevelopmental Outpatient Clinic. She was asked to comment on the content validity of the tools to enhance them further. She suggested that the researcher should use the wording "neurodevelopmental disability" to describe a "child with special needs", as perceptions of disabilities differ and it is an evolving concept, since most parents are sensitive about the term used to describe their child. A suggestion to include questions on respite care was also made, since most parents were not aware of the availability of such a service in communities. The researcher took one day to complete the pilot study. It took at least 60 minutes to complete the demographic forms and conduct the interview.

Data collected during the pilot study addressed the aims and objectives of the study.

3.7 DATA COLLECTION

Data collection started in April 2011 and was completed in July 2011. Dr. Springer provided the researcher with private office space at the Neurodevelopmental Outpatient Clinic to perform the interviews. This was done to ensure parents and children did not have to walk to the researcher's office, and to ensure privacy and prevent interruptions during interview sessions.

Data collection followed the following steps:

1. Information about the purpose of the study was explained to participants, why they were chosen to participate in the study and the researcher answered any questions they had.
2. If they were still happy to participate, they were asked to sign the consent form (Appendix 1). Consent was also asked to audio tape interviews.
3. Following this the socio-economic demographic data sheet (Appendix 2) of the parents was completed.
4. The child's personal and medical information was collected from the medical folders to complete the demographic data sheet (Appendix 3) of the child. Only the child's gender, age, and ethnicity information was verified with the parents.
5. The Identification (ID) details code list was completed from the medical folders of the participant's child and this was verified with the parents.

Once these administrative tasks were completed, the researcher conducted the individual interviews in Afrikaans, English or isiXhosa according to the language preference of participants. Since the researcher is not fluent in Afrikaans, a research assistant acted as a translator during the Afrikaans interviews. De Vos, Strydom, Fouche and Delport (2005) highlighted the danger in using translators who may fail to accurately communicate the effective meaning and expression of the participant.

To minimize this risk, the researcher provided training to the research assistant/translator on the purpose of the study, ethics and conducting interviews. In addition, the research assistant/translator was present as an observer during two interviews performed by the researcher before the research assistant performed four interviews. The researcher was available to clarify any questions. The research assistant was an employee of the Desmond Tutu TB Centre and had prior research experience including data collection, obtaining informed consent and performing interviews.

Interviews were recorded on an audio tape recorder. During the interviews the researcher provided participants the opportunity to talk freely and elaborate on issues as they wished to gather valuable data.

Two participants did not complete the interview at the study site. Therefore, the researcher completed these interviews after hours via telephone. Short notes were made during these telephonic conversations.

3.8 DATA ANALYSIS

The study consisted of qualitative data that the researched analysed thematically. To familiarise herself with the data, the researcher listened repeatedly to the audio tapes, and then personally transcribed all except the Afrikaans interviews. The research assistant transcribed the Afrikaans interviews and translated them into English. According to De Vos (2005) generating categories and themes in the data is the most difficult phase of data analysis. During this phase of the analytic process, the researcher identified emerging themes which she then broke down into categories, through content analysis of the interviews which recorded participants' perceptions and experiences (see Table 4.4). Interviews were numbered by each participant. Transcriptions were then coded to highlight similar words or phrases that were mentioned by different participants.

3.9 RIGOR OF THE STUDY PROCEDURES

The following strategies were used to ensure rigor:

- Piloting the interview schedules and socio-economic demographic data forms. In addition, content validity was verified by a peer reviewer who is a neurology specialist and employed at the Neurodevelopmental Outpatient Clinic.

- A peer reviewer who has extensive qualitative research experience ensured that qualitative data were accurately transcribed from the audio tape recordings. This person did not assist with the analysis of the study data.

3.10 ETHICAL CONSIDERATIONS

3.10.1 Approval

The study protocol was submitted for approval to the Health Research Ethics Committee at Stellenbosch University in November 2010; it was approved in February 2011 and permission was granted to conduct the research (Appendix 5). An Ethics reference number (N10/11/371) was granted for the approval of the study.

Once this approval had been obtained, in February 2011 the study protocol was submitted for approval to the Provincial Health Research Ethics Committee of the Department of Health, and to the Chief Director of Tygerberg Academic Hospital. The study protocol was approved on 1 April 2011 and permission was granted to conduct the study at TAH (Appendix 6).

3.10.2 Informed consent

The researcher provided detailed information to the participants about the purpose of the study and why they had been chosen to participate in the study. They were given an information leaflet and an informed consent form in the language of their choice (Afrikaans, English or isiXhosa), which explained the study in detail (Appendix 1). The participants were given the opportunity to ask questions. If they agreed to participate in the study, they were asked to sign the consent form. The researcher explained the study and obtained written consent obtained from English- and Xhosa-speaking participants. A trained research assistant obtained written consent from Afrikaans-speaking participants since the researcher is not fluent in Afrikaans**.**

3.10.3 Nature of participation

Participation in this research study was voluntary. Participants had the right to withdraw from the study at any time and withdrawal or refusal to participate did not affect his/her child's healthcare at TAH in any way.

3.10.4 Confidentiality

All information was kept confidential. This included data collection in a private and friendly environment using one of the offices at the Neurodevelopmental Outpatient Clinic, anonymous coding of audio tape recordings, and analysing data. An ID code list with participants' information was stored separately from data sheets. The ID code list was not to be used for study findings, but simply to keep a record of the enrolled participants. It was stored on the researcher's computer and was password protected. Data was stored electronically on a computer's external hard drive which was password protected. The study information was only accessible to the researcher and the person who checked the accuracy of the transcriptions.

3.10.5 Payment

Participants were not paid to participate in the study. However, transportation money was provided for the study visit, if necessary.

3.10.6 Usage of data from participants

The researcher explained, and requested permission from participants, that direct quotes of the data would be used in the presentation of results. The researcher also explained that results from the study would be presented at conferences and in publications and journals.

3.10.7 Actions should there be a need

Emotional reactions occurred during the interviews. After completion of the interviews participants were referred to the neurologists at the Outpatient Clinic. With the permission of the participants, they were then referred to support groups and social workers in the community.

3.11 CHAPTER SUMMARY

This chapter has outlined the research design and methodology applied to gather information and analyse data. The following chapter will describe the study findings in detail.

CHAPTER 4: RESULTS AND DISCUSSION

4.1 INTRODUCTION

The results of the study are depicted and discussed in this chapter according to the objectives of the study. It also includes the demographic profiles of parents and the children with neurodevelopmental disabilities. The qualitative data are presented as emerging themes that were identified from the semi-structured interviews and were broken down into categories. These themes were based on the experiences and perceptions of the study participants as explored during the study. The emerging themes focused on the objectives of the study.

4.2 SOCIO-DEMOGRAPHIC PROFILE OF PARENTS

With regard to gender, one male and 10 females participated in the study. The parents' ages ranged from 20–57 years old. The mean age of parents was 31.3 years. As indicated in Table 4.1 the majority (seven) of parents was between 18 and 29 years of age and three were older than 40 years.

4.2.1 Demographic details of parents

Table 4.1 Gender, age, ethnicity, home language, and marital status of parents (n=11)

Gender	
Male	1
Female	10
Age	
18-29	7
30-39	1
40+	3
Ethnicity	
African	2
Coloured	8
Zimbabwean	1
Home language	
Afrikaans	7
English	1
Xhosa	2
Ndebele	1
Marital Status	
Single	4
Married	7
Divorced	0
Widowed	0

The largest ethnic group of participants was Coloured (8), the other participants being Black African (3), one of whom was a Zimbabwean citizen. The Cape Town area of the Western Cape Province is historically known to be a Coloured area. According to the Provincial Government of the Western Cape (2009), the estimated population figures for Cape Town in 2007 by ethnic group were Coloureds (47%), Black African (38%), White (15%) and Asian (less than 1%). Afrikaans was the mother tongue of seven participants, isiXhosa of two, English of one and Ndebele of one, as indicated in Table 4.1.

Seven participants in the study were married, and four were single mothers. The number of single mothers is concerning because fathers were absent from the children's lives. These fathers did not contribute financially or emotionally and provided no psychosocial support to the well-being of the children and the mothers who care for the children. Being a single parent is a very common occurrence in South Africa: Ellis and Adams (2009) state that almost half of the families in this country are single-parent families. Usually a woman, often a mother or grandmother, is at the helm of these families.

4.2.2 Employment status of parents

Only one parent was employed, and in only in a part-time capacity. The other 10 parents were unemployed.

4.2.3 Level of education

Figure 4.1 (next page) shows that the majority (10) of the parents had completed different grades in high school. All participants had some degree of education, but none had been to tertiary institutions, such as college or university.

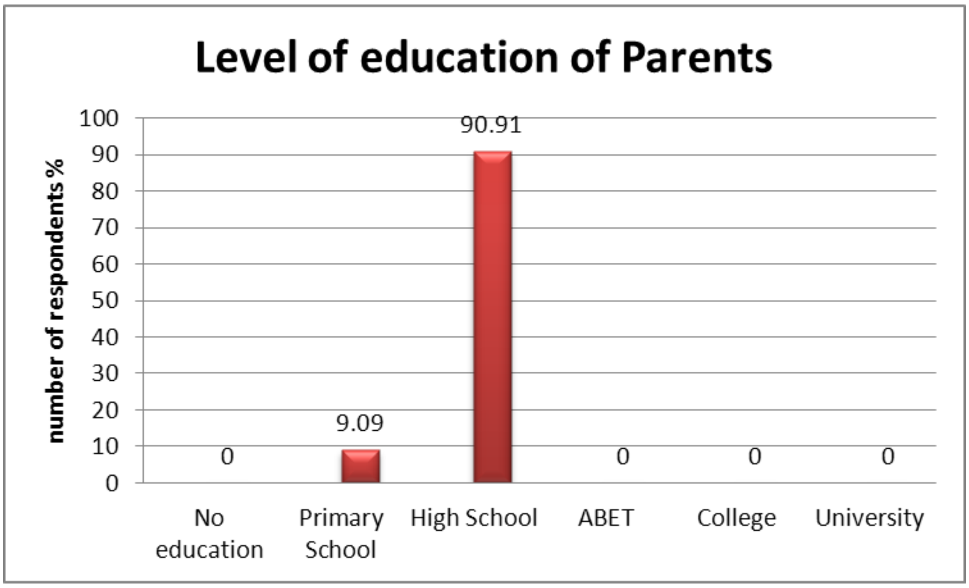

Figure 4.1 Level of education of parents

4.2.4 Accommodation

4.2.4.1 Types of accommodation

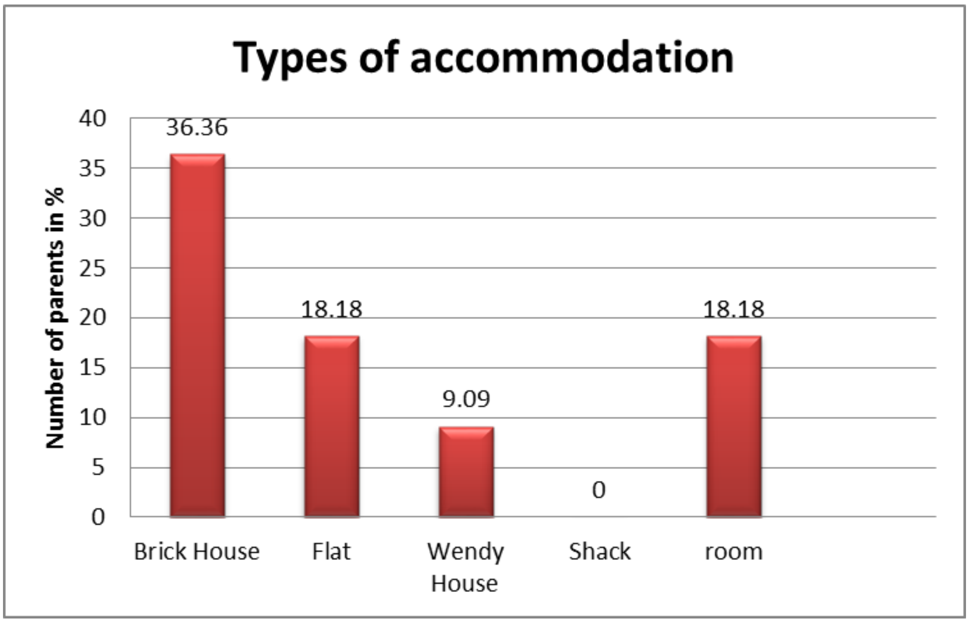

Figure 4.2 Types of accommodation

Figure 4.2 shows the type of dwellings the families lived in. The majority **(**six) lived in a formal brick house. These parents had running tap water, electricity and a toilet inside the house. The two parents who lived in a flat both had running water, toilet facilities and electricity inside the flat. The parent living in a Wendy house had no running tap water or toilet facilities inside the Wendy house. She filled buckets of water from the main house that had running tap water, and shared electricity and toilet facilities with the main house. This parent described the amenities:

> *I have a Wendy house at [the] back of my parents' house. My two children is staying with me. I only buy electricity for my parents' house, because we are sharing it. We also use the inside toilet, but in the evening we use a bucket to urinate, which is placed under the bed. I empty it in the morning. I don't want to wake up my parents in the evening if I want to use the toilet and I also don't have a key of the house if I want to use the toilet in the evening.*

A Wendy house is usually made of wood. In South Africa it is used as a form of accommodation usually indicative of low-socio economic status. This is an informal form of accommodation. It is usually built in the back yard of someone's property. This particular type of housing is very popular amongst the Coloured population in South Africa, as opposed to the African black population who live in "shacks" as a form of informal housing (Pinnacle, 2012).

The other two parents reported living in single rooms. They had electricity inside the room, but no running tap water or toilet facilities. They shared communal toilets and public running tap water outside the rooms. Single room accommodation is also commonly found in South Africa (Ellis and Adams, 2009).

4.2.4.2 Accommodation owned, rented or other

Two parents reported that they owned the property they lived in: one parent owned a house and the other a Wendy house. Five parents rented their accommodation. The four parents who indicated "Other" stayed with relatives. The most commonly mentioned relatives were the parents of the participants (see Figure 4.3).

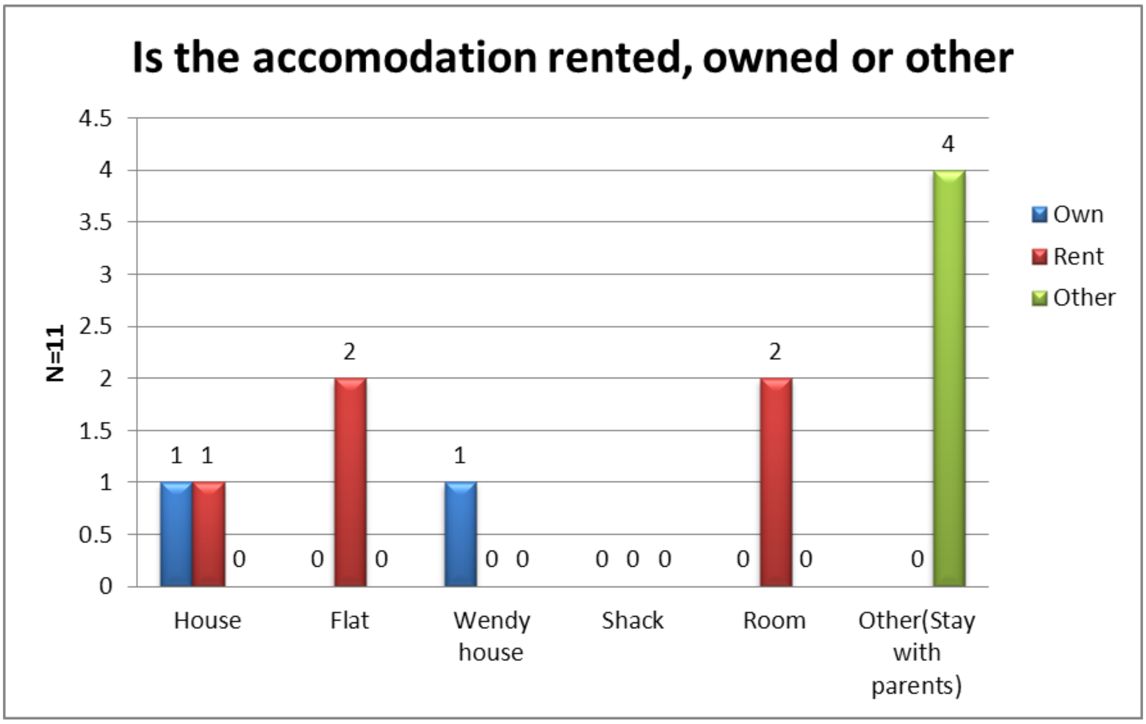

Figure 4.3 Accomodation owned, rented or other

4.3 DEMOGRAPGHIC PROFILE OF THE CHILDREN

4.3.1. Gender and age

Seven and three female children were included in the study.

Table 4.2 Summary of children's demographic information (n=10)

Child	Age of the child during the study	Gender of the Child	Child's age at diagnosis
Child 1	13 years	Female	24 months
Child 2	3 years	Male	1 year old
Child 3	1 year and 9 months	Male	12 months
Child 4	4 years	Male	12 months
Child 5	6 years	Male	12 months
Child 6	1 year and 4 months	Male	12 months
Child 7	14 years	Female	13 years
Child 8	3 years	Male	2 years
Child 9	4 years	Female	12 months
Child 10	5 years	Male	12 months

The age of the children varied from 21 months (1year and 9 months) to 14 years of age. The majority five (5) of the children were between 3 and 5 years of age. The mean age of the children was 5.5 years.

4.3.2 Medical status

Table 4.3 Neurodevelopmental disabilities diagnoses of the children (n=10)

Child	Medical status
Child no.1	Cerebral palsy with severe spastic quadriplegia and global development delay
Child no. 2	Cerebral palsy and epilepsy
Child no. 3	Cerebral palsy, epilepsy and severe global development delay
Child no. 4	Hemiplegia with basal ganglia infarction and epilepsy
Child no. 5	Cerebral palsy spastic diplegia and global developmental delay
Child no. 6	Intellectual disability and epilepsy
Child no. 7	Congenital hydrocephalus and cerebral palsy with severe spastic quadriplegia
Child no. 8	Severe asphyxia, cerebral palsy, spastic quadriplegia and swallowing difficulty
Child no. 9	Congenital macrocephaly, cerebral palsy, epilepsy and global developmental delay
Child no. 10	Dystonic cerebral palsy, epilepsy and global development delay

Table 4.3 presents the medical status of study participants' children. These children had multiple impairments that led to severe disability. For example, Child no. 9 presents with congenital macrocephaly, CP, epilepsy and global developmental delay. World Health Organization statistics indicate that 10 per cent of children live with some form of neurodevelopmental disability (Department of Health, 2002). A community-based study conducted in Kwazulu-Natal indicated the prevalence of epilepsy in 7 per 1 000 children; 70 per cent of these children have neuro-developmental disabilities. It was also found that the occurrence of CP was 3 per 1 000 children (Kromberg, Christianson, Mange, Zwane, 1997). The occurrence of severe conditions in the current study might be due to the fact that TAH is a tertiary referral centre and is thus accessed by patients who cannot be managed in the community or at district level. It can be expected that the severity of the impairments and resultant disability had a major impact on the parents, since in most instances these children will require constant care for all basic needs such as feeding, toileting, dressing and mobility.

4.4 THEMES IDENTIFIED FROM THE INTERVIEWS

Emerging themes were identified from the interviews, which was based on the participants' perceptions and experiences that were explored in the study. These themes were broken into various categories and are presented in Table 4.4.

Table 4.4 Themes and categories identified from the data

Themes	Categories
Emotions	Shock Guilt Grief Acceptance
Parents life and relationships	Impact on the parent Impact on marital relationship Financial strain
Lack of support systems to deal with the pressure of caregiving	Lack of family support Lack of knowledge on respite care services
Social Workers	Lack of interaction with social workers
Challenges with compliance with healthcare provision	Taxing
Gaps identified	Parent support groups Counselling for parents

4.4.1 Emotions

All parents in the study went through many emotions with regard to the child having a neurodevelopmental disability. The emotions mainly experienced by parents were shock, guilt, grief, and acceptance.

4.4.1.1 Shock

The majority (10) of the parents indicated that they were shocked when the doctor informed them that their child had neurodevelopmental disabilities. They realised that the child's development milestones would not be the same as for other children who aren't affected by neurodevelopmental disabilities. One of the mothers explained her experience:

> *My daughter was diagnosed with CP at age of two years. The doctor told my husband and I that our daughter's brain is damaged [which] affects her body development and she won't be normal as any other children at her age that can talk, walk or eat by themselves. It was big shock to us. Everything during the pregnancy was fine. I never expected that our first child will be like this. It is really a big shock.*

It seems that having had a normal pregnancy increased this mother's shock since nothing prepared her to expect that something might be amiss with the child.

Another mother also explained her experience:

> *At the age of 13 years, my child always gets regular fits [convulsions]. The nurse at the clinic refers us to Tygerberg Hospital; the doctor told us that she has a learning disability and epilepsy. I sometimes realised that she was struggling to read and she always repeat twice one grade. I thought she was just being lazy and don't want to read at all. It was a big shock. I never realise that she has learning disabilities. She did all normal things such as playing and talking at a very young age. To find out that she isn't at all, it was a shock.*

This participant thought her daughter had no difficulties with learning, even though the child repeated grades, but "suddenly" she realised her daughter struggled to read. In addition, her daughter had spoken at a very young age. It seems from the quote that she could have experienced some denial and shock, and blamed poor school progress on laziness rather than cognitive problems. Ockerman (2001) stated that shock is the first reaction of parents after hearing the news that their children have neurodevelopmental disabilities. Shock becomes denial. Lessing and Strydom (2001) differentiate four common forms of denial:

1. Refusal to recognise the child's disability;
2. Rationalise the child's disability (as the mother above did, by explaining the poor school progress as 'laziness' rather than considering an impairment);
3. Seek healthcare professional's confirmation that there is nothing wrong with the child; and
4. Quickly become too cooperative with healthcare professionals.

4.4.1.2 Guilt

During the interviews, some mothers expressed guilt in relation to being responsible for the child's disability. They thought it was caused by something that they did, or that they could have done more to prevent it:

> *I feel guilty for my son's disability. I was 17 years old when I found out I was pregnant. His father died when I was four months pregnant. I drank poison, because I could not accept his father's death and I was young and still at school. I think the poison affected my child during the pregnancy. I'll always blame myself for his disability. If I didn't drink the poison then my child would probably be normal today. Today he has CP and difficulties in swallowing food, and epilepsy. The doctor told*

> *me has some other disabilities as well, but with these big names, I can't remember it all.*

Another mother said:

> *Maybe I did not give enough attention to my child's learning problem. Help her with her schoolwork. If I did, she won't have learning disability today, but you didn't really know.*

Both these quotes also indicate that the parents have not stopped blaming themselves. Counselling might be able to assist them to face these issues of guilt and move on from it. Niedecken (2003) stated that parents blame and feel responsible for their children's neurodevelopmental disabilities.

4.4.1.3 Grief

Some parents expressed grief about their children's disabilities. Sometimes the child's disability is expressed as sorrow by the mother for the discomfort that the child experienced. One mother expressed her sorrow as heart breaking:

> *It is heart breaking to see my five-year-old child cannot eat normal solid food that we eat, since he has swallowing difficulties. He sometimes vomits the food out. He can't even hold a toy in his hand. Most of the day we spend in the bedroom. Let him lay on the bed. It is even more heart breaking to see that my child will never play with other children.*

They also experience sadness. One parent expressed her feelings of sadness in relation to her child's disability:

> *Before I cried almost every day and I ask God what did I do wrong to deserve such a child. When the doctor told us she has severe brain damage then I realised my child won't become normal as other children and do activities on her own. She is 14 years old, but she looks like a five-year-old child.*

This mother also experienced a sense of loss about what her child will never be able to do. Ferguson (2002) stated that grief experienced by parents of children with neurodevelopmental disabilities can become permanent and it is an understanding of how the parents' lives are different from those families who have children without disabilities. These parents have the right to grieve about their children.

4.4.1.4 Acceptance

During the interviews, one of the mothers expressed some form of acceptance in relation to her child's disability and focused on a future for the child:

> *In the beginning, it was very difficult to accept my daughter with cerebral palsy, but as time go on we are getting use to her. The best was to accept her disability and ensure we took good care of her. Even the doctor told us, is not the end of the world to have a child with a disability.*

Another mother of a child with a learning disability decided to focus on her daughter's strengths:

> *I would like to support my child on the things that she are currently doing. She is very creative with her hands, such as baking. I think she will become a good baker one day.*

Another mother viewed her child (with learning disabilities and epilepsy) as part of the family just as her other children were part of the family. She said her child with learning disabilities has the same rights as any other child without disabilities.

Lerner and Kline (2006) stated that acceptance is an important stage. Parents must accept their child with disabilities along with their special needs, while continuing to live a normal life. Research also indicates that after parents developed knowledge about their children's neurodevelopmental disability, they began the process of acceptance; and searched for and engaged with support systems to help them deal with the current problems (Walton, 1993; Davis, 1993; Siklos & Kerns, 2006).

Day-to-day living changes when disability is presented in a family structure. Parents therefore cannot continue to live a "normal life". Acceptance includes accepting the changed way of living. Parents do not accept their child's disability; they learn to live with it. At most, they make peace with the disability (Walton, 1993; Davis, 1993; Siklos & Kerns, 2006).

4.4.2 Parents' life and relationships

Having a child with neurodevelopmental disabilities affected the parents and the family units in many ways. From this theme, the following categories were identified.

4.4.2.1 Impact on the parent

Parents indicated they experienced financial and personal challenges and sacrifices. They had no time for their own needs, found the care-taking process tiring and struggled to balance household and caring responsibilities.

> *Seriously [to] have a child with cerebral palsy with other complicated disabilities put a lot of financial pressure, time consuming and tiring. It seems like my life is only rotate around him. I don't even have time for my own needs.*
>
> *I am not hiding him from anybody, but don't want people to see me crying all the time, when they ask about his disability.*
>
> *Taking care of her 24/7 is tiring and I don't have time for [my] own needs. Being a housewife is more difficult, because my husband [expects] me to clean the house, cook and doing laundry.*

Research studies found that parents of children with neurodevelopmental disabilities, for example CP, are more likely to experience high levels of stress due to the child's sensory and intellectual impairments and limitations in self-care functions. As a result of the complex limitations, children with CP may require long-term care from parents, which can be a burden and may impact on the family functioning (Raina et al., 2004; Majenemer et al., 2012).

Another mother whose child has severe asphyxia, CP with spastic quadriplegia, and swallowing difficulties, expressed her feelings:

> *Sometimes when I think about my life it is a nightmare, especially to have a child with complicated disabilities. I can't even go back to school at all to complete my grade 11.*

Rörich (2008) stated that parents may feel that disability is a large-scale problem for them. Therefore, it can also put constraints on relationships and careers of the parents. These problems also can negatively influence the parent’s future as shown in the above quote (Sperry and Duff, 2002).

A counsellor or social worker should assist parents with their decisions, which may influence the entire family unit (Sperry and Duffy, 2002). Hudson et al. (2003) provide a list of perceived needs of families in dealing with children with disabilities and their challenges:

- assist parents to establish structure in the home environment;
- assist in dealing with stress;
- provide respite care; and
- assist parents to engage in advocacy.

4.4.2.2 Impact on marital relationship

It was evident in the interviews that a child with neurodevelopmental disabilities puts strain on the parent’s relationship with their partners. One mother explained her child (who has CP with severe spastic quadriplegia and global developmental delays) had put strain on the marriage, due to difficulties of raising a child with neuro-developmental disabilities. She believed she didn’t spend enough time with her husband since she always had to give her attention to her daughter.

> *My husband doesn’t understand when I say I am tired and I want to rest in the evening. I am taking care of my daughter every day and even in the evening. I am the only one who takes her to her hospital appointments. Sometimes she gets unexpected fits. It’s very difficult. I do feel guilty that I don’t give him much attention, but I don’t have a choice.*

The Balfour (2007) study found that having a child with neurodevelopmental disabilities can put severe stress on the marital relationship. The marriage could be pulled apart due to strain and resentment by the husband.

4.4.2.3 Financial strain and poverty

In the study, it was found that a child with neurodevelopmental disabilities required extra financial resources, than a child without disabilities. Some parents indicated they struggled on a monthly basis to provide the basic needs of the child. The state

Care Dependency Grant (CDG) of R1 140 (at the time of the study) does not last for the entire month until the following payday and non-South African citizens do not receive state grants.

> *To take care of a child with CP is most expensive. The child needs special food, nappies, clothes and additional medication, like Panado. I do not even receive government grant for my child, since I am non-South African citizen … Financially a huge burden, financially I am not coping at all.*

Children with complex neurodevelopmental disabilities may need extra medication, equipment or transportation money to attend to hospital appointments (Ellis & Adams, 2009). These extra costs put financial strain on parents who are already struggling to make ends meet.

Unemployment is often the main cause of an inability to maintain the basic needs of the family unit (Ellis & Adams, 2009). During the interviews, one parent stated the reason for being unemployed is to take care of the child with neurodevelopmental disabilities. According to parental perceptions, a child with neurodevelopmental disabilities, especially with CP, needs a mother's substantial care and attention 24 hours per day. It seems as if some of them believe a child with complex disabilities cannot be taken care of by other people in the society, because it is only the mother's responsibility.

> *When the doctor told me my child's brain is damaged and she will not be normal as other children when she grow up, which means she won't be eating, dressing, and playing on her own. I don't have a choice not to work anymore, but to take of care her. I worked before my child got sick. I can't let someone take care of her.*

The other nine parents stated the reasons for unemployment were not the children's disability, but rather a struggle through generations against poverty.

> *I can't find a job, because I didn't complete high school. My parents couldn't afford my school fees and that's why I drop out of school (grade 8). As a child we struggled a lot. Now I have a child with complex disabilities, which need more money to support. I am single mother, which make my circumstances even more worse. At least I am getting the disability grant for my son, but it doesn't last the whole month.*

Another married parent expressed his feelings about unemployment due to poverty:

> *Work is very scarce in Cape Town, especially if you don't have skills and grade 12. No one will hire me, so life is very tough for me. I am married and as a man, I am supposed to provide for my family (wife and child). We are living with my parents. Can you see we are struggling? The grant is only covered for my child's needs.*

Even though poverty in South Africa is not confined to one racial group, it is more common in the Black and Coloured populations. The poorest South Africans tend to be women and single parent households. (Republic of South Africa, 2004).

Ellis and Adams (2009) reiterated the impact of poverty on families, with a spectrum of challenges that relate to socio-political and economic forces, such as family structure and family disintegration, poverty and migration, disabilities, HIV and Acquired Immune Deficiency Syndrome (AIDS) and globalisation.

It was noted during interviews that 10 parents (90.91%) indicated they received a CDG of R1 140 per month because their children had permanent and severe disabilities and required permanent care. This was their only source of income. Grants are administered by the South African Social Security Agency (SASSA) and are only available to South African citizens (SASSA, 2011). Therefore the Zimbabwean mother's child did not qualify for the CDG, because he was not a South African citizen. This mother expressed her disappointment at the South African government's policy for not qualifying for the CDG:

> *I asked the doctor before if I do qualify for the disability grant for my child. He told me I do qualify for disability grant for my child. He referred me to the social worker. The social worker told me I don't qualify for a disability grant for my child, since we are not South Africans. I decided to go the SASSA office in Kraaifontein to make sure if my child can't get this disability grant. The woman at the grant office told me I don't qualify, since I'm Zimbabwean. Only South Africans can get this grant for their children. I was very disappointment and sad that I can't apply for a grant, because of my nationality. My husband and I are struggling and you know we as Zimbabweans are poor. I don't work and my husband does 'piece jobs'. At least my child gets free medication at Tygerberg Hospital and the doctors are very helpful.*

This mother with her husband has migrated to South Africa for a better life, but they are struggling to make ends meet.

The CDG is intended to provide support to parents, primary caregivers or foster care parents of children with permanent and severe disabilities who require permanent care, until the age of 18. To qualify for a CDG, a child with severe disabilities needs to be assessed by a medical doctor and a means test of total family income is applied (Ellis & Adams, 2009; Hall, 2012). In 2011, the means test for a CDG stated that the joint income for married couples should be less than R22 800 per month or R273 600 per year; a single parent's annual income should be less than R11 400 per month or R136 800 per year. The income of foster care parents is not taken into consideration (SASSA, 2011).

To apply for a CDG parents should submit an application form at the nearest SASSA branch or at counter service points at a regional office (SASSA, 2011). At TAH the neurologist will complete the medical assessment of the child to obtain the CDG. The family is then referred to the social workers who assist with completion of the CDG documentation, and call the SASSA centre to process the application. This eliminates inconvenience and disappointments. Grant application forms must be accompanied by necessary support documentation, to be supplied by the parents. This documentation includes:

- A medical report from the doctor who assessed the child with severe disabilities. In this case it will be children with neurodevelopmental disabilities and the neurologist at the TAH Outpatient Clinic completes this form;
- The parents' South African identity documents;
- The child's birth certificate;
- Proof of marital status, such as marriage certificate; or divorce papers; or death certificate of spouse; or an affidavit if the parent was never married;
- Proof of family income (married) and
- Proof of maintenance paid by a father, if applicable.

Parents use the grant money to buy the child's necessities such as purified food (especially for children with swallowing difficulties), nappies, clothing, transport money to attend hospital appointments, and paying monthly rent. One parent illustrated how she was using the CDG:

> *I use the grant to buy baby food for my son, since he has difficulties to swallow normal food that I eat at home. He is five years old and still eat baby food and it is expensive otherwise the food will stuck in his throat. I am buying him nappies and clothes. I am also paying R350 rent per month at my parents, because my father told me I must pay rent since I am getting my son's grant's money. Although I am, I share a bedroom with two my other younger siblings. I don't work and his father died when I was four months pregnant. Sometimes the grant money doesn't last for the entire month. Life is very difficult.*

According to Hall (2012) The General Household Survey of 2010 revealed that in the Western Cape Province 30 per cent of children with severe disabilities and chronic illness live in low-income households. Children that receive CDGs need significant attention and caregiving.

According to Cosser (2005) disability is experienced as a financial burden. It was found that families of children with neurodevelopmental disabilities were significantly more economically disadvantaged then those who have children without any disabilities (Emerson, 2003). According to Hall (2012) children with chronic health conditions create financial burdens on families that are already struggling to survive on a daily basis. Therefore, parents who are struggling financially will have increased parental distress.

4.4.3 Lack of support systems to deal with pressures of caregiving

During the interviews it was indicated that there is lack of support systems for parents of children with neurodevelopmental disabilities. These parents experienced extreme burn-out and parental distress.

4.4.3.1 Lack of family support

Parents expressed a lack of family support. They felt very isolated and needed support from the family to assist them in taking care of the child with complex disabilities:

> *My parents don't physically support me with my son. Whenever I want to go the hospital for my child's appointment my dad refuse to take us to the hospital. We do have a car at a home. Then I can take his "buggy" [special wheelchair for children with cerebral palsy]. He always said it's my problem and I should deal with it, since I fall pregnant while I was at school. It's very difficult to take a taxi to the hospital especially when he is getting heavier to carry him on the back. Sometimes my dad will take my younger siblings for Sunday afternoon drive and when I asked him if my son can go with them, he will still say no … it's my problem I should deal with it… It's really hurtful to see my father's reactions towards me. (Parent cried.) My mother is too scared to help me to take care with my child then my father will shout at her. It makes me so angry that sometimes I wish to commit suicide with my son. The worst part of it I am paying rent at my own parents home. I am unemployed, but still have to use the child's grant money to pay rent.*

> *My mother doesn't help me to take care of my child. My son needs constant attention and sometimes as single parent you need an extra hand to help you. It's really frustrating and I always think maybe it's my punishment and I should deal with it on my own.*

> *No one at home wants to take care of him, especially my parents. They told me he is my problem.*

These comments indicate these mothers experienced no support from their parents, which increased their levels of parental distress.

Another mother also felt that her husband doesn't experience any emotions regarding the child's disabilities: "*My husband doesn't get emotional about our child's conditions…*" She wished he could also experience the same emotions that she experienced about their child.

The Zimbabwean mother voiced her frustration about her husband as not being supportive (he does not assist her in coping with their child's neurodevelopmental disabilities):

> *In our culture it is compulsory for a woman to be a stay-at-home mom and take care of the child and household … then my husband doesn't help me to take care of our child. He expects that I should do it on my own.*

Married couples experience conflict due to the frustration about the husbands not being as involved with children with neurodevelopmental disabilities as the wives. The wives feel they are dealing with the children's' situation alone (Balfour, 2007).

One of the married couples in the study stated that they supported each other and made decisions concerning their child together. They also viewed the demands of raising a child, who has hemiplegia with basal ganglia and infarction and epilepsy, as a shared experience. They acknowledged that the child's disability could cause some stress on marriages. Glass (2001) noted that spousal support plays a vital role in the stability of the family unit. Shared parental duties, regular spousal communication, mutual respect for one another and acknowledgement of each other's daily endeavours will assist in developing a supportive family unit.

Support from the immediate and extended family members is also important for parents of children with neurodevelopmental disabilities in assisting with reducing levels of parental distress. Daily these parents face extreme challenges in raising a child with neurodevelopmental disabilities who has complex needs, which will eventually exhaust them emotionally. Sadly, the findings of the current study showed that these participants' family members do not provide much support. This is disappointing. According to Wang and Brown (2009) family support systems within their home environment are very important to parents, to empower them and decrease financial, social, health and emotional burdens associated with parental distress. Therefore, family support systems can successfully improve and enhance the lives of the parents and the children with neurodevelopmental disabilities.

4.4.3.2 Respite care services

Parents indicated a severe lack of information about respite care services in the Cape Town area.

> *I didn't know that there are such services in the community. How do I get information about it? The doctors here at the hospital are too busy to refer us to such service.*

That there is a need of respite care is expressed by this mother who seems not to have high expectations of such service:

> *I wish there was a place where my child can be temporary taken care of for at least one day. I am so tired and no family members want to relieve me at all from my caring. I would be grateful if there is such service available at the Tygerberg Hospital.*

If respite care services were available they would give these parents the opportunity to take short breaks to rest, enabling them to continue care of their children without neglecting their own needs. As already mentioned, in Cape Town there are free respite care facilities for parents of children with disabilities, such as the Woodside Special Care Centre in Rondebosch East and Iris House Children's Hospice in the northern suburbs. It could also be that there are other respite care facilities within the surrounding areas unknown to the researcher.

These parents also indicated that there is a lack of in-home respite care support in the family. This is how a mother expressed her experience of burn-out and her husbands' negative support towards her:

> *My husband is at home on weekends and I sometimes want to go the salon and do my hair or just need some fresh air ... I am sometimes very tired to take care of my daughter. He doesn't allow me at all. He rather told me that he is working everyday (Monday to Friday) and he needs to rest on weekends. I don't have a choice but to stay at home.*

In-home respite care services may also reduce mothers' distress through improving her health, social, physical, and emotional situation. It is important that community home-based carers should provide training to family members in the familiar surroundings of their homes, which will give these family members the opportunity to observe and develop skills and knowledge, while interacting with their children. According to Chan and Sigafoos (2002) where in-home respite care service is provided, parents may develop positive attitudes toward caring for their children with neurodevelopmental disabilities.

4.4.4 The role of social workers

In the study, parents indicated they only interacted with social workers with regard to CDGs. They felt that the social workers could have provided them with support and guidance on how to sustain their own parental well-being while providing continuing care to a child with complex neurodevelopmental disabilities. They felt very disappointed in the social work services at the hospital. From this theme, the following categories were identified:

4.4.4.1 Lack of social workers' interactions with parents

Parents expressed disappointment in the social work services at the tertiary hospital and the wish that social workers had provided support to them as parents of children with neurodevelopmental disabilities. One parent (who has a child with CP with severe spastic quadriplegia and global development delay) shared her disappointment at the social work services at the hospital:

> *When the doctor diagnosed my child with severe brain damage at the age of two years and said she is disabled, he referred me to the social worker for grant application. She only assisted me with grant application for my daughter. No other support services I received from her. My daughter is 13 years old, and still I didn't see a social worker at all. Maybe social workers at the hospital are only providing support to patients and not parents. It is not easy to have child with multiple disabilities and I wanted to share my problems with a social worker to receive guidance to cope with it.*

Another parent, whose child has congenital macrocephaly, CP, epilepsy and global developmental delay, also expressed her disappointment with the social services at the hospital; she hoped social workers could assist parents in finding support groups within the community:

> *I expect that the social workers at the hospital should refer me to support groups in the community. When you have a child with complicated disabilities, you wish to have support from a social worker and from mothers who have children with the same conditions that my child has. It's not easy to have a child who needs continuous care from his mother.*

Another parent expected that the Neurodevelopmental Outpatient Clinic should have at least social worker service for parents' needs, especially during the children's hospital appointments:

> *Sometimes when the doctor asked me how I am doing? … Always saying I am fine, but deep down in my heart I'm not fine. It would be much better to see a social*

> *worker for my particular needs. Especially if you don't have a good support structure at home.*

Ellis and Adams (2009) reported a lack of social services amongst parents of children with disabilities and the need for the development of parental support groups and counselling. Findings from the current study supported their assertions. Support and counselling given to parents of children with neurodevelopmental disabilities will impact positively on the levels of parental distress. Regular social worker services to parents would assist in addressing the needs of parents and provide opportunities to identity problems parents may be experiencing in caring for a child with neurodevelopmental disabilities. They would also assist parents in developing their own coping mechanisms through allowing parents to analyse their problems, determine opportunities and formulate strategies of dealing with their life situation. According to Canary (2008) the major goal of the social worker is to reduce stress and depression, and assist the parents affected by the child's disability to strengthen their coping abilities and acceptance of their child's disability.

4.4.5 Challenges with complying with healthcare provision

4.4.5.1 Taxing

One mother felt the pressure of attending regular healthcare appointments:

> *I always have to take him to the day hospital for his regular occupational therapy appointments. I do not see any difference in his disability. Everything is still the same. The occupational therapist always expects me to do home exercises with my son.*

It is important that parents attend their children's healthcare appointments, but for a variety of reasons, including lack of counselling and support, parents felt frustrated. It could also be that the healthcare services do not focus on the parents' own needs as caregivers for the child and that the parent does not see an improvement in the child's abilities or quality of life. Given the complex nature of most of the disabilities the parents won't ever see an "improvement".

Sperry and Duffy (2002) stated that parents experience frustrations due to never-ending appointments with healthcare professionals. According to Ho and Keiley (2003) parents will sometimes refuse to allow professionals to provide alternative healthcare services to their children. This can result in children missing out on valuable early interventions. Rörich (2008) concurs that therapeutic interventions are of vital importance for the progress of the child. Thus it is advisable that healthcare professionals inform parents about the important purpose of different therapies and how they may assist the child's developmental stages. Hastings and Beck's (2004) findings conclude that healthcare professionals should create a model where a particular person who works closely with parents can mediate between them and healthcare professionals; this could lead to more positive outcomes for parents regarding their children's disabilities. It is important to involve parents in the therapeutic care and set treatment goals in consultation with them.

4.4.6 Gaps in support and counselling services

During interviews parents indicated further gaps in the services provided at TAH. They mentioned the lack of a support group for parents, and counselling sessions.

4.4.6.1 Parent support groups

Mothers identified this as a lack of support for parents. They considered starting a parent support group with the assistance of a social worker at TAH. They felt that mothers sometimes needed to share the experiences of fear, guilt, anger and hope, and what is hard for them to deal with their children's disabilities.

A parental support group will provide an opportunity for parents to interact with each other and share with others in the same situation their experiences, fears and frustrations in caring for a child with neurodevelopmental disabilities. The support group could assist meeting needs of parents such as social and emotional support, information sharing, and advocacy for better counselling services within the hospital setting. It would also assist in reducing family distress and isolation and in providing assistance regarding coping abilities. These benefits are noted by Davis and Spurr (2000) who report parents gain more information and understanding of their child with a neurodevelopmental disability, information about available resources within their communities and practical management strategies.

King et.al. (2004) state that parents should be empowered through advocacy to become involved in activities such as lobbying for government funding to aid the support groups and addressing environmental barriers. This would give them the opportunity to gain control over circumstances they are experiencing and they could become active social change agents for their children. One parent in this study demonstrated this potential: she could be a strong leader for others as she indicated that her child with disabilities had the same rights as other children.

There is a severe lack of parental support groups at a hospital level. Even though there are a number of community-based organisations that provide services, they are not represented at the hospital level. In the Western Cape, family-centred services for parents of children with disabilities are provided by well-know organisations such as Western Cape Cerebral Palsy Association, Autism Western Cape, Cape Mental Health, Epilepsy South Africa, and the Western Cape Forum for Intellectual Disability. In the study the majority of participants have children diagnosed with CP and epilepsy, and these organisations provide needed services to parents who experience parental distress. The researcher supports the parents' suggestion that TAH should at least establish a parental support group around managing children diagnosed with complex disabilities as it could provide much needed information, skills, knowledge and emotional support, as voiced by the parents in this study.

4.4.6.2 Counselling services for parents

This challenge was exposed earlier under the discussion of social worker service provision and is further explored here. Currently the social work services provided for parents by social workers at the Neurodevelopmental Outpatient Clinic mainly focuses on social grant applications. Parents shared experiences of lack of coping abilities due to the severity of problems that are present in their lives. They are in need of counselling as the pressure of caregiving is becoming overwhelming.

Given, as discussed in the literature review, that a positive effect of counselling on parents has positive effects on the psyche of the child with neurodevelopmental disabilities, the researcher strongly believes that counselling services at hospital level would greatly benefit these parents and that these counselling services should be conducted during their children's hospital appointment day. This is supported by what parents said about wanting to see a social worker.

4.5 CHAPTER SUMMARY

The socio-demographic profile of the study participants showed most parents were between 18 and 29 years old. The majority of parents were Coloured, Afrikaans-speakers. Participants were mainly mothers. Only one 24-year-old father who was part of married couple (father and mother) was interviewed. Ten parents were unemployed and were dependent on government financial assistance in the form of a CDG. Only a Zimbabwean mother did not receive any financial assistance and she was experiencing a very heavy financial burden. It was indicated by the findings that caring for a child with neurodevelopmental disabilities requires more financial resources and parents experienced extreme financial hardships.

The study found that children with neurodevelopmental disabilities have a serious impact on family life and marital relationships. Lack of both informal support and of support from family members was found during the course of the study. Parents felt very isolated and needed support to assist in caring for a child with multiple disabilities.

Parents expressed their disappointment at the lack of social worker services at the hospital, which only focused on social assistance (grant applications) and patient healthcare services, and did not deal with the needs of the parents. Because parents see a number of different professionals (neurologists, doctors, nurses, social workers, physiotherapists, occupational therapists, radiologists) it would be useful if these professionals were able to inform them about community resources. From this one can infer that parents are looking for counselling and/or therapy services.

CHAPTER 5: CONCLUSION AND RECOMMODATIONS

5.1 CONCLUSION

The aim of the study was to determine the role that psychosocial counselling at TAH plays in the lives of parents of children with neurodevelopmental disabilities. Findings revealed no counselling services at TAH per se, but only social work support for applying for social assistance grants. There was also no indication that any other member of the multi-disciplinary team parents engaged with gave any formal counselling. Participants found this lack disappointing and it can be inferred that it is a shortcoming in the healthcare management of the Neurodevelopmental Outpatient Clinic at Tygerberg Academic Hospital.

Findings also indicated that having children with neurodevelopmental disabilities had a major impact on parental well-being. Parents felt very isolated and needed support systems to assist with continued caregiving of a child with neurodevelopmental disabilities.

An additional challenge was financial in nature. Poverty and unemployment negatively impacted on the well-being of both the parents and the child with neurodevelopmental disability. The strain was alleviated to an extent by Care Dependency Grants (CDGs). South African social security regulations exclude non-South African citizens from applying for social security. This left a Zimbabwean mother without financial resources to provide for her child's basic needs.

The presence of a child with neurodevelopmental disabilities created significant stress on normal family functioning. The child's disabilities also strained parents' social relationships and careers. Children with neurodevelopmental disabilities required long-term caregiving from parents and parents had to make several sacrifices to accommodate their child. It was also indicated that some parents were frustrated by attending multiple appointments with healthcare providers. In some families a child with neurodevelopmental disabilities put strain on the marriage. Some mothers experienced conflict due to frustrations directed at husbands not being involved in caring for the child with neurodevelopmental disabilities, and lack of support to them in their caregiving role. In some cases husbands were actively obstructive. In other families, both parents supported each other and made decisions regarding their child’s disabilities. Parents felt physically and emotionally isolated, physically and mentally burnt out and in much need of informal and formal support systems to deal with parental distress. In this regard they experienced a lack of in-home respite care support from their immediate family members. They also expressed lack of information about respite care services in the communities. They felt that medical staff should inform them about respite care facilities in the surrounding Cape Town area.

The study identified lack of counselling services at TAH and parent support groups as gaps. The mothers felt they sometimes needed to share experiences of emotions, such as fear, frustrations, guilt, anger, acceptance and hope in dealing with a child with complex disabilities. The interviews gave parents just such an opportunity to express their perceptions, experiences and needs. From the parent responses and based on her research, the researcher believes formal counselling services offered at TAH would be highly beneficial to these parents. Parents should also be empowered with information about the support services available to them provided by a variety of community-based organisations, including centre- and home-based respite care opportunities and support groups in the Cape Town environs operating around a number of neurodevelopmental disabilities.

5.2 RECOMMONDATIONS ON SUPPORT SERVICES

5.2.1 Parent support groups

Parent support groups can be established by parents from different socio economic backgrounds that they would lead themselves, as self-help groups. The self-help group will empower and encourage parents to deal with aspects of their children’s neurodevelopmental disability and as well as with family functioning. Empowerment will also give parents the opportunity to gain management over circumstances in their lives. It will also help them to develop a greater sense of self-efficacy with great value for parenting their children with complex disabilities. Such self-help groups can focus on parent-to-parent support, information sharing and advocacy for better services in general. Parents will have the opportunity interact with other parents, to share and discuss their difficulties and psychosocial needs, coping strategies and gain information and knowledge on the children’s disabilities. They may also gain emotional support in addition to that available from their family, to reduce their sense of isolation. Immediate (husbands and siblings) and extended family (grandparents, aunts and uncles) members may also benefit from the support group through gaining knowledge of and insight into shared child caregiving responsibilities.

5.2.2 Counselling

"I need someone to share my problems with…" This plea for support, which could include counselling, comes from a mother who participated in the study. Counselling is of significant benefit to parents and families caring for a child with complex disabilities (Davis and Spurr, 2000) and is vitally important to the psychosocial functioning of the family unit. The researcher recommends that counselling services at the healthcare setting should focus on the psychosocial needs of the parent and not only the needs of the patient (child) who has neurodevelopmental disabilities. The hospital social workers could render these services to parents of children with neurodevelopmental disabilities. Counselling should focus on maternal self-esteem, parenting stress, guilt, anxiety and depression, relationship within the family and social support, amongst other things. Counselling could assist with adapting to difficulties in caring for children with neurodevelopmental disabilities. It could also provide emotional and informational support which is required to assist parents to come to terms with the child's disabilities. The stresses of the parents would be decreased if counselling services are in place.

It is recommended that parents are routinely referred to social workers for counselling services.

5.2.3 Respite care service

5.2.3.1 Formal respite care

Regular respite care services for parents are beneficial to promote healthy psychosocial functioning of the family unit and for prevention of parental burn-out. Currently, the researcher is aware of only two respite care facilities in the Cape Town area, as discussed in Chapter 2. The multidisciplinary professional team should inform parents about these facilities. It is likely there are insufficient respite care facilities in the Cape Town area, but this needs further exploration.

5.2.3.2 In-house respite care services

It is further recommended that home-based caregivers are provided with the skills to assist in training family members to provided in-home respite care. By observing the carers, parents (and family members) from different socio-economic backgrounds could enhance their skills and increase their knowledge of how best to interact with the child with neurodevelopmental disabilities. The home-based caregivers can look after the child for short periods to give parents time out for activities such as shopping or leisure pursuits. More research is needed into how to set up such programmes, what training the respite carers need, and how to maintain confidentiality and build trust.

5.2.4 Professional support in the community

Continuing support from healthcare service providers in the community is vitally important to the well-being of the parents. Social workers at TAH should assist parents in identifying and using available community-based professional resources such as doctors, nurses, social workers, occupational therapists, physiotherapists, clinical psychologists and community organisations, especially the latter, as all the professionals are likely to be in private practice and therefore not affordable to people who are unemployed.

5.2.5 Family support

It is recommended that family support should be provided immediately from the diagnostic stage, when the child’s neurodevelopmental disabilities are confirmed. It would be useful to provide therapeutic services on an individual-, family- or even peer-group- basis, and within their communities where possible. These services could include parenting programmes, peer support groups and individual counselling. They would enhance social functioning of the family unit and give families the opportunity to share their problems with other families to help each other overcome the stressors they experience. The process of coping can be improved by sharing problems with others, who can provide unconditional support and, possibly, a resolution to some of the problems.

5.2.6 Social support

The common resource of social support will give parents the opportunity to receive assistance and help from others to take care of their children with neuro-developmental disabilities. Skilled users of social support resources, in particular familial social support, can inculcate resilience in parents.

5.3 FURTHER RESEARCH

The following recommendations for further research are made:

- Conduct qualitative research on counselling needs of all family members e.g. siblings and grandparents of children with neurodevelopmental disabilities
- Assess the impact of long term therapy on the quality of life of parents and children with neurodevelopmental disabilities
- Assess the adequacy and role of respite care services with regard to respite care for parent of children with neurodevelopmental disabilities
- Conduct further research with a view to developing an effective in-home respite care service model for parents that can be rolled out in the homes and communities of the families of children with neurodevelopmental disabilities.
- Conduct further research with a view to developing a community-based model called “Peer Advisors” to provide assistance to one another (parents) in terms of skills development, knowledge and insight into caring for a child with neurodevelopmental disabilities.
- Explore factors that may influence the resilience of parents in supporting they children with neurodevelopmental disabilities.

5.4 LIMITATIONS OF THE STUDY

The following limitation to the study should be taken into consideration:

The duration of the interview sessions (45 to 60 minutes) was not adequate for some participants due to their emotional reactions. Most participants came for their children’s healthcare appointment scheduled by different health professionals on the same day. This included the doctor, occupational therapist, physiotherapist and the pharmacy. Completing all of these visits can last the entire day and is physically and emotionally taxing. The researcher had to arrange to complete the interviews after hours, by telephone. The information obtained was recorded in short notes, but some of the nuances could have been missed.

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APPENDICES

Appendix 1: Participant information leaflet and consent form

Title: The role of psychosocial counselling in the lives of parents of children with neurodevelopmental disabilities, treated at Tygerberg Academic Hospital

Reference Number: N10/11/371

Principal Investigator: Lizzie G Witbooi

Address: Desmond Tutu TB Centre

Stellenbosch University

Tygerberg; 7505

Contact details: Tel: 27 21 938 9764 Cell: 27 74 172 4684

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You are invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied and that you clearly understand what this research entails and how you could be involved. Also, your participation is entirely voluntary and you are free to decline to participate. If you say no, this will not affect you or your child negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Health Research Ethics Committee at Stellenbosch University **and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.**

What is this research study all about?

The purpose of this research study is to determine the role that psychosocial counselling at Tygerberg Hospital plays in the lives of parents having children with neurodevelopmental disabilities and to identify possible shortcomings in the counselling services with a view to improve these services. We are inviting you to participate in this research study aimed at getting better understanding of parents' experiences of children with neurodevelopmental disabilities. This study will take place at the Neurodevelopmental outpatient clinic in Tygerberg Hospital. You are not forced to participate in this research study. We will include 10 participants in this study.

What will happen if I do agree to participate in this study?

After you have read this information leaflet, the researcher will obtain written informed consent from you and ask you to answer a few questions. These questions are based on your experiences of having a child with neurodevelopmental disabilities and the current counselling services. We will do voice recordings. The voice recordings will not take longer than 45 to 60 minutes and it will not be identifiable. Your information will be kept anonymous.

Why have you been invited to participate?

You have been invited to participate because you have a child with a neurodevelopmental disability. Through sharing your experiences, you can help the researcher gain information that might help to improve counselling services.

What will your responsibilities be?

We will conduct a voice-recorded interview with you. You can tell us if you do not want to answer any questions or if you wish not to be recorded.

Will you benefit from taking part in the research?

This study may not benefit you directly. The research findings of the study may help the researcher to gain knowledge and understanding of what impacts children with neurodevelopmental disabilities have on parents and to see if psychosocial counselling can help parents. The researcher hopes that the information you give may possibly benefit parents who also have children with neurodevelopmental disabilities in the future.

Are there any risks involved in your taking part in this study?

There will be no physical risks related to participation in the study. The principal investigator, who is a professional social worker, will provide social support in case emotional reactions arise during and after interviews.

Who will have access to study information?

The study information such as voice recordings will be kept private and confidential, and will be safely stored on an external computer hard drive locked in the office of the researcher. Only the researcher and research assistant will have access to this information. If information generated from this study is published or presented, your identity will not be revealed.

Who will have access to your medical records?

Only the researcher will have access to your child's medical information. These records will be used to get contact details for you and the date on which your child was diagnosed with a neurodevelopmental disability.

Will you be paid to take part in the study?

No, you will not be paid to take part in the study. Your transport costs will be covered for study visits.

What if I have any questions?

If you have any questions regarding this research study, you can contact the Principal Investigator of this study anytime, Ms. Lizzie Witbooi at 021 938 9764 or 074 172 4684. You can contact the Health Research Ethics Committee of Stellenbosch University at 021 938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher. You will receive a copy of this information and consent form for your own records.

Declaration by Participant

Signing below indicates that you have been informed about the research study in which you voluntarily agree to participate and you have asked questions about the study. A copy of the original of the signed consent form will be given to you.

I (name) ______________________ have been invited to take part in the above mention research study.

The Principal investigator has explained the information of the study to me and has clearly understood it.

I have read this information and consent form and it is written in a language with which I am fluent and comfortable.

I give permission to participate in voice recordings.

I understand that taking part in this study is voluntary and I have not been pressurised to take part.

I understand that all the information given to the investigators will be kept private and confidential and will only be available to the study team.

I choose to leave the study at any time and will not be penalised in any way.

Signed (place) ……………………………………on (date)…………………………2011

…………………………….. Signature of Participant

……………………………… Signature of witness

Declaration by Investigator

I (name) ______________________________declare that:

I explained the information in this document to__________________________

I encourage the participant to ask questions and take adequate time to answer them.

I am satisfied that the participant adequately understand all the aspects of the research as discussed above.

I did/did not use translator (if a translator is used, then the translator must sign the declaration below)

Signed (place)……………………………………on (date)……………………………2011

…………………………….. Signature of Investigator

…………………………………. Signature of witness

Declaration of translator

I…………………………………………………. declare that:

I assisted the investigator ………………………………. to explain the information in this document to participant…………………..…..…… using the language medium of Afrikaans.

We encourage the participant to ask questions and take adequate time to answer them.

I am satisfied that participant fully understand the content of this informed consent form and had all his/her questions satisfactorily answered.

Signed (place)……………………………………on (date)……………………………2011

…………………………….. Signature of Investigator

…………………………………. Signature of witness

Appendix 2: Socio demographic data sheet of the parents

DEMOGRAPHIC DETAILS

1. Gender

Male	
Female	

2. Age Group

<18	
18–29	
30–39	
40>	

3. Ethnicity Group

African	
Coloured	
Indian	
White	
Other(specify)	

4. Home Language

English	**Afrikaans**	**isiXhosa**	**isiZulu**	**Sesotho**	**Setswana**
Tsonga	**Venda**	**SiSwati**	**Ndebele**	**Tsonga**	**Other(specify)**

5. Marital status

Single	
Married	
Divorced	
Separated	
Widowed	
Other	

6. Level of Education

No education	
Primary school	
High school	
ABET	
College	
University	

ACCOMMODATION

7.1 What type of accommodation do you live in?

House	
Flat	
Wendy house	
Shack	

Room	
Other(specify)	

7.2 Do you own or rent the accommodation?

	Yes	**No**
House		
Flat		
Shack		
Wendy house		
Room		

8. Employment status and financial status

Employed	
Unemployed	
Care dependency grant	
Other (specify)	

Appendix 3: Demographic details of the child

1. Gender

Male	
Female	

2. Age Group

12– 24 months	
3–5 years	
6–10 years	
10–15 years	

3. Ethnicity Group

African	
Coloured	
Indian	
White	
Other(specify)	

4. Medical status of the child

Appendix 4: Interview guide schedule for audio tape recording

Specific aim: To determine the role that psychosocial counselling at Tygerberg Academic Hospital plays in the lives of parents of children with neurodevelopmental disabilities and to identify possible shortcomings in the counselling services with a view to improve these services.

General/opening statement: The purpose of the interview is to help us to share your experiences of having a child with neurodevelopmental disabilities and your experience of current counselling services. All your answers will remain confidential. Speak freely and ask questions whenever you need clarity.

Specific questions:

1. Tell me about your life as a parent having a child with disability? In other words, what are your experiences as a parent having a child with special needs?
2. How does the child's disability influence your life regarding:
    a. Employment
    b. Social & relationships
    c. Financial
    d. Health and well-being
    e. Emotional
    f. Psychosocial impact
    g. Support
3. What are your psychosocial needs and how are they?
    a. Did a healthcare worker or social worker address them?
    b. How has it been for you?
    c. Is it difficult?
    d. Did you see a social worker?
4. What are your experiences of respite care services?
    a. In other words, has someone taken care of your child while you take care of your own well-being and needs?

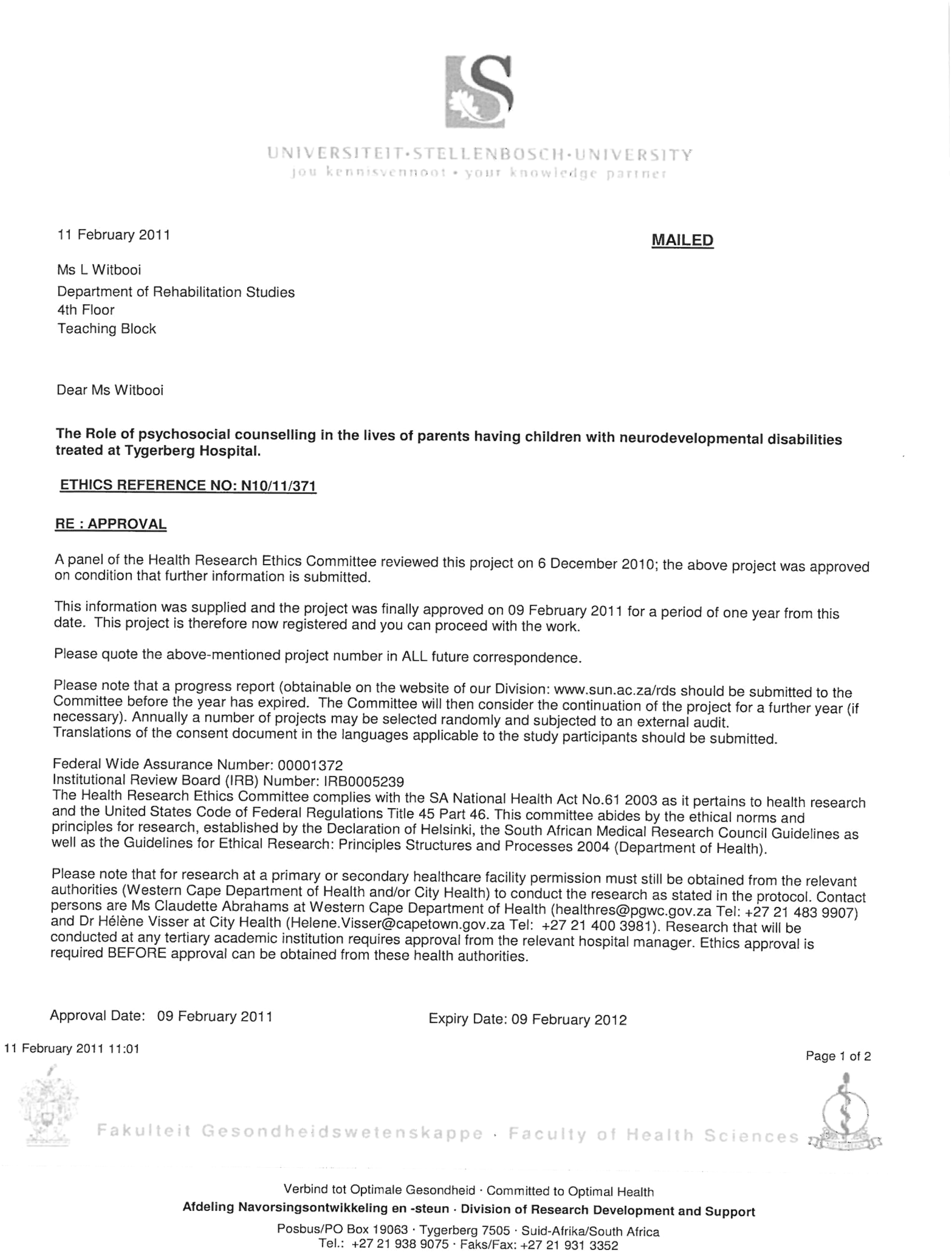
    b. What were your experiences and perceptions of such services?
5. What are your current experiences of counselling services?

6. What are your suggestions to improve counselling services?

Examples of probing questions

a. What do you mean by…? What do you feel when...?
b. Tell me more about…Why?
c. That is really interesting…
d. I don't quite understand, but you said earlier…

Appendix 5: Ethical approval



UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

11 February 2011

MAILED

Ms L Witbooi
Department of Rehabilitation Studies
4th Floor
Teaching Block

Dear Ms Witbooi

The Role of psychosocial counselling in the lives of parents having children with neurodevelopmental disabilities treated at Tygerberg Hospital.

ETHICS REFERENCE NO: N10/11/371

RE : APPROVAL

A panel of the Health Research Ethics Committee reviewed this project on 6 December 2010; the above project was approved on condition that further information is submitted.

This information was supplied and the project was finally approved on 09 February 2011 for a period of one year from this date. This project is therefore now registered and you can proceed with the work.

Please quote the above-mentioned project number in ALL future correspondence.

Please note that a progress report (obtainable on the website of our Division: www.sun.ac.za/rds should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit.
Translations of the consent document in the languages applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239
The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Hélène Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

Approval Date: 09 February 2011 Expiry Date: 09 February 2012

11 February 2011 11:01

Page 1 of 2

Fakulteit Gesondheidswetenskappe · Faculty of Health Sciences

Verbind tot Optimale Gesondheid · Committed to Optimal Health
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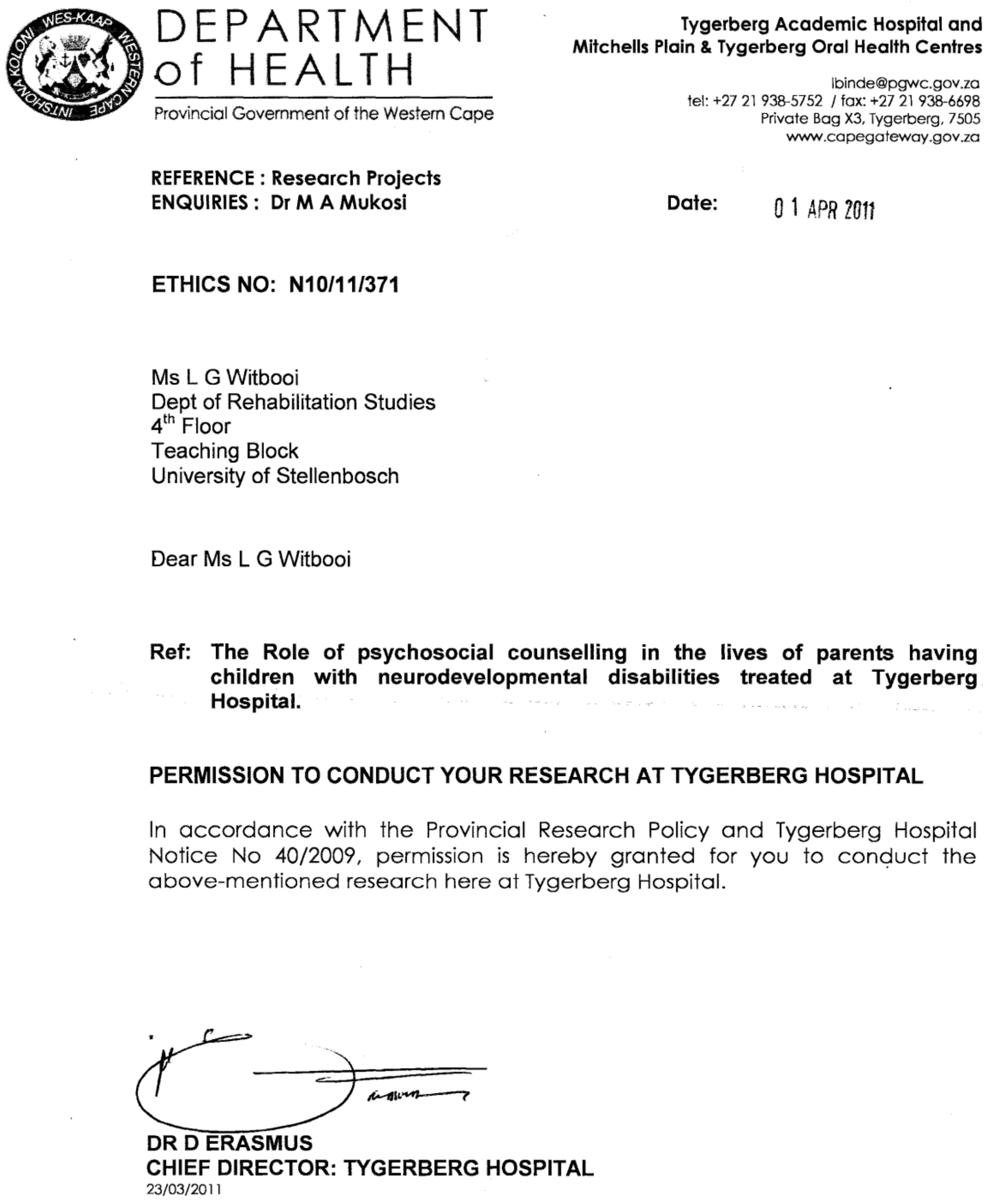
Yours faithfully

<u>MS CARLI SAGER</u>
RESEARCH DEVELOPMENT AND SUPPORT
Tel: +27 21 938 9140 / E-mail: carlis@sun.ac.za
Fax: +27 21 931 3352

Appendix 6: Permission to conduct research at Tygerberg Academic Hospital



DEPARTMENT
of HEALTH
Provincial Government of the Western Cape

Tygerberg Academic Hospital and
Mitchells Plain & Tygerberg Oral Health Centres

lbinde@pgwc.gov.za
tel: +27 21 938-5752 / fax: +27 21 938-6698
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www.capegateway.gov.za

REFERENCE : Research Projects
ENQUIRIES : Dr M A Mukosi

Date: 01 APR 2011

ETHICS NO: N10/11/371

Ms L G Witbooi
Dept of Rehabilitation Studies
4th Floor
Teaching Block
University of Stellenbosch

Dear Ms L G Witbooi

Ref: The Role of psychosocial counselling in the lives of parents having children with neurodevelopmental disabilities treated at Tygerberg Hospital.

PERMISSION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL

In accordance with the Provincial Research Policy and Tygerberg Hospital Notice No 40/2009, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital.

DR D ERASMUS
CHIEF DIRECTOR: TYGERBERG HOSPITAL
23/03/2011